Achieving a Secure Collaborative Environment in Patient-Centred Healthcare with Legacy Information Systems

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A thesis submitted in partial fulfilment of the

requirement for the degree of Doctor of Philosophy

Declaration

This work has not previously been accepted in substance for any degree and is not concurrently submitted in candidature for any degree.

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Dedicated to Laila Khadr

To my darling mother who selflessly sacrificed her own PhD to take care of me so one day I could pursue mine. So, this one is for you, Mama!

Also dedicated to the loving memory of my uncle, Adel Khadr (1947-1967)

To those who give us the ultimate sacrifice of their lives so we can continue to live in the nation as free thinkers, doers, and believers.

"Do not stand at my grave and weep
I am not there. I do not sleep.
I am a thousand winds that blow,
I am the diamond glints on snow.
I am the sunlight on ripened grain,
I am the gentle autumn rain.
When you awake in the morning's hush
I am the swift uplifting rush
Of quiet birds in circled flight.
I am the soft star-shine at night.
Do not stand at my grave and cry.
I am not there. I did not die."
Mary Elizabeth Frye

Summary

Modern healthcare is taking an evolutionary approach towards the adoption of an integrated Patient-Centred (PC) delivery approach, where care provision is tailored to meet an individual patient's needs holistically. Enabling PC care requires the flow of information with the patient between different healthcare providers as they support the treatment plan, so the Care Team (CT) can seamlessly and securely access relevant information held in different discrete Legacy Information Systems (LIS). LIS used in PC fall short of meeting these needs because they cannot comply with the information security policies for shared information which can block the CT access to information. Achieving a Secure Collaborative Environment (SCE) in PC care helps address this LIS issue by attaining a PC-driven information security approach at the collaboration level that meets the overall care goal, while retaining local LIS information security. An empirical study identified a common information security for PC care, security threats occurring when LIS are brought into an SCE, and eight information security controls to help LIS cope with this emerging need. These controls manage information through an information layer and control access to this information through a novel Patient-Centred Access Control (PCAC) model. Implementation of these controls in a prototype system to achieve a Secure Healthcare collaborative Environment (SHarE) has been achieved and assessed. SHarE constructs an independent treatment-based information layer that lies on top of the LIS to formalise and manage a unique treatment journey, while the PCAC model enforces access rules as the patient progresses through their treatment journey. Also, this layer is loosely coupled with the LIS to embrace the local organisation-driven access controls without interruption and maintain their local information security. Thus, SHarE achieves the SCE required to adopt PC care and attains the security balance necessary for LIS supporting PC care in a collective environment.

Abstract

Modern healthcare has been shifting from a traditional fragmented disease-centred delivery approach towards a more integrated Patient-Centred (PC) one to support comorbidities, when the patient suffers from more than one condition or disease. In PC delivery the patient is at the heart of its services which are tailored to meet an individual's needs holistically. Enabling PC care requires the flow of medical information with the patient between different healthcare providers supporting the patient's treatment plan, and sharing of information across healthcare organisations so that the Care Team (CT) can seamlessly access relevant medical information held in different information systems. In many countries this PC movement is taking an evolutionary approach that involves Legacy Information Systems (LIS) as they are the backbone of the healthcare organisation's information. However, this collaboration reveals weaknesses in LIS in this role, as they may block a CT from accessing information, as they cannot comply with the information security policies for shared information that is needed in this collaborative environment to support PC. This is mainly because each of these LIS was designed as an autonomous discrete information system that enforces an organisation-driven information security policy protecting only local information resources through an Access Control (AC) model. This creates a single local point-of-control, limited by the system's physical perimeter, to meet local information sharing and security contexts. This means PC adoption may require incorporation of multiple autonomous discrete information systems which presents four challenges - inconsistent policies, perimeter-bounded AC models, multiple points-of-controls, and heterogeneous LIS. First, such collaborative environments lack collaboration-driven information security policies that best meet the protection needs in the collaboration sharing and security contexts. Second, they deploy incompatible AC models that are not perimeter-transparent, and thus, unable to stretch across the discrete information systems to cover the whole collaborative environment. Third, these environments do not deploy a single obvious point-of-control with authority for policy enforcement. Finally, they need to access heterogeneous LIS that are not compatible with each other, and thus, it is essential that solutions can be integrated and coupled with these LIS to facilitate the utilisation of information stored in these systems. Current solutions addressing this situation fall short of meeting these challenges in establishing secure collaborative

environments with LIS because they lack a comprehensive information security approach to meet the information sharing and security contexts driven by the collaboration. This research introduces a roadmap towards achieving a Secure Collaborative Environment (SCE) in collaborative environments using LIS from diverse organisations that addresses the above challenges, and meets the collaboration information sharing and security contexts without interrupting the local contexts of these LIS.

An empirical study is used to determine how to create an SCE in modern healthcare which addresses the problems raised by incorporating LIS. This meets the collaborative information sharing context by creating an information layer that manages the information flow between healthcare providers based on treatment points. It also meets the information security context in the treatment pathways by controlling access to information in each treatment point using a Patient-Centred Access Control (PCAC) model. This model creates a PC-driven information security policy at the collaboration level that meets the overall care goal, enforces this balance in a neutral security domain with a single authority point-of-control that stretches across-organisations anywhere within the collaboration environment, while retaining the local medical information security of shared information among the CT. Using domain analysis, observations, and interviews, the PC-driven balance of information security in cancer care, threats in LIS currently used in cancer care to attain that balance, and eight information security controls are identified. These controls manage information through an information layer and control access to the information through the novel PCAC model needed by these systems to attain that balance and address the problem. Using Workflow Technology (WfT), a prototype system implementing these controls to achieve a Secure Healthcare collaborative Environment (SHarE) has been fully studied, developed, and assessed. SHarE constructs an independent information layer that is based on treatment and lies on top of the interface of the currently used LISs to formalise and manage a unique treatment journey, while the PCAC model enforces access rules as the patient progresses along their treatment journey. This layer is designed as a loosely coupled wrapper-based system with LIS to embrace the local organisation-centred access controls without interruption and sustain the balance of information security. Finally, using interviews, SHarE was assessed based on three criteria: usefulness and acceptance, setup and integration, and information governance. Results show that all interviewees agree that currently information does not always flow with the patient as they go along their treatment journey and nine different causes for this were suggested. All interviewees with no exception agreed that SHarE addresses this problem and helps the information flow with the patient between healthcare providers, and that it would be possible for SHarE to be adopted by a CT in cancer care. Over half the interviewees agreed that it is an easy to use system, useful, and helps locate information. The results also show there is an opportunity for SHarE to be integrated with CaNISC as some interviewees thought it is a much simpler system. However, multiple patient identifiers for a patient, as each

system can have its own identifier, is predicted to be the biggest integration challenge. Results also show that SHarE and its controls attain the right balance of information security defined by the Caldicott Guardian and comply with the six Principles of the Caldicott Guardian. Although the assessment of SHarE highlighted a number of challenges and limitations that may hinder its adoption and integration if not carefully considered in the future, this proposal allowed the achievement of creating an SCE required to adopt PC care and attain the security balance necessary to support PC care systems.

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"Education of the mind without education of the heart is indeed no education at all." Aristotle
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Thank you all, I'm blessed and will be forever thankful!

List of Acronyms

A list of acronyms used throughout the thesis is presented in this page, along with where each appears in full and where it is defined, if one is provided.

AC Access Control *ch.1, p.4. ch.2, p.21*

A&E Accident & Emergency *ch.2, p.19*

ASP Active Server Pages *ch.6, p.108*

BPM Business Process Modelling *ch.3, p.52. ch.6, p.97*

BPMN Business Process Modelling Notations *ch.6, p.100*

CaNISC Cancer Network Information System (Cymru) *ch.2, p.35*

CIU Clinical Information Unit *ch.3, p.52*

CT Care Team *ch.1, p.2. ch.4, p.60*

DRM Digital Rights Management *ch.2, p.34*

ER Entity Relationship *ch.3, p.52. ch.6, p.97*

GP General Practitioner *ch.1, p.2. ch.3, p.51*

HC Hepatocellular *ch.3, p.50*

ICP Integrated Care Pathways *ch.3, p.50*

ICT Information and Communications Technology *ch.2, p.15*

IM&T Information Management & Technology *ch.3, p.52*

ISCO Information System for Clinical Organisations *ch.4, p.73*

ISO International Organization for Standardization *ch.2, p.20*

LIS Legacy Information Systems *ch.1, p.2. ch.2, p.15*. Defined in *ch.1, p.2*

MDT Multi-Disciplinary Team *ch.1, p.2*

MoM Map of Medicine *ch.3, p.50*

NHS National Health Service *ch.1, p.9*

NWIS NHS Wales Informatics Services *ch.7, p.141*

OMG Object Management Group *ch.6, p.100*

PC Patient-Centred *ch.1, p.1. ch.4, p.61*. Defined in *ch.4, p.63*

PCAC Patient-Centred Access Control *ch.1, p.6*

PDP Policy Decision Point *ch.2, p.24*

PEP Policy Enforcement Point *ch.2, p.24*

PSP Policy Storage Point *ch.2, p.24*

SCE Secure Collaborative Environment *ch.1, p.5. ch.2, p.29*. Defined in *ch.2, p.45*

SHarE Secure Healthcare collaborative Environment *ch.1, p.9. ch.5, p.84*

SPIDER Self-protecting Information for De-perimeterised Electronic Relationships *ch.2, p.37*

UGI Upper Gastrointestinal *ch.3, p.50*

UHW University Hospital of Wales *ch.2, p.35*

WffICP Workflow for Integrated Care Pathway *ch.6, p. 97*

WfT Workflow Technology *ch.1, p.11. ch3, p.53. ch6. p.97*

WFMS Workflow Management System *ch.6, p.97*

XACML eXtensible Access Control Markup Language *ch.2, p.24*

Contents

List of Publications

Some of the work introduced in this thesis was published in the following publications.

- Alsalamah, S. Alsalamah, H. Gray, W. A. and Hilton, J. (2014). A Secure Collaborative Environment Implementation in Patient-Centred Healthcare using Workflow Technology. In: 7th Saudi Students Conference in the UK (SSCUK). 1-2 February 2014, Edinburgh, UK. p. 91.

- Alsalamah, S. Gray, A. Hilton, J. and Alsalamah, H. (2013). Information Security Requirements in Patient-Centred Healthcare Supporting Systems. In: the 14th World Congress on Medical and Health Informatics (Medinfo), 20-23 August 2013, Copenhagen, Denmark. pp. 812- 816.

- Alsalamah, S. Gray, A. and Hilton, J. (2011). Sharing Patient Medical Information among Healthcare Team Members while Sustaining Information Security. In: the 15th International Symposium on Health Information Management Research (ISHIMR), 8-9 September 2011, Zurich, Switzerland. pp.553-554.

- Alsalamah, S. Gray, A. and Hilton, J. (2011). Towards Persistent Control over Shared Information in a Collaborative Environment. In: the 6th International Conference on Information Warfare and Security (ICIW), 17-18 March 2011, Washington, DC, USA. pp.278-287.

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Chapter 1

Introduction

1.1 Introduction

The world's population is ageing and the health of older people has led to a realisation that modern integrated healthcare services to provide a holistic Patient-Centred (PC) care are needed. A diabetic patient visits an endocrinologist for long-term treatments, medications, and readings following a planned treatment pathway. If this same patient develops cancer at some point in his lifetime, he sees an oncologist to be treated with radiotherapy and is following a second treatment journey planned by the cancer specialist. Normally, each of these two specialists focuses on treating the disease by collecting disease-related information and running tests to make the right decisions to achieve the best treatment for their disease and this means they work independently. Both diabetes and cancer are common diseases with tremendous impact on health worldwide, and comorbidity happens when a patient suffers from more than one condition at the same time resulting in the patient following multiple treatment pathways in parallel. Comorbidity is more common in older patients than in younger ones [8], and the health condition of patients with comorbidity requires a more holistic care because it is important to consider all the treatments, medications, and readings when making decisions as they may interact. Therefore, comorbidity needs integrated healthcare services to obtain a fuller picture about the patient's condition, which adds pressure on healthcare providers to shift their thinking and practice to treat the patient as a whole and not treat each disease in isolation from other diseases. This led to many countries modernising their healthcare delivery systems, in order to cope with this emerging need to address the issues of comorbidity. This is achieved by shifting the delivery of healthcare from a traditional fragmented disease-centred approach towards an integrated PC one. In a disease-centred approach, healthcare professionals use a treatment approach reflecting the needs of the diagnosis for that disease, and care for the patient focuses around the needs of the healthcare professionals treating the patient for this disease [9, 10]. This leads to the healthcare professionals using an information silo to store information about patients with the same disease, which is held in their organisation and managed by an autonomous discrete information system not integrated with any information silo for another disease held

by another organisation [10]. Hence, access to patient information is limited to the physical boundaries of the provider [10], and decision-making processes are fragmented and based on the limited available information [9].

PC healthcare has a more holistic view of a patient in that care provision is tailored to meet an individual patient's needs taking account of all conditions in cases of comorbidities [11, 12, 13, 14, 10, 15]. It encourages healthcare professionals to collaborate and work as a Care Team (CT) [11], collecting and sharing relevant information with other CT members. This collective information forms a complete holistic patient record about the condition of the patient covering all the patient's multiple conditions, and supports decision-making in Multi-Disciplinary care Team (MDT) reviews [9, 16]. The movement from disease-centred towards a PC healthcare is illustrated in Fig 1.1.

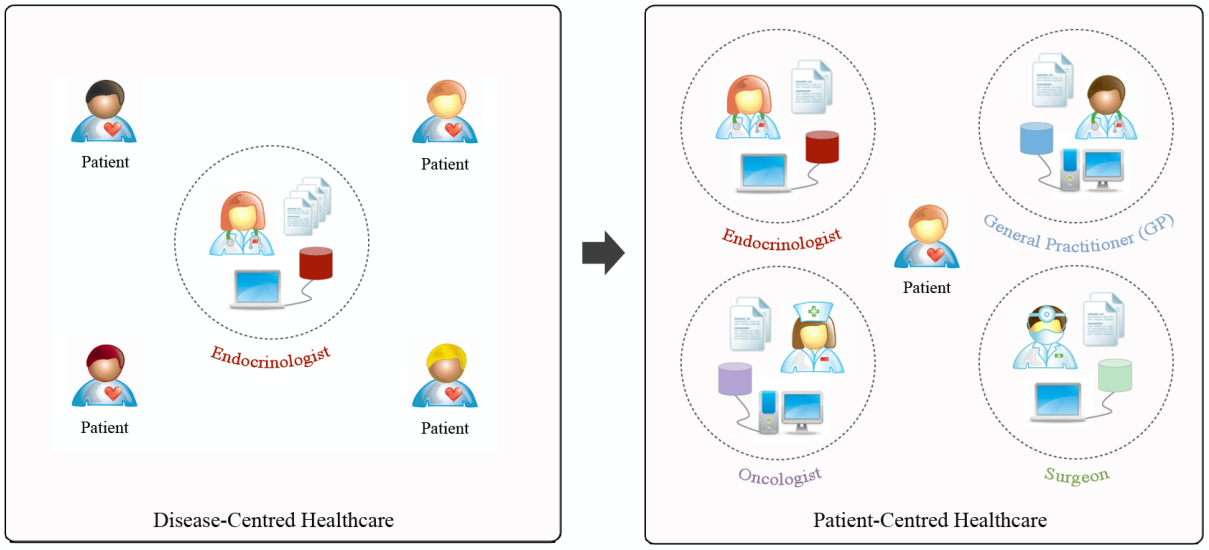


Figure 1.1: Movement from a disease-centred towards a PC healthcare.

This movement to PC creates a new information sharing context that requires medical information to flow with the patient between different healthcare providers as they follow the patient's treatment plans, and share information across healthcare organisations. This allows the CT to seamlessly access relevant medical information held in different discrete information systems, so that a complete picture is available if required. Fig 1.2 illustrates the flow of diabetes-related information with the patient following his diabetes treatment pathway. Most countries adopting PC care favour an evolutionary approach over a revolutionary one that involves using Legacy Information Systems (LIS), so that the LIS are gradually replaced with newer systems [17, 18]. Bisbal *et al.* define a LIS as "any information system that significantly resist modification and evolution" [17]. Although LIS are often brittle, slow, nonextensible, expensive to maintain, and harder to integrate with other systems [17], they represent the backbone of the healthcare

organisation's information, hence it must be used in this movement. Also this evolutionary approach is less expensive and has a lower risk of failure than alternative approaches [17], where the LIS are totally discarded and replaced with newer ones which can have a serious impact if the information becomes unavailable for a period or lost. Hence, it is important not to discard an LIS but evolve it [14, 17, 18].

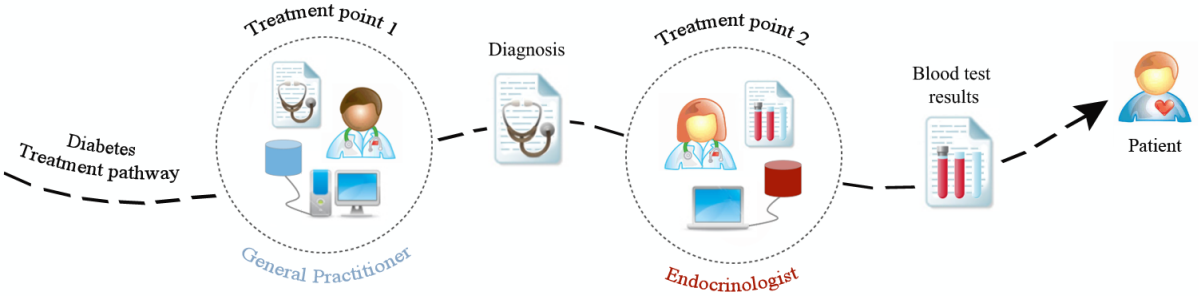


Figure 1.2: Information flow along a single treatment pathway.

However, LIS were not designed to support a holistic view of a patient record needed in comorbidity, as they were developed to meet the needs of the disease-centred approach at a time when information sharing was not common. LIS are unable to support seamless access to information because they are unable to comply with the information security policies for the shared information that is coming together in this collaborative environment supporting PC care, whether this information is related to a patient following one treatment pathway or has comorbidities. Consequently, a LIS may block a CT from accessing information they need to care for the patient and so interrupt the care continuity. This is because the LIS incorporated in PC collaborative environments as part of the evolutionary approach are autonomous discrete information systems, where each of these systems protects its information using an information security policy that is suitable for its local information sharing and security contexts. This block of information flow (represented in a padlock) across LIS in a single treatment pathway and comorbidities, is illustrated in Fig 1.3. There is, therefore, a need to check these policies are suitable for the new PC context, if the LIS is to be accessed in the collaborative environment.

Designing an information security policy in a discrete information system is achieved through three stages: 1) setting the information security goals that suit the information sharing and security contexts within the scope of the information system; 2) defining what is needed to achieve these goals; and 3) how these goals are to be achieved. The upper levels of this conceptual information security design aim to set a high-level balance between information confidentiality, integrity, and availability to ensure the information is kept from unauthorised users, is accurate and complete at all times, and has timely availability for decision-making processes. These three information security goals should be in the right balance for an application. The weighting of each will vary to meet specific organisational or business needs, and ensure its continuity

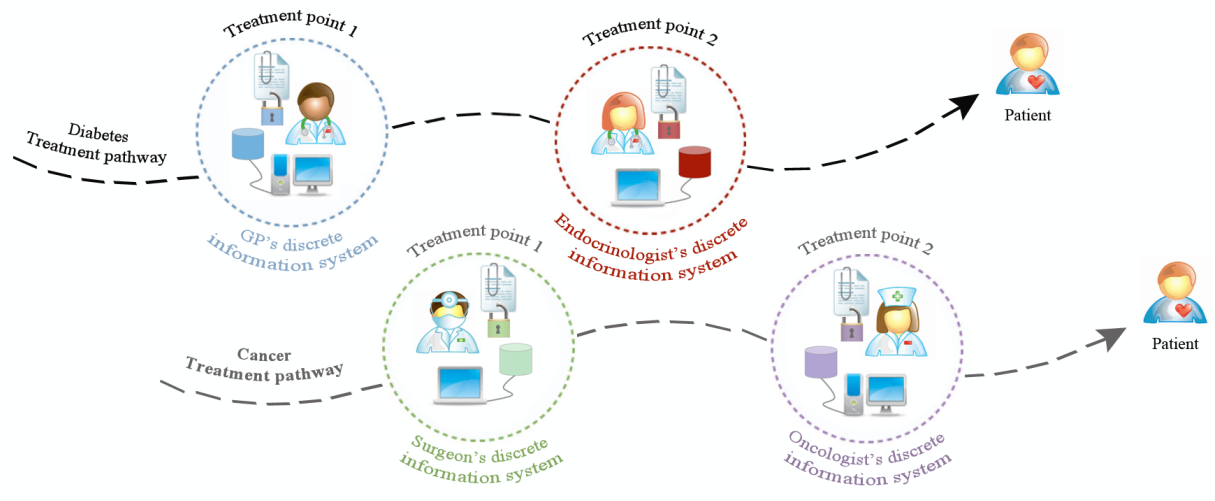


Figure 1.3: Block of information flow across LIS in a single treatment pathway and co-morbidities.

[19, 20, 21, 22]. For example, businesses engaged in e-commerce must keep personal identifiable information (i.e. that can be traced to a particular individual [23]) related to existing customers confidential to create a trusting relationship on which customers' confidence in dealing across the web depends [21, 23]. Also, to ensure revenue such businesses must maintain an accurate updated list of inventory that shows the availability of products for customers online at all times. Here, information availability is a particularly important goal that is outweighed in the balance of information security in such businesses [21]. This goes back to the fact that the existence of retailers adopting such business models are highly dependant on the availability of their websites, and thus, failing to take adequate steps to ensure they are up and running properly around-the-clock has a higher risk of business failure than traditional "Brick-and-Mortar" retailers adopting a touch-and-feel business model, who are unable to open its shop doors for a few days [21]. Whereas, information confidentiality in an intellectual property system is more dominant than the other two goals, as it is a prerequisite for a patent application where information must be only available to the absolute minimum number of people before the patent is granted. The right balance of the information security goals, regardless of the application system, is attained by creating an organisation-driven information security policy that defines the normal rules for access to information within the physical boundaries of the organisation, and prevents any threats from breaching that balance.

The lower levels of the information security design aim to enforce the information security policy in an information system using Access Control (AC). Maintaining the interaction between these elements without interruption creates a point-of-control. Consequently, discrete LIS have a single local point-of-control for the policy enforcement that is limited to the system's physical perimeter to meet local information sharing and security contexts, which makes them

autonomous by definition. Therefore, an LIS cannot support PC care's new information sharing context beyond a single disease or condition, and needs enhancement to be able to share information cross-healthcare organisations in a Secure Collaborative Environment (SCE) to provide a fuller picture about the patient's condition, see Fig 1.4. In this picture each organisation has its own point-of-control.

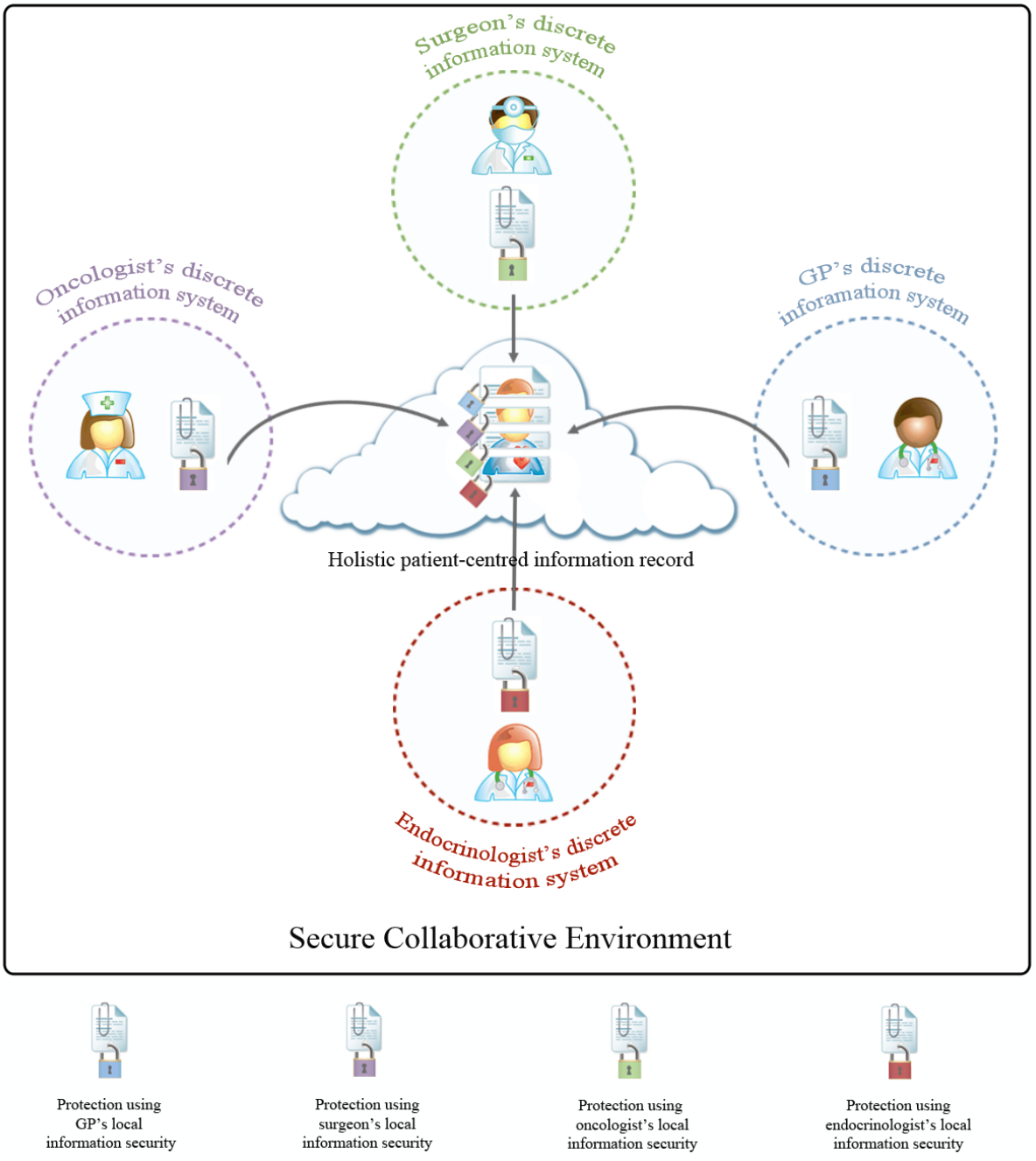


Figure 1.4: Information sharing and security needs in PC collaborative care for the achievement of an SCE.

Enforcing information security policies in a collaboration with multiple inconsistent points-of-control is complex due to the number of points-of-control especially when LIS are present. Firstly, these environments lack collaboration-driven information security policies with the right balance in the information security that best meets the protection needs in the collaboration sharing and security contexts. Secondly, there is no single obvious point-of-control with authority in these environments for policy enforcement, and hence, shared information is left to be protected using a foreign external point-of-control resulting in a possible misinterpretation of the information security policy, which may block access to information. Thirdly, the AC elements in the points-of-control need revisiting to be perimeter-transparent and stretch across the discrete information systems to cover the whole collaborative environment. Finally, such collaborative environments involve heterogeneous LIS that are not compatible with each other, and thus, it is essential that solutions can be integrated and coupled with these LIS to facilitate the utilisation of information stored in these systems. Current solutions addressing this situation fall short of meeting these challenges in securing collaborative environments with LIS because they lack a comprehensive approach that targets all levels of the information security design to meet the information sharing and security contexts driven by the collaboration. Based on the information security design levels, this research proposes a comprehensive approach towards the achievement of an SCE in such collaborative environments with LIS that meets the challenges presented by them. Also, this research studies the implementation of this SCE roadmap in PC collaborative care to virtually integrate multiple inconsistent points-of-control in harmony. This helps the formation of a complete information record about the patient's holistic condition, covering all the patient's multiple conditions in cases of comorbidity, that meets the PC care information sharing and security needs for the achievement of an SCE.

1.2 Research Aim and Objectives

The research aims to achieve an SCE in PC collaborative care and towards achieving this aim the following research questions are formed:

1. Can we define the right collaboration-driven balance of information security goals (availability, confidentiality, and integrity) required to establish a PC treatment approach, where information is held in one or more LIS?

2. Can we identify threats in using LIS that can breach the balance?

3. Can we implement an Patient-Centred Access Control (PCAC) model to achieve a balance of information security, which also addresses the threats?

Achieving the aim needs a holistic and comprehensive information security design that fits the collaborative environment's information sharing and security contexts. Therefore, the research objectives carried out to achieve the aim are:

1. Define a common information security policy that is collaboration-driven.
2. Develop a single authority point-of-control that:
   (a) Attains the right balance of the information security goals for the collaboration,
   (b) Stretches the logical perimeter to cover the whole collaboration environment,
   (c) Is compatible with the autonomous heterogeneous LIS, and
   (d) Embraces the local organisation-driven information security policies of the LIS, while enforcing the common one in harmony.

1.3 Research Scope

To complete this research within the available timescale, it was important to draw boundaries around the scope of the project, as follows:

- **Healthcare collaborative environments:** this research investigates information security challenges in healthcare collaborative environments (using PC care as a key exemplar) leaving all other types of collaborative environments beyond the scope of this research. Although each collaborative environment has its own information access needs based on the overall goal of its collaboration, this choice was made on the basis that healthcare collaborative environments are more complex than most other collaborative environments due to the life and death factor that can be the reason for asking for information access. Therefore, this must be factored into any solution which should make any solution in this complex environment easy to apply in less demanding environments after it is adapted to the specific needs of the new environment. However, it is important to consider whether the approach can be applied in other healthcare environments, for example with different LIS and/ or different hospitals and this is discussed in future work.
- **Discrete LIS:** many countries have decided to adopt a PC treatment approach to modernise their healthcare systems. Most of these countries, including the UK, are taking an evolutionary approach based on the principle of keeping what works and discarding what has failed. This means the new integrated systems are built on sound foundations of the discrete LIS designed years ago to meet the needs of traditional treatment models.

This is because LIS represent the backbone of their healthcare organisations' information. This research aims to ensure the information security of LIS when used in the movement towards a full PC care adoption. This allows these systems to be used in this transition period without either discarding them or compromising on patient safety.

- **Cancer treatment pathways:** this research addresses cross-organisational information sharing to facilitate PC care by creating an SCE, whether a patient is following a single treatment pathway or has comorbidities as the issues with incorporating LIS are the same in these situations. To study the implementation of an SCE in PC care that meets its information sharing and security contexts, this research narrows down the scope by choosing cancer treatment pathways as the information sharing context and uses these pathways to investigate their information security context. Achieving an SCE in cancer care can also be applied to any number of treatment pathways to reflect comorbidities as long as the information sharing context is well defined although multiple pathways can add a level of complexity when understanding the different needs.

- **Meeting information access needs in routine and urgent treatment cases:** this study categorises information access needs in cancer care in Wales into two groups: information access in emergency situations with a time constraint, and in routine care points based on pre-defined access rules following treatment pathways without any time constraints. Interviews revealed that there are no special mechanisms in current practice to address the block of information flow issue, and hence, if a CT member is blocked from access to required information, he/ she contacts the information originator in another hospital to request that access rules associated with this information are overridden to help them gain access. Although this mechanism is time-consuming, it is used in both information access groups. Therefore, the boundaries drawn around the scope of this research focused on the implementation of these two groups. This was highlighted as a key issue in the interviews with staff conducted as part of the problem definition and requirements identification phase, and also because it was not well addressed and fully investigated in the literature.

- **Information security targeting all levels of information security design:** this research proposes an information security design for the achievement of an SCE. This approach is adapted from widely used information security design that governs information security in discrete information systems with a single point-of-control. It has three conceptual levels: the upper level aims to define the information security goal, the middle level identifies "what" is needed to achieve it, while the lowest level identifies "how" to achieve this goal. Fig 1.5 shows the three conceptual levels.

  This approach is adapted to suit collaborative environments with multiple points-of-control for the achievement of an SCE. This research focuses on a qualitative approach looking

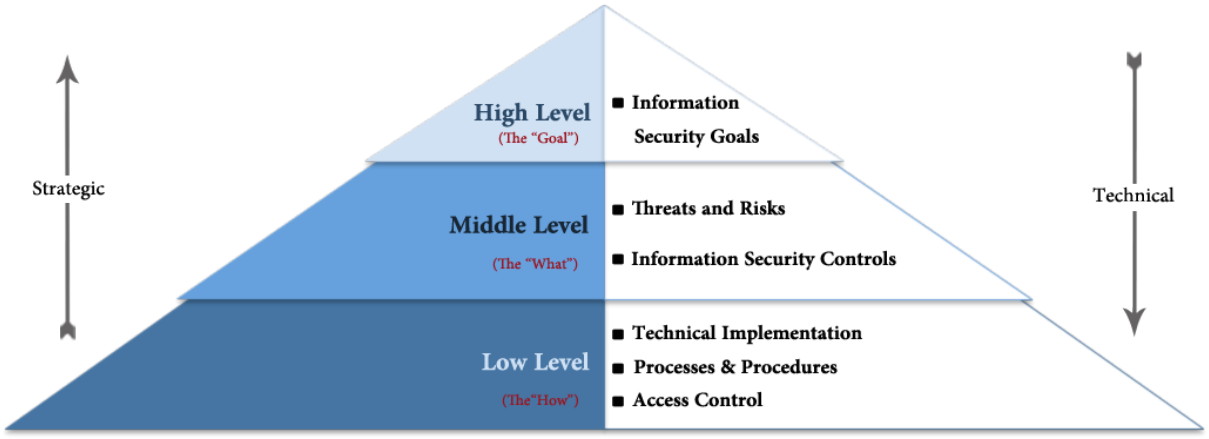


Figure 1.5: The adopted information security design for the achievement of an SCE in PC care and its outcomes.

at the perceptions of the actors involved to define the information security goal at the high level of the conceptual model, which lays the foundation for the achievement of the remaining levels of information security design down to the implementation of the SHarE prototype at the lowest level. This research proposes a comprehensive approach that bridges a gap in the literature. Therefore, it aims to design a method of achieving information security in collaborative environments with inconsistent information security policies in the constituent parts, and targets all levels of the conceptual model to virtually integrate these policies in harmony. However, SHarE is a proof-of-concept prototype that shows the SCE idea can be implemented and that the adopted information security design is valid. Although SHarE primarily shows that this can be achieved, it is not a full implementation at the low level as it was mainly implemented to show how a system would look in practice and looks at the implication on potential system users. Also the design of SHarE has a limitation due to the small number of users within cancer care in Wales who were interviewed for its design requirements. The main role contributing to the design was the Caldicott Guardian, who is responsible for taking decisions regarding information security for the whole cancer care community, and this could mean that the outcome is only suitable for this environment. Therefore, the evaluation of this research does not cover the performance, scalability, complexity and completeness of the technical implementation. This is future work that should be done when a robust system is developed.

- **What about the patient?** Although the aim of PC care is to improve the quality of care by making more shared information available for making decisions about how best to care for patients. It must be remembered that only the patient will live with the consequences of that decision and it can affect their quality of life. The decision to exclude the patient

from the scope of this research was made at the very early stages of this project for a number of reasons:

- *Reality.* The key aim of this research is to assist in the flow of information with the patient when LIS are involved to allow these systems to cope with the emerging needs in healthcare delivery. Today, at least in cancer care, patients do not use healthcare systems to access information about themselves. If they would like to keep information about their treatments, allergies, medications, and so on, they have to deviate from the norm by personally requesting it from each healthcare professional, they see. However, as patients today are not given privileges to access current systems, it is more realistic to improve current systems without adding any more pressure and affecting factors that would hinder achieving that goal.
- *Priority.* Involving the patient in the development of new systems could be as important as involving CT members, as it could help improve the patient's experience. However, current systems are evolving and still need to give more support to help healthcare professionals do their jobs better. Since involving the patient may compromise these objectives, it was decided to focus on a CT member's experience and not the patient's. This is in line with why the ten year National Health Service (NHS) plan kept the patient's right to access their information as one of the later developments [14] as they claim:

  > *"Many women, for example, have welcomed the opportunity to plan the arrangements for the birth of their child with midwives as well as doctors. Our new NHS Charter will balance the patient's rights of access to NHS services with their responsibility to use services wisely"* [14].

- *Complexity.* Healthcare collaborative environments have a high level of complexity. Such complexity requires breaking down the problem into smaller ones and drawing boundaries around the scope of the problem addressed in this research to simplify its nature. There is no question about the fact that adding considerations of the patient is going to add more complexity to an already complicated situation.
- *Practicality.* It would have extended the project into new issues which could not be covered in the time available as it would involve getting ethical approval and conducting interviews with patients.

It is clear that the outcome of the project will not affect patient involvement in PC care in the future, so the decision not to cover the patient viewpoint is not seen as a major drawback.

1.4 Research Contribution

This inter-disciplinary research contributes to the domains of information security and health informatics, in particular:

- **Healthcare LIS:** it provides a roadmap, discussed fully in Chapter 2, that empowers discrete LIS to be utilised as part of the modernisation of the healthcare systems by ensuring their information is available and an evolutionary approach can be taken as this information is available securely outside the local security domain within an SCE supporting PC care.

- **PC care adoption and comorbidities support:** the proposed security solution, designed and implemented in Chapter 6, assists hospitals with LIS in the transition towards a fully integrated PC healthcare approach. It also supports national strategies towards addressing comorbidity issues.

- **AC techniques:** it develops a novel PCAC model that reflects PC care information sharing needs, while maintaining local organisation AC models for the LIS. This will contribute to the anticipated national development stages. This security model is discussed in Chapter 2 and implemented in Chapter 6.

- **Security patterns:** Security Patterns [24] work as a roadmap to solve recurring security problems in a proven and successful way by giving guidance on building reusable secure software [25]. Key achievements of this research lay the foundation to develop the underpinning for a set of security patterns in the area of AC that can enrich the security pattern community, as they can be considered for adoption as solutions in other domains with similar attributes.

- **Information classification scheme:** Information classification schemes are one way to represent protection requirements, and because they can be standardised among different parties, it is a suitable way to communicate these requirements in collaborative environments. Although it is out of the scope of this research, results from this project lay the foundation for research aiming to develop an information classification scheme for modern healthcare that reflects the protection needs in PC care.

- **Workflow Technology (WfT):** this research selects WfT as an appropriate tool to implement the neutral information layer on which the information security policy is enforced, and tests this functionality in routine access needs and emergency cases. This contributes to the WfT community in the way this tool is used to address concrete real-world issues in a collaborative environment.

The novelty of this research resides in the PCAC model in PC healthcare that balances the fine line between information availability and confidentiality in these demanding collaborative environments to meet the information sharing and security contexts required. The PCAC model makes access decisions on a "need-to-know" basis in both routine and emergency information access needs. This is discussed fully in Chapter 5. In routine access, the PCAC model attains the information security balance at each treatment point based on four conditions: who the patient is, the condition being treated, the current treatment point, and the role of the CT responsible for treating the patient at that care point. It uses the concepts of "circle of trust" and "break-glass" in emergency information access, when it needs to relax the levels of information availability and only trusts healthcare professionals in that circle who can then use break-glass to gain speedy access to information they may need to save the patient's life. The security level is restored once the emergency is over. The "circle of trust" and "break-glass" concepts are first introduced in Chapter 5, implemented in Chapter 6, and evaluated in Chapter 7.

The key achievements of this research is the proposed information security design for the achievement of an SCE. This approach is a comprehensive and holistic way to address security in collaboration with multiple points-of-control. The development of a Secure Healthcare collaborative Environment (SHarE) is a successful prototype implementation of an SCE for use in PC collaborative healthcare and is a proof-of-concept prototype system that validates this new approach. This SCE approach bridges a gap identified in the literature by meeting the SCE challenges which current solutions do not address. This research is at a high-level of the information security design conceptual model and defines a common collaboration-driven information security goal that meets the needs of information sharing and security contexts in PC care. At the middle level of the security design, it identifies information security threats to this goal and controls that can help address these threats to achieve that goal, as presented in Chapter 4 and 5. SHarE implements these controls at the low-level of the information security design to achieve the goal that meets the four SCE challenges. This is enforced in a single point-of-control using the PCAC model in a neutral information layer, that stretches to include all LIS needed in a patient's treatment, and most importantly SHarE is designed as a loose-coupled system which retains the local information security of its LIS without interruption. Details of the design and implementation of SHarE are presented in Chapter 6, and its evaluation in Chapter 7. SHarE contributes to improving information security in collaborative environments and allows LIS to be incorporated in such environments without being discarded allowing an evolutionary approach to the migration of healthcare systems to PC. Fig 1.6 illustrates at each level of the information security design the achievements which led to the SCE in PC care.

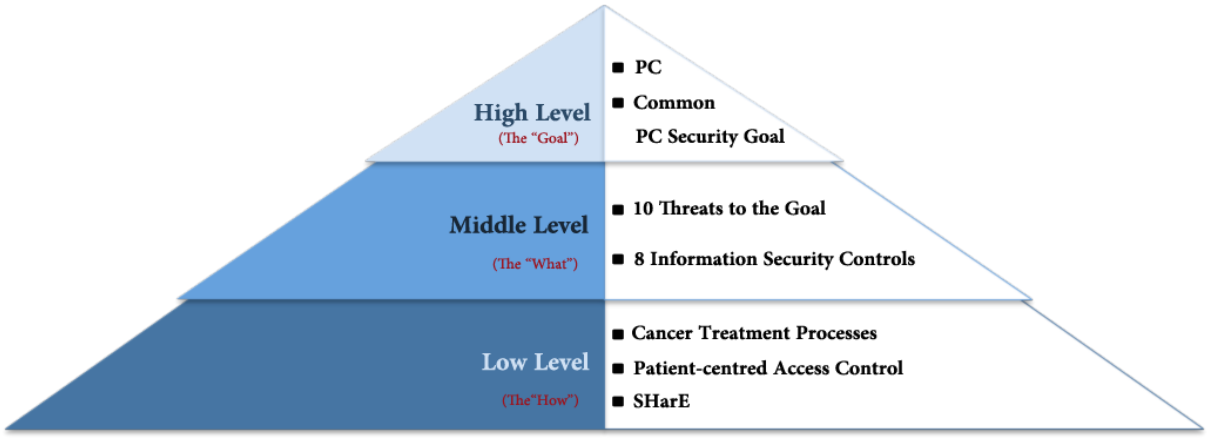


Figure 1.6: The adopted information security design for the achievement of an SCE in PC care and its outcomes.

1.5 Thesis Structure

The thesis is structured as follows:

- **Chapter one:** introduces the research, states its aim and scope, highlights the achievements, novelty, and contribution. It also outlines the thesis structure.

- **Chapter two:** introduces information security as a general concept by explaining the general process of securing an information system to answer a number of questions including: Why is information security important to business organisations? How can it be achieved in discrete information systems? It also highlights the challenges in securing information in collaborative environments with multiple discrete information systems and discusses the limitations of existing approaches in the literature to overcome these challenges. Finally, this chapter introduces the notion of a SCE as a general roadmap towards achieving information security in collaborative environments.

- **Chapter three:** introduces the scientific research methodology used in this research. It explains the mixture of qualitative research methods and approaches used at the various stages to develop this research in order to achieve its main aim. The methodology covers the following research stages: research problem identification, research questions formation, SCE design and implementation, and research evaluation.

- **Chapter four:** This chapter describes modern healthcare and introduces the reader to PC care which is the basic exemplar of healthcare collaborative environments, to which modern healthcare aspires. In addition, it defines PC care, highlights its main characteristics

in comparison with a traditional disease-centred care approach, explains the global movement towards PC care, and the adoption of this new approach. This chapter explains the initial steps towards the achievement of an SCE in this environment by defining a common collaboration-driven information security policy in PC healthcare using LIS. This task involves defining information sharing contexts, highlights key threats to the balance of information security in this context, lists the requirements that would reduce the impact of these threats to achieve a collaborative-driven information security policy.

- **Chapter five:** presents the core of this research by introducing SHarE, which is the implementation of an SCE in PC care using LIS. SHarE is the low level enforcement of the common collaboration-driven balance of information security in a wrapper-based system, to meet the challenges in creating SCEs. The requirements for this high level collaboration-driven policy, identified in the last chapter, are used to define eight controls in SHarE.

- **Chapter six:** explains the steps followed to design, and implement the proposed wrapper-based system, SHarE. It initially discusses in finer detail the use of a Business Process for the design, using the selected breast cancer treatment scenario, and the automation of the treatment process using WfT. It also explains how the access decisions are executed and enforced in SHarE throughout the treatment process. Finally, the chapter illustrates SHarE through a number of screen shots.

- **Chapter seven:** evaluates SHarE. It aims to evaluate the usefulness and acceptance of the proposal, the possibility of integration with LIS to achieve the research objectives, and the significance of the information security requirements identified and implemented. It starts with a description of the evaluation process and criteria. It explains the evaluation approach which used interviews with healthcare providers and senior personnel in a number of healthcare organisations mainly involved in cancer care in Wales. The findings are presented along with potential challenges identified and the limitations of SHarE.

- **Chapter eight:** highlights the key aspects of the work, assesses the achievements against the aims, draws conclusions from this research, and concludes with an appraisal of the overall research experience and outcomes. Future work which could be carried out based on this research are identified.

Chapter 2

Information Security in Collaborative Environments

2.1 Introduction

Legacy Information Systems (LIS) were designed as autonomous discrete information systems at a time when sharing information across organisations was not common. Each of these discrete information systems protects its information using an information security policy that is designed to meet the needs of its local information sharing and security contexts. The information security policy is created through an information security design that has three conceptual levels: the first, sets a strategic goal towards achieving information security that suits the information sharing and security contexts within the scope of the information system and the organisation; the second, defines what is needed to achieve that goal; and the third, how this goal is to be achieved. Hence, the upper levels of this information security design aim to carefully set a high-level balance between information confidentiality, integrity, and availability, to make sure the information is kept from unauthorised users, accurate and complete at all times, and has timely availability for decision-making processes, and has the right balance by creating an organisation-driven information security policy that defines the normal rules for access to information within the physical boundaries of the healthcare organisation, and prevents any threats from breaching that balance. Whereas, the lower levels enforce this information security policy in an information system using the three AC elements responsible for policy storage, decision, and enforcement. Maintaining the interaction between these elements without interruption creates a point-of-control. Discrete LIS have a single local point-of-control for policy enforcement that is limited to the system's physical perimeter to meet the local information sharing and security context. This makes them autonomous.

Recent developments in Information and Communications Technology (ICT) are enabling the sharing of information from diverse sources to obtain fuller pictures of complicated situations and to address a common problem or purpose [26, 27, 28, 29, 30, 21]. This involves extens-

ive use and sharing of information from diverse information systems to achieve overall goals [28, 26, 30, 31, 23], among collaborating organisations forming a virtual organisation of users and distributed resources from geographically and administratively distributed physical organisations that collectively own and manage the resources [28, 29, 30, 21, 32, 31, 23]. It is challenging and difficult to ensure information security in these collaborative environments due to the complexity added by the multiple distributed information systems. Such information rich and technologically intensive collaborative environments create information sharing and security contexts that are different from any of the single individual information systems. Collaborative environments tend to diminish the effect of geographical locations around the world and may generate information resources as a result of the collaborative effort that cannot be provided solely by one of the participating organisation, meaning no single organisation can claim the sole ownership of such information resources [30, 21]. Therefore, the information sharing and security contexts may have different requirements than the ones in the autonomous discrete information systems [33, 22]. Consequently, security and privacy related issues are more challenging and complex in such collaborative environments than in the current traditional discrete information systems [30, 21, 33]. This chapter explains the process of designing information security in autonomous discrete information systems, and highlights the challenges to achieving this in collaborative environments with multiple discrete information systems. It also identifies a gap in the literature by examining related work and the limitations in existing proposals to overcome these challenges. This chapter introduces the notion of an SCE as a comprehensive general roadmap towards achieving information security in collaborative environments in today's world that meets the challenges and bridges the gap.

2.2 Information Security is Important

Information is at the heart of business organisations today and is the lifeblood of any 21st-century organisation [20, 21]. Hence, it is an extremely valuable business asset that plays a significant role in the organisation's survival [20, 21]. According to Posthumus and Von Solms [20] business information in any organisation depends on three functional elements to assist in the execution of the organisation's business operations. These elements are: technology, stakeholders, and business processes. Technology is used to store, process, and transmit the business information, while stakeholders access the information primarily to make decisions, and business processes manipulate the information to provide services. These are the main components of an information system [34]. Stair and Reynolds [34] define an information system as: "A set of interrelated components that collect, manipulate, store, and disseminate data and information and provide a feedback mechanism to meet an objective" [34]. This feedback mechanism

enables organisations to achieve their goals [34]. Therefore, information in any organisation is the glue that holds it together and facilitates the management of its resources [20]. Despite the three elements (technology, stakeholders, and business processes) playing a key role in supporting the business operation, they also expose the organisation to immediate threats as they have the potential to put the information at great risk that can threaten the stability and well-being of the business [20, 21].

According to Calder and Watkins [21], risks fall into three categories based on the potential damage they cause: operation, reputation, and legal risks. Damage in any of these categories can have potential impacts on the organisation's reputation, revenue, and/ or profitability. Furthermore, threats to information assets are statistically proliferating and increasingly becoming more complex, sophisticated, serious, and costly [21, 35]. Newspapers and magazines are full of stories about cyber criminals, making cyber crimes as prevalent as traditional ones, according to the European police agency [21]. This is clearly reflected in the most recently published Information Security Breaches Survey [35] in 2014 by the British Department for Business, Innovation and Skills. The survey shows, 81% of large organisations in the UK experienced a security breach in 2014, and over half of small businesses (60%) shared the same fate [35]. Moreover, according to experts, over the last decade threats are becoming more lethal with a terminal-impact on operations [21]. This highlights the serious fact that organisations are facing a "tsunami" of threats, which is why Calder and Watkins [21] state that no organisation is immune. Consequently, it is self-evident that organisations should give a high priority to information security and take appropriate steps to secure and protect their information assets. This is particularly important as "a thickening web" of legislation and regulation makes organisations in both public and private sectors "criminally liable" [21].

2.3 Information Security in Discrete Information Systems

Security is a general term that can have various meanings in different contexts [19]. For instance, the term "financial security" may refer to adequately funded investments, while a "security system" can refer to physically protecting homes or business premises from intruders by using keys or more sophisticated biometric access control mechanisms and video surveillance [19]. However, security in the context of information systems means ensuring the confidentiality, integrity, and availability of information is preserved [36, 37, 19, 20, 21, 22]. These are fundamental goals and the first step in information security is attaining a balance between these goals by creating an information security policy.

2.3.1 Information Security Policy

An information security policy is fundamental to any organisation's information system, and the foundation and bottom line of information management in the organisation [38, 37]. The policy defines how to protect information from identified threats that can breach the balance between information confidentiality, integrity, and availability [37, 36, 21]. It provides a basis for decision makers, is required by legislation, and considered a method to articulate the information security and how security is ultimately achieved in the organisation [38]. An information security policy is created through an information security design that defines how an organisation plans to create its information security within an information system. This design has a hierarchical approach with three conceptual levels having increasing level of details: the first sets a strategic goal for information security that suits the information sharing and security contexts within the scope of the information system; the second defines what needs to be done to achieve that goal; and the third how this goal is achieved [36].

1. **High-level: *Defining the Goal***

   The high-level information security design reflects the organisation's strategic intent with respect to information security [36], and carefully sets a high-level balance between the information security goals of confidentiality, integrity, and availability without defining the mechanisms to achieve the policy.

   - *Information confidentiality* is ensuring that sensitive information is kept from unauthorised disclosure [19, 36, 39, 20, 21, 40]. In other words, the information is not freely available to whoever wants access, but is only available to authorised users [20, 21]. Confidentiality is easily breached by accidentally sending an email with sensitive data to the wrong recipient, or when an unencrypted CD disc with important data is stolen or mislaid. If information falls into the wrong hands, it may tarnish an organisation's reputation [20].
   - *Information integrity* is safeguarding the accuracy and completeness of the information [20, 21] by ensuring that the information is whole, complete, accurate, and can only be changed by authorised people [19, 36, 39, 20, 21, 40]. The integrity of information can be breached by intentional modification by an unauthorised user. Clinical information has value as a basis for healthcare professionals in decision-making [41, 20], and corrupted information can lead to misguided decisions with harmful or lethal consequences for a patient [41, 20].
   - *Information availability* is ensuring that the information is accessible for use by authorised people, at the right time [19, 36, 39, 20, 21, 40]. Without timely information, organisations cannot make well-timed decisions which may cause financial

loss, hinder normal operation, or even lose a competitive advantage over rivals [20]. Also, lack of access to relevant medical information can harm the patient as it prevents informed clinical decisions being made, especially in life-threatening emergency situations when decisions may mean life or death [42].

Since information is at the heart of organisations, its confidentiality, integrity, and availability is crucial to any organisation's long-term survival [21]. Information security deals with three information security goals ensuring they are in the right balance for applications [19, 20, 21, 43, 22]. However, information security is a complex issue that is not always straightforward as the act of balancing these goals is a challenge when building secure information systems, especially as the goals are often in direct conflict [19, 44, 21, 40]. For instance, preserving information confidentiality through access prevention can compromise its availability, and allowing more availability can result in an insecure information system [19, 40]. Therefore, establishing a balance that satisfies the information user and the information security officer is a trade-off between the three information security goals [40].

However, the balance between the goals for an application may not be constant, but subject to adjustment depending on the current situation. Thus one goal can be more dominant in one situation and less in another to meet the current needs. In a healthcare application, a patient's information is confidential [45], and access in a regular diagnosed treatment pathway requires a reasonable level of confidentiality in the balance, as this information should only be available to healthcare professionals treating the patient on a "need-to-know" basis [45]. So, to guarantee care continuity, this information is made available to a small group of healthcare professionals involved in the treatment plan. However, if this patient is involved in a car accident and rushed to the hospital's Accident & Emergency (A&E) department, the balance may need to change by lowering confidentiality to allow the emergency team speedy access to this information as time is the enemy in this treatment. Without this change, decisions would have to be made on incomplete information and this may cost the patient's life. Thus in this situation availability is dominant in the balance, and once the emergency is over the level of confidentiality must be put back to its original level to prevent unauthorised access. In an intellectual property system, information confidentiality is even tighter than in the context of healthcare, as it is a prerequisite for a patent application. Hence, if information about the invention is made available even to one person prior to filing a patent application, that disclosure may invalidate any patent granted and leave the applicant with no rights [46]. In such cases, information must be only available to the absolute minimum number of people. Here, it may be necessary to sign a Confidentiality Agreement, if speaking to a professional before the application is made [46]. This agreement is a legal means to maintain this extremely high

level of confidentiality. However, after the patent application is approved the balance must be revisited to change its availability to make the information available publicly through designated channels to help with marketing. This means the level of confidentiality is no longer important. Organisations attain the right balance between the three goals by creating a high-level information security policy, which is reflected in the design's middle and low levels by increasing technical detail [36, 21]. This high-level policy is a long term document, and hence, should be a technology independent description of the security countermeasures that are required to enforce this balance of the information security goals [36].

2. **Middle-level:** ***Defining What Needs to be Done***

   The middle level defines what needs to be done to ensure the right balance between the security goal which is achieved by identifying threats that can upset the balance and the controls that help enforce this balance within an information system. According to the International Organization for Standardization (ISO) [47], organisations must take a comprehensive and systematic approach to protecting the confidentiality, integrity, and availability of their information, otherwise it will be vulnerable to a wide range of possible threats [48, 21]. Threats are "things that can go wrong or that can 'attack' the identified assets" [21]. Threat Modeling [49] and Risk Assessment [21] are two well-known and widely used methods which identify threats associated with information assets, but Risk Assessment is more comprehensive and goes beyond Threat Modelling by identifying risks as well as threats. Risk Assessment is a systematic study of assets, threats to these assets, vulnerabilities, and impacts. This is used to identify risks by assessing the probability and consequences of these threats [21, 48]. This assessment helps organisations identify the potential business harm resulting from each of the identified risks, and assess the likelihood of failure, to allow selection of information security controls as countermeasures to risks [21]. Information security controls fall into five types: directive, preventive, detective, corrective, and recovery. The ISO standards suggest a wide-range of controls for risk mitigation (for some examples see [48, 50]). Organisations must select appropriate controls using their risk assessment as guidance, to enforce the defined balance of information security within the information system. Thus, identifying threats and information security controls in the information security policy creates a foundation for making decisions about how the information security is implemented in the lowest-level of information security design, to mitigate the impact of threats using the identified controls to achieve the initial goal [36].

3. **Low-level:** ***Defining How it is Going to be Done***

   The lowest level of information security design gives details of the implementation of

the identified controls in a specific technology by describing the processes, procedures, mechanisms, and countermeasures used to protect the information system from the identified threats and enforce the information security goals [36, 21]. These should reflect the risk assessment outcome [21]. At this level, the identified information security controls from a higher level need to be interpreted when applied in a specific technology context [50], and therefore, the information security policies at this level change if the technology changes [36]. One of the most widely used security mechanisms today to control users' actions in the information system is Access Control (AC) [39]. It consists of three elements responsible for the storage, decision, and enforcement of these low level policies in a controlled environment. AC enables the implementation of business practices that limit abuse and system vulnerabilities to threats [36, 39, 1].

The three conceptual levels of information security design are presented in Fig 2.1.

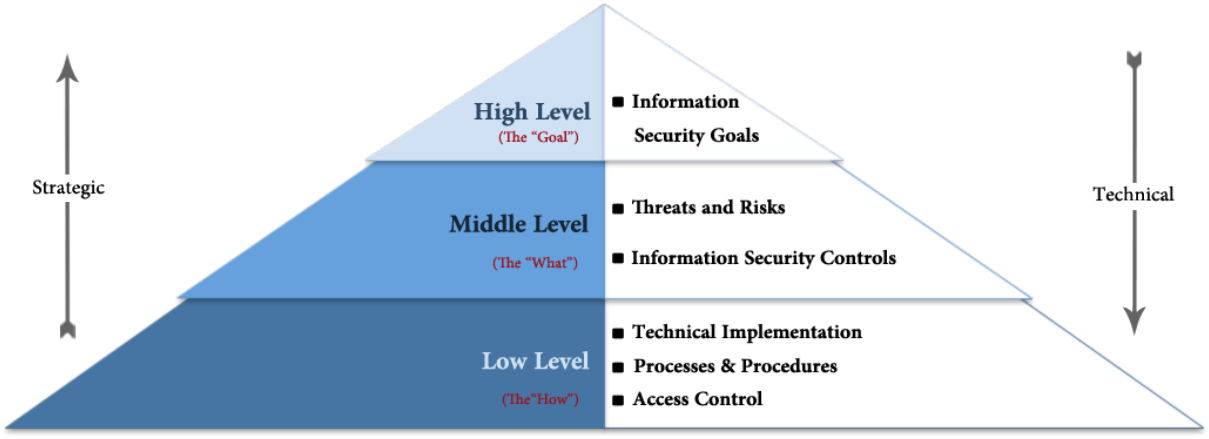


Figure 2.1: Information Security Design Conceptual Levels.

The upper levels of this conceptual information security design aim to carefully set a high-level balance between information confidentiality, integrity, and availability to ensure the information is kept from unauthorised users, is accurate and complete at all times, has timely availability for decision-making processes, and attains the right balance by creating an organisation-driven information security policy. This defines the normal rules for access to the information within the physical boundaries of the healthcare organisation, and prevents any threats from breaching the balance. Whereas, the lower levels aim to enforce this information security policy in an information system using AC elements. Following an information security design approach helps derive an organisation-driven information security policy that reflects the style and culture of the organisation. This helps its acceptance within the organisation [21]. However, there is no perfect information security because what is secure today may not be secure tomorrow, and hence, information security cannot be absolute as it is not static, but highly dynamic [39, 21, 40,

22]. Therefore, it is considered to be an on-going process and not a goal [21, 40]. This makes it crucially important to continually reevaluate and revisit the balance of information security through continuous monitoring, and measurement [21, 22] which ensure as little "wiggle room" as possible [21]. This is to make sure the high-level balance of the information security goals, middle-level threats and information security controls, and low-level processes and procedures and technical implementation are completely up to date, and reflect current risks [21]. Calder and Watkins [21] state it is good practice for an organisation to revisit this balance at least once a year at the high-level of information security design, and more frequently at the lower levels as they are more technology-dependent.

2.3.2 Information Security Policy Readability

According to James [38], the information security policy can be manifested in documentation, system configurations, or technical controls. These variations are interpretations of the same high-level information security policy to suit the targeted level of information security design (see Fig 2.1). Therefore, an information security policy is expressed in different formats categorised by Creative Commons [51] as security officer-readable, human-readable, and machine-readable information security policy formats.

- **Security officer-readable format.** This format contains a full description in "legal code" that satisfies legal requirements and is understood by a specialised information security officer. It is used in the creation and implementation of the information security policy at both the human and machine-readable levels [51, 37].
- **Human-readable format.** This format targets all stakeholders who fall within the risk assessment scope and use the technology to access the information. This format should communicate the policy in a readable and easy-to-understand language to educate these stakeholders about its content and get a buy-in from all of them. This ensures the information security is well received, accepted, and implemented by them [36, 37, 21, 7].
- **Machine-readable formats.** This format consists of a set of programatically coded technical controls and implementations which are carefully selected to reflect the information security policy and enforce it at a low machine-readable level transparently to the users [51, 7].

The scope of the business information, as well as, the risk assessment includes consideration of people and it is crucial to consider the human factor as part of the overall process of information security management [37, 20, 21, 40]. However, this research focuses on threats related to information security policy inconsistency in the context of collaborative environments and studies

the virtual integration of these policies in harmony at the machine level and not the human level, and hence, it does not focus on this aspect, and mainly draws boundaries around the policy implementation and enforcement at the machine level with a slight unavoidable incursion into the human factors; mainly when it affects these implementations.

There is a direct link between the information security design (section 2.1) and the policy formats in terms of comprehensiveness, technical-richness, and human readability. The higher the level of information security design, the more strategic and comprehensive the policy becomes and easier for stakeholders to understand, but it also becomes less technical. In the lower levels of the design, the information security policy is more system-dependent and focused which makes it less comprehensive and human-readable, but more technically rich. However, no matter what the format of an information security policy is, it will link back to one core policy (namely the high-level information security policy) that defines the basis for all representations [38] as this ensures a consistent policy is being implemented in the organisation. An information security policy contains a number of information security rules that define the conditions under which someone is permitted to access information resources in an information system and what specific privileges they need [1, 37]. Each of these different formats expresses the same set of information security rules at different levels of abstraction and technicality to help with the acceptance, implementation, enforcement, and compliance with the information security policy [37]. These information security rules are what defines the balance of information confidentiality, integrity, and availability.

2.3.3 Information Security Policy Enforcement

One of the key aims of an information security policy is to control user's access to information assets within an information system. According to Ferreira *et al.* [52] this is achieved through three interrelated steps: identification, authentication, and authorisation. Identification is the act of the user saying who he or she is, using a username and a password for instance [52]. The user is authenticated, by checking the username and password match the records. This is the act of verifying the user's identity [53, 33] to prove that the user is who he or she claims to be [52]. An authenticated user is then authorised to access requested information [52, 36]. Authorisation is the process of granting users access, based on their access rights or privileges and it allows a user to perform a business process [36, 33].

- **AC**

  An AC is part of the authorisation process that controls the users' actions in the information system [52]. It ensures that an authenticated user only accesses what they are authorised to do, and determines if authorisation should be granted or rejected [36, 52]. There-

fore, AC is claimed to be "the most fundamental and most pervasive security mechanism in use today" [39]. OASIS eXtensible Access Control Markup Language (XACML) [54] is the de-facto AC standard referenced by ISO standards [55]. Burnap *et al.* [1] summarise the OASIS XACML architecture as consisting of three main elements (see Fig 2.2): Policy Storage Point **(PSP)**, Policy Decision Point **(PDP)**, and Policy Enforcement Point **(PEP)**. The PSP stores and manages the information security policies. The PDP evaluates access requests against the stored policies to make an access decision as to whether the user is or is not allowed to perform the requested action on the target information resource. The PEP submits access requests to the PDP and enforces the decision made by the PDP.

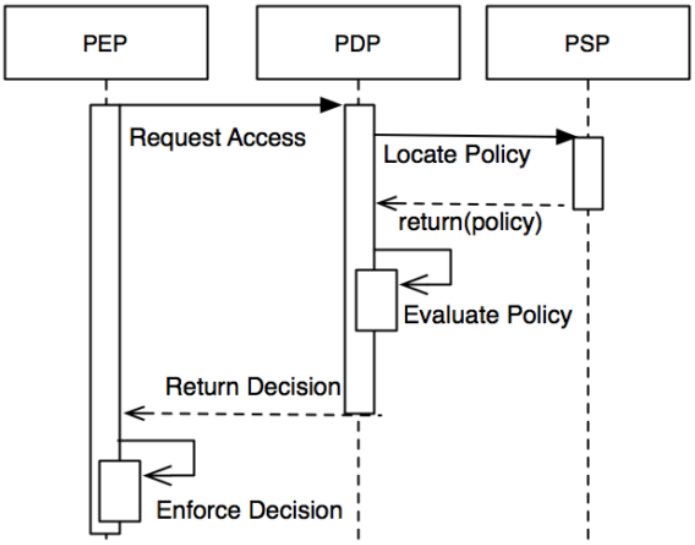


Figure 2.2: Interaction between access control elements [1].

AC has been extensively investigated in the literature, and a large number of different AC models have been delivered [26, 39, 43]. These AC models (also known as policy-enforcement models) are efforts to tackle different aspects of the information security problem in information systems in a wide range of application domains [26, 43]. AC models include, but are not limited to, Role-based AC [39], Team-based AC [56], Identification-based AC [43], Lattice-based AC [57], Position-based AC, Icon-based AC [7], Provenance-based AC [58], Temporal Role-based AC [59], Context-aware Role-based AC [60], and many more. The key difference between these models of AC is the targeted goal(s) of the balance of the information security that is causing the problem [43]. This is because each of them has been developed to address an application-specific information security problem with a particular balance of information security goals. This links back to addressing the three information security goals so that they are in the right balance for the application to meet the specific needs of the situation. For example, the

Identification-based AC model was developed in the early days of the mainframe, to preserve integrity in a multi-user computer system and prevents one user from interfering with the work of others [43]. The Lattice-based AC model was developed in the 1970's to deal with the confidentiality of military information and the Theory of Lattice is used to define the levels of security that an object may have (based on a classification scheme), and that a subject may have access to (based on their clearance level) [61, 57]. However, no matter what the application domain targeted by these AC models is, they all share a key commonality, namely that their access decisions are made through a PDP which uses information security rules from an information security policy stored in the PSP and there is PEP to enforce them [43, 1].

- **Point-of-Control Creation via an AC**

  Regardless of the type of AC model an information system employs, a maintained interaction between its three elements (PEP, PDP, and PSP) without any interruption creates a point-of-control [1] (also known as point-of-enforcement [28], control domain [26], and security domain [21]). Calder and Watkins [21] define it as a "discrete logical or physical area of an organisation or network that is the subject of security controls designated to protect it from outside access." Hence, this point-of-control is a consistent administration point within the organisation which controls its information resources [36, 1]. Thus, an AC's effectiveness depends on the communication between the three elements. Nevertheless, a maintained communication between the three AC elements for the creation of a point-of-control defines a logical boundary for this action called a "perimeter" [1] inside of which a continuous communication between the three AC elements and their availability is not lost. This perimeter is referred to in this thesis as the *"logical perimeter"* to differentiate it from the *"physical perimeter"* representing the organisational premises and the local computer network. An AC model creates a logical perimeter if it meets Burnap *et al.*'s four rules [1]:

    1. ***"Rule One:*** *An information owner must be able to access a PSP and modify access control policy.*
    2. ***Rule Two:*** *A PDP must be able to reference the PSP.*
    3. ***Rule Three:*** *A PEP must be able to invoke the PDP.*
    4. ***Rule Four:*** *A PEP must be available and able to enforce the policy on shared information." [1]*

- **Discrete Information System with a Single Local Point-of-Control**

  Traditional LIS were designed as discrete information silos, at a time when sharing information was not common. They were built and implemented with only local usage in

mind [14, 30, 33, 1]. Therefore, the information security design defines a balance between information security goals that meet the local needs of both information sharing and security contexts, and thus, it defines access rights locally based on "rules of the house" to work for these systems' agendas [14, 30, 33]. This results in information security policies defining a user's access rights to information resources within the boundaries of the organisation's physical perimeter [10]. Therefore, these information security policies are organisation-driven and reflect the required balance of information security meeting the local information sharing needs [28, 30]. This information security policy is implemented and enforced through a single local point-of-control with a well-understood AC model for policy enforcement [28] that creates a well-defined logical perimeter meeting Burnap *et al.*'s rules. This logical perimeter is normally equivalent and limited to the organisation's physical perimeter [1], where the interaction between the AC elements is maintained without interruption. This means these discrete information systems are autonomous, and the information is controlled through a single local point-of-control.

2.4 Information Security in Collaborative Environments

It is difficult to ensure information security in collaborative environments with multiple distributed information systems because they create new information sharing and security contexts that are different from any of the individual systems [30, 21, 33, 23, 1, 22]. Such collaborative environments consist of a collection of users and distributed resources from geographically and administratively distributed organisations that own and manage the resources[26, 28, 29, 30, 21, 32, 31, 23]. Such information-rich environments generate information resources as a result of the collaboration, and thus, require seamless cross-organisational information sharing that deals with access rights from outside the local organisation [30, 23, 1]. Also they always have to consider a dynamic set of users as the group of collaborators may change continually in this environment as can the aim of the collaboration [30, 33, 22]. Therefore, both information sharing and security contexts may have different requirements than the ones in the discrete autonomous information systems involved in the collaboration. ISO standards help organisations comply with the requirements of the Data Protection Act 1998, and the other regulations related to information security and privacy mainly through the ISO/IEC 27000 family [21, 36], which are global standards well-known and used for discrete information systems. However, history of the ISO standards related to information security management are gradually providing more consideration for collaboration contexts, but they lack a comprehensive list of information security controls suitable for collaboration [22]. Thus while information security and privacy related issues are more important in collaborative environments than in the current traditional discrete

information systems [30, 21, 33], the lack of standardisation makes it more challenging and difficult to achieve.

2.4.1 Characteristics of Collaborative Environments

Attaining the balance of information security in collaborative environments is challenging due to the four main characteristics these environments have:

1. **Inconsistent information security policies.** Collaborative environments bring multiple autonomous organisations together [30]. Each of these organisations has its own information security policy defined by an information security design which reflects its risk environment, style, and culture [21]. These policies are local organisational-driven policies, controlling local information resources in these autonomous organisations [30]. However, bringing these local policies together for the collaboration can mean dealing with different and inconsistent - vocabularies; balances of the information security goals; threats; controls; procedures; and technical implementations. This may cause confusion when it comes to understanding another organisation's information security policies [30]. Furthermore, according to Yau and Chen [30] these policies normally do not consider the collaboration security requirements. Wasson *et al.* [28] strongly argue that virtual organisation creators and administrators coming together in collaborative environments should express new collaborative information security policies that are fundamentally different to the organisation-driven information security policies used by local administrators, so that they concentrate on information security policies to meet the needs of the virtual organisation at the collaboration level. Therefore, these collaborative environments lack information security policies that are collaboration-driven to define access rights for the new information sharing and security contexts [30, 22].

2. **Multiple points-of-control.** Each organisation has a single local point-of-control to enforce its local policy, with its AC model for policy enforcement that may be incompatible with that of other organisations [28, 30]. Also, as normally none of the collaborating organisations serves as an authority to coordinate or manage all access requests among the various collaborating organisations, there is no single obvious point-of-control designated to meet the collaboration needs [28, 30]. Therefore, shared information is left to be protected using a foreign external point-of-control resulting in a possible misinterpretation of its information security policy, which may block access to information.

3. **Inflexible logical perimeter.** The new information sharing context in such environments often requires extensive cross-organisational information sharing that breaks down the

geographic boundaries between the collaborating organisations [21, 30, 1]. This means information will have to leave the organisation's physical perimeter, which may break the linkage with the AC elements governing this information [10, 1, 28]. In other words, the logical perimeter governing the information is no longer well-defined and equivalent to the physical perimeter of the organisation. Consequently, once information leaves its local perimeter the linkage is broken and information is no longer under local control [1], as it is beyond the capabilities of the organisation's point-of-control to enforce its policy outside the organisation's physical and logical perimeter once it is shared [1]. Maintaining communication between the different AC elements is difficult in cross-organisational information sharing contexts, and needs a redefinition of the logical perimeter which stretches it across collaborative organisations [1]. This redefinition is required to break-down boundaries between information systems, and maximise the information sharing opportunities [1].

4. **Incorporation of LIS with a level of autonomy and heterogeneity.** Collaboration aims to utilise ubiquitous computing capabilities bringing multiple computing resources to work together in a cooperative fashion to solve problems or improve the quality of services [14, 13, 62, 30, 9, 11, 42]. The formation of such collaborative environments sometimes result from an evolutionary approach towards modernising systems to improve the quality of care, as for example in healthcare systems [14, 13, 9, 18]. According to Thiran *et al.* [62] "system evolution most often implies the integration of legacy components, such as databases, with newly developed ones, leading to mixed architectures that suffer from severe heterogeneity problems" [62]. Moreover, this process always has to consider a dynamic set of participating LIS that may change continually being linked in the environment [30, 33, 22]. Although LIS are often brittle, slow, nonextensible, expensive to maintain, and harder to integrate with other systems [17], they are "typically the backbone of an organisation's information flow and the main vehicle for consolidating business information," [17] which makes them "mission critical" [17]. However LIS have a level of autonomy and heterogeneity that adds an element of complexity making them harder to bring together in harmony. Therefore, it is crucial that any integration of LIS with other systems in the collaboration should be able to meet the overall goal and dynamism of the collaboration, while embracing the LIS's local autonomy and independence.

2.4.2 Challenges in Securing Collaborative Environments

Four characteristics represent challenges that make compliance with the information security policies of the collaborating organisations a complicated task [28], and hinder the attainment

of the right balance of information security required to achieve a Secure Collaborative Environment (SCE). Hence, traditional discrete information systems are ill-equipped to adjust to the emerging information security needs in collaborative environments, and this highlights the need for enhanced AC technology to implement authorisation across an organisation's physical perimeter [1] that meets the four challenges for achieving an SCE, namely:

1. **Common information security policy:** collaboration-driven information security policies with the right balance of information security that best meets the needs in the new information sharing and security contexts.

2. **Single point-of-control:** a single obvious point-of-control for policy-enforcement anywhere within the collaborative environment.

3. **Stretchable logical perimeter:** conforming to Burnap *et al.*'s rules [1] (section 2.3.3), while stretching across the information systems to cover the whole collaborative environment with flexibility.

4. **Compatibility with LIS with a level of autonomy and heterogeneity:** ensures any solution can be integrated with any heterogeneous LIS in a loose coupling federation to ensure its flexibility for full compatibility with these systems anywhere they are used within the collaborative environment, while maintaing the LIS local information sharing and security context to maintain its routine operation support.

Meeting these challenges makes the integration of multiple local points-of-control in harmony for seamless and secure cross-organisational information sharing a fundamental information security issue in modern collaborative environments, and further investigation is needed to determine how to achieve an appropriate SCE.

2.5 Related Work and Limitations in Existing Proposals

There are a number of proposed solutions aiming to enforce policies across organisations in the literature. Using the four SCE challenges in section 2.4.2 to compare solutions helps identify their strengths and limitations, which can be used to determine how to create an SCE meeting the challenges. The following cross-organisational information sharing scenario is used in this comparison.

There is a collaboration between two companies' security domains, D_A and D_B, that aims to deliver a solution to a shared goal. Each company has its own local information security policy P_A and P_B respectively, which protects its local information and is enforced by a single local

Table 2.1: Categorisation of related work in the literature.

Group Number	Group Name	Group Description
Group #1	Traditional Approaches	These target none of the information security design levels
Group #2	Upper Level Approaches	These target the upper levels of the information security design
Group #3	Lower Level Approaches	These target the lower levels of the information security design
Group #4	Holistic Approaches	These are holistic targeting all levels of the information security design

point-of-control with a local AC model, AC_A and AC_B. These AC models are independent and may be inconsistent. If D_A shares some of its information, I_A, with D_B, then this information must be protected when it leaves D_A's local point-of-control to reside in D_B. There are many ways to provide this protection proposed in the literature. These proposals can be assigned to one of the four groups in Table 2.1 based on the conceptual levels of the information security design (see Fig 2.1), this section categorises these solutions into four groups based on which level of P_B's information security design the proposal targets when I_A is passed on from D_A to D_B.

2.5.1 Group #1: Traditional Approaches

This group does not use the information security design levels when sharing information as it surrenders the security policy once the information is shared. Traditional AC models [26] were designed for autonomous discrete information systems to meet local needs. They can only control information when it is located within the local physical perimeter [26]. Therefore, when information leaves D_A there is no option but to surrender its information security policy as it leaves and moves to D_B [26], where it can only be protected using D_B's AC model. Clinical Portal is an example of an organisation-centred information system that deploys a traditional AC model. It is a web-based healthcare support system providing test results and letters to healthcare professionals at different NHS Trusts or hospitals. Each hospital has its own separate implementation of the Clinical Portal viewing local clinical information within the hospital's perimeter, and although all the portals have a similar idea, look, and feel, each is a local implementation [18]. Therefore, their security models are not designed to share information across these local implementations. In order to share information, CT members have to log in to the different hospitals' portals using a hospital number to collect all relevant information about a particular patient [8]. This hinders the implementation of information access on a "need-to-know" basis in healthcare required by national guidelines [45]. Since this group cannot enforce

P_A outside D_A [26], the result is D_A totally loses control over its information when it leaves [26] and then D_B will have to make all the access decisions to this information complying with P_B. This is why solutions falling within this group are compatible with an LIS as they do not oblige these LIS to be integrated and do not interrupt their routine, at the expense of losing ownership over the information. Consequently, organisations may find it too risky to share information if it contains even a small range of sensitive content, and thus, the effectiveness of collaboration is hindered in this group.

2.5.2 Group #2: Upper Level Approaches

There are two solutions in this group which target the upper levels of P_B's information security design considering the "what" and not the "how." Traditional proposals hinder collaboration as D_B controls the information coming from D_A using its policy P_B. In this group, a solution is used which helps D_A govern its sensitive information using its local rules when it is passed to D_B. A policy that reflects D_A's needs is passed to D_B to enforce. Although the solutions in this group agree on the fact that originators must govern their information, they disagree on the best approach to make that possible.

- **Sticky Policies [23].** This solution creates P_a, where P_A represents D_A's holistic information security policy, $P_a \subset P_A$ that is only limited to the protection of I_A in its new home in D_B. Also, it recommends sticking this policy to the shared information using cryptographic mechanisms to communicate it securely to D_B and oblige D_B to enforce the policy using AC_B [23]. This is achieved by a technology called Sticky Policies [23]. Although this solution aims to enforce P_a remotely, D_A still does not have much control over the information, as according to this proposal, all that D_A can do, to guarantee the enforcement of its policy, is rely on D_B being a trusted authority [63, 23]. These trusted third parties keep track of promises D_B makes to access requests on I_A using audit trails, and uses these logs for forensic analysis to take legal action if D_B fails to comply with the stuck policy [23]. This solution yields control to D_B and chooses it to be the point-of-control, which guarantees a single obvious policy-enforcement point, which is compatible with any LIS in D_B as they won't be interrupted by D_A. However, it fails to create a logical perimeter stretching across D_A because this domain interrupts the linkage between the AC elements by the choice of moving only P_a, so that PDP_A cannot reference it. This breaks Rule Two of Burnap *et al.* [1]'s logical perimeter rules. Furthermore, the enforcement of P_a in D_B is not sufficient to consider it to be the sharing context created by the collaboration. This is because future information generated from this collaborative effort is neutral to both domains (no single domain claims its sole ownership [30] - let us

call it I_N) as it is not covered by P_a stuck to I_A. Also, if this neutral information ends up being governed under D_B's policies, it will still only reflect the local information security needs of D_B and not D_B and D_A. Sticky Policies technology raises another information security concern by relying on D_B to enforce a foreign policy, namely P_a. In order for D_B to enforce the stuck policy, it has to interpret and express it at the lower levels of its information security design to enforce it at the machine-level using its deployed AC_B model. Although Karjoth *et al.* [63] propose a dedicated language for Sticky Policies to formalise high-level policies into machine-level policies [63] to help D_B enforce it, there is still an element of interpretation in this approach not only by D_B, but also by the trusted authorities [23]. This means there is no guarantee that I_A will be protected in the same way or at the same level once it is located in D_B, because the AC model deployed in D_B may not be compatible with all the rules in P_a stuck to I_A or even capable of implementing them. Thus, it falls short of providing the protection level needed. Secondly, if the collaboration includes other domains, D_B may have to deal with more than one sticky policy which can introduce further inconsistencies and sometimes they may conflict, this puts D_B in a complex situation that is hard to solve, limits its capabilities, halts the collaboration, and may even prevent it.

- **Policy Integration and Conflict Reconciliation Solutions.** Yau and Chen [30] propose a solution that can address both issues raised from mentioned solutions: multiple inconsistent policies and lack of a common policy for D_B and D_A. This is addressed by enforcing one and only one sufficient neutral policy, P_N in both domains as a result of the integration of P_A with P_B [30]. This new policy aims to fully consider the local needs of both domains [30], while meeting the needs of the new sharing context created by the collaboration to govern any future information [30]. Therefore, both domains have to accept the resulting policy to govern all information resources used in the collaboration [30], P_N, which can be used locally in D_A and D_B without conflicting with either P_A or P_B. The implementation of this integration is at the upper levels of the information security design of participating domains. This decision avoids any constraint resulting from domain-specific applications and technologies. Hence, this proposal uses an ontology-based approach for the integration of high-level information security policies (expressed in natural language), where an information security policy specification language was developed to unify the expression of all policies before the integration took place. Thus Yau and Chen [30] address the policy conflict in Sticky Policies, by using a "similarity-base policy adaptation algorithm" for similar-policies integration, and a "negotiation protocol" for conflicting policies' reconciliation [30]. In the former case, assuming D_A and D_B are like-minded with similar-policies, the adaptation algorithm of this solution helps them reach an agreement on a single common policy P_N to be enforced anywhere within the scope of the

collaboration environment without boundaries. P_N is collaboration-driven and reflects the needs of all participating organisations, which by default stretches the logical perimeter "virtually" as the new policy will be interpreted and stored in each domain's PSP and enforced by the remaining elements of the domains' AC model without interruption. However, reconciliation is required in a collaboration with conflicting policies as no single participating organisation's policies takes priority over those of other organisations, and thus the only way for organisations to participate in such cases is to take certain risks by relaxing their security policies and adopting weaker security policies to resolve the conflicts and move forward with the collaboration [64, 30]. Thus, organisations may have to compromise on their information security needs for the collaboration's sake. Furthermore, the information security policies are reconciled manually, which is frequently a complex and time-consuming process especially in complex collaborative environments with a large number of participants [64]. Finally, the open question is once there is a common policy in each domain, who owns the neutral information? However, this solution does not meet the collaboration-specific protection needs due to the compromises it demands, human intervention it requires, and ownership issues it raises.

In this group, all solutions aim to assist the information originator domain, D_A, to maintain the protection levels outside its domain. However, solutions are highly dependent on the interpretation of received policies at lower-levels of their information security design to enforce this policy at the machine level. This interpretation introduces a threat to these collaborative environments by making them vulnerable to inaccurate or different interpretations by different organisations in the collaboration, because the organisations will be constrained when implementing and enforcing these policies at the lower levels by their existing applications and technology. This misinterpretation of information security policies is a serious threat that will lead to inconsistencies of policies at the machine-level which is the main issue these solutions tried to solve in the first place. Consequently, this group does not fit the needs of the type of collaborative environments discussed in this thesis.

2.5.3 Group #3: Lower Level Approaches

This group utilises the lowest level of D_B's information security design and are concerned with implementation. Solutions in this group address the misinterpretation of policies in collaborative environments. The approach is to tackle this issue by sticking, not only the policy with the information, but the AC_A elements as well. This maintains the same level of protection as the original rules over I_A remotely even after it moves to D_B as D_A's policy-enforcement model, AC_A, is used and not D_B's AC_B.

- **Digital Rights Management (DRM) [65].** DRM is a well-known AC technology that can continue to be applied to information after it has been copied, transferred and stored on another organisation's information system [65]. It is mainly used in the commercial sector since it is largely focused on payment-based dissemination controls by delivering licensed digital content, like music, to the end user to reside on his/ her machine and protect it using its original rules of D_A's AC model even after dissemination [26, 65, 7]. This is achieved by not only moving the policy along with the information as suggested by Sticky Policies, but all the other AC elements, PDP_A and PEP_A. This ensures P_A is properly enforced remotely [26, 65] using all D_A's AC elements to ensure a single obvious point-of-control with a maintained connection between the AC elements that is always stuck with the information and governing it. However, this solution is limited to the machine it resides on and the number of users having access to it. Even if the user needs to listen to music on another machine, like a tablet for instance, then this is limited to the number of times using the watermarking technique and individualisation which DRM employs [7]. This is because this technology does not allow policy update once the information, along with the stuck policy-enforcement point, leaves the physical perimeter [7, 1], which breaks Burnap *et al.*'s Rule One. Also, DRM is not flexible enough to create collaboration-driven policies in these information sharing and security contexts, as its sole aim is to retain D_A's protection in the new domain. Thus, DRM is not concerned with the security of D_B, its focus is the security needs of I_A to protect D_A's intellectual property [65, 7]. Moreover, DRM requires a viewer or browser, normally in the form of an application-compatible plug-in (i.e. add-on) that is compatible with D_B's applications [26, 65, 7]. This special software encompasses D_A's-specific policy-enforcement components and elements stuck to the shared information [26]. However, current DRM technologies lack standardisation with client-side applications [65, 7], this means it may not be compatible with heterogeneous and LIS applications, and a new version will have to be implemented specifically to suit all sorts of computing platforms and applications in all participating organisations which is not practical.

- **Welsh Clinical Portal [66].** This solution addresses the static policy used in DRM to help D_A maintain its protection level even after information is shared with D_B and be able to change it at any time remotely. It achieves this by choosing to use a unified AC, with neutral PEP_N that invokes a PDP_N, and this PDP_N references the local PSP for each domain. This unified AC can access and enforce the PSP_A in D_B and enable the information owner, D_A, to access and modify this policy which meets Burnap *et al.*'s Rule One. The Welsh Clinical Portal is an electronic front door to the various local autonomous Clinical Portals which creates a virtual electronic health record for the patient [67, 18]. This is an ongoing project designed to be delivered in different phases and

deployed incrementally, so that each completed phase is rolled out across Wales [67]. The initial phase is complete and it focuses on enabling users to only "view" records across organisations maintaining the information security of local systems, and in later phases in the future it will develop a new information security model for the Welsh Clinical Portal that is different from the local systems [67, 18]. Therefore, this solution at the current stage of development allows the PSP_A to move along with the information so the unified AC can enforce it at any time, and make it accessible locally for any later modification. This would allow each domain to maintain its local policy, so that users at D_B can only view I_A based on D_A's local rules P_A. This solution can meet some of the SCE challenges because it uses the centralised portal as an enforcement point for P_A in a single point-of-control that stretches across all integrated Clinical Portals. Also, it is designed to be loosely coupled with incorporated LIS to increase its flexibility and compatible with these heterogeneous systems, while maintaining on LIS's support for its local sharing and security contexts. However, these local policies do not meet the collaboration's sharing and security contexts, and hence, this solution lacks a common security policy and so it falls short of meeting the four SCE challenges.

- **CaNISC [68].** Short for Cancer Network Information System (Cymru), is a stand-alone disease-centred information system designed to be used for cancer care across Wales. It aims to design and implement Cancer Data Sets by creating just one set of case-notes per patient to be used for all organisations and groups across Wales [4]. However, this design holds patient information in partitions, each dedicated for an individual healthcare organisation. For example, it has a section for the oncologists at Velindre Hospital, another section for the surgeon at the University Hospital of Wales (UHW), and a third for the pathologist at Landough Hospital [3, 4]. This solution also uses a unified AC model that represents a single point-of-control that is flexible enough to stretch across all partitions. However, this AC model uses a different policy for each partition that reflects the hospital's local access rules, so that healthcare professionals at Landough hospital, representing D_B, can only view a patient's information that is located at Velindre's partition, D_A, if users at Velindre remotely allow them to based on P_A. This makes CaNISC similar to the Welsh Clinical Portal in the sense that it allows each domain (i.e partition in CaNISC) to maintain its local policy, so that each hospital can control and manage its system partition based on its local rules without consideration for the sharing and security contexts of the collaborative cancer care. Therefore, this solution does not allow clinical information to follow a patient between hospitals for treatment because it lacks a common security policy for the collaboration required for the implementation of information access on a "need-to-know" basis in healthcare when all healthcare organisations working under the NHS umbrella expect mutual capabilities to equally interpret the national rules requiring

this information access need [45, 18, 69]. However, the main difference between CaNISC and the Welsh Clinical Portal is the integration approach, where the Welsh Clinical Portal is designed as a federated loosely-coupled integration approach with LIS, while CaNISC is tightly-coupled. This is because CaNISC was designed in 1991 before collaboration needs emerged in 1997, and thus, it mostly consists of LIS that are gradually being replaced by newer systems with unified codes [18]. Since CaNISC is tightly coupled with these LIS, it lacks the flexibility required in collaborative environments to incorporate a dynamic set of other heterogeneous LIS. Failing to meet all of the challenges makes CaNISC unsuitable for the achievement of an SCE.

- **Usage Control [26].** Usage Control attempts to address the static policy issue raised by the DRM technology to provide a more flexible solution, but it uses a different approach from the one adopted by the Welsh Clinical Portal and CaNISC. It modifies the DRM solution by having two policy-enforcement points in each domain that are linked together. This technique uses the concept of a "reference monitor" [26], which is an abstract concept [39] controlling rights and usage of rights on digital objects [26]. Usage Control suggests having a reference monitor in D_A (the service provider in our scenario) named "server-side reference monitor," and another reference monitor in D_B named "client-side reference monitor" [26]. This gives more flexibility by enabling both policy-enforcement points to make access right decisions for any number of access requests against the P_A and enforce it equally in both domains to ensure consistency. However, like DRM, this technology cannot be used in collaborative environments of a heterogeneous nature which include LIS, as it requires a piece of software to be used remotely and all systems must be compatible with this software.

Thus, although this group addresses the misinterpretation of policies problem by targeting the lower levels of D_B's information security design, this machine-level implementation only considers D_A, and hence, does not consider D_B's information security needs fully in this collaborative context.

2.5.4 Group #4: Holistic Approaches

This group addresses two issues presented by previous groups, first, the lack of consideration of the information security needs of both domains when meeting their new information sharing and security contexts for collaboration and not solely D_A's needs. Second, the misinterpretation issue resulting from the need to interpret inconsistent policies at the lower levels. This group aims to combine the strength of each of the previous groups to achieve a more holistic approach that targets all levels of the information security design of all domains in the collaborative

Table 2.2: Traffic Light Information Classification Scheme [7].

Classification Name	Label	Targeted Information Resource	Protection level
Red		highly sensitive	used for information classified as "highly sensitive" that should only be shared with named recipients
Amber		sensitive	used for "sensitive" information with limited distribution requirements
Green		normal business	used for "normal business" information used within the community
White		public	used for "public" information that does not require any sort of control

environment. This is achieved by creating a collaborative driven policy, P_N, that is different from the organisations' local ones, and common to all organisations reflecting the needs of the new information sharing and security contexts at the upper levels. This policy is not organisation specific or a compromised integration of all these policies, but is a unified neutral one to all domains, which is not achieved by solutions in groups 1 to 3. While at the lower levels a unified neutral AC model, AC_N, is used to enforce this high-level policy equally in both D_A and D_B.

- **SPIDER [32].** Self-protecting Information for De-perimeterised Electronic Relationships (SPIDER), and its extension for healthcare application in [1] are examples of such holistic approaches. In order for SPIDER to meet the common information protection needs for the collaboration information security context, it uses a unified information classification scheme for the collaboration. This scheme aims to classify information resources in the collaboration based on their sensitivity level and assigns the right protection level for each category. It provides guidance around what needs to be done to protect the information resources, at the upper levels of the information security design of all domains in the collaboration. It is based on the widely used Traffic Light Information Classification Scheme [7], see Table 2.2.

  By enforcing this unified classification scheme and their protection levels at the lower levels of information security design, SPIDER avoids the need for any organisation to interpret the policy, and so, addresses the misinterpretation of information security policies issue. It enforces the policy using a unified neutral AC model, AC_N, that allows users in D_A to label the information they want to share with D_B with the right class. Then the AC_N places the appropriate information security controls to meet the protection level of classified information only around labelled content within the information resource, which then

creates the right information access rules for this labelled information before the sharing takes place and stores it in a PSP_N. Once the information is shared with D_B, only appropriate ranges of information are accessed by the right user in D_B through the PDP_N and PEP_N. The three AC elements are linked flexibly to ensure D_A's rules are enforced remotely as far as the information may travel and anywhere it may reside, yet remain flexible enough to allow modification to D_A to retain control over its owned I_A even after dissemination [32]. This maintained linkage creates a logical perimeter that stretches across organisations, and is enforced through a single neutral point-of-control. However, implementation of such a solution requires a specific application to be developed and used in this collaborative environment. This means, both D_A and D_B need to install SPIDER in their domains to prepare information for collaboration, as well as, to access it. This application may not be compatible with heterogeneous LIS and thus they cannot be integrated with them. Although this classification scheme considers the information security needs of the new information security context resulting from the collaborative environment, it only considers the sensitive ranges of information within the information resource. However, the Traffic Light classification scheme contains four classes adopted from the early developments of the the Lattice-based AC model [61, 57], which addresses confidentiality issues of military information. This means it meets specific information sharing and security contexts that may not be suitable for all types of collaborative environments with a diversity of needs. This is because the Traffic Light is mostly concerned with the confidentiality of information in the collaboration without consideration of the levels of information availability and integrity in the balance. Therefore, it is not comprehensive enough to attain the right balance in all types of collaborative environments such as healthcare. For example, Burnap *et al.* argue that information owners cannot claim full control over their information after dissemination across organisations without the ability to revoke access to this information remotely [1]. However, the nature of healthcare collaboration prohibits the revocation of access to medical information after a treatment point as it is part of the patient's history used to make decisions for future treatment plans. Therefore, it is important to adopt a more comprehensive approach that is flexible enough to meet the information sharing and security contexts of any type of collaborative environments regardless of the diversity of their needs.

- **Information Labelling Palette [7].** It proposes a solution that can target a wider range of collaborative environments by choosing a more comprehensive information classification scheme and developing a unified AC model as a plug-in to Microsoft Word applications that can enforce this scheme at the machine level for any Word application user. Information Labelling Palette creates a set of reusable icon-based for an information classification scheme based on Protective Commons [7], that extends SPIDER's classification scheme

by communicating a bigger range of information security needs "visually" to all participating organisations within the collaborative environment. Table 2.3 shows the icons.

The solution uses nine icons to create a collaboration-driven policy at the upper level and communicate it to all participating organisations in security officer- and human-readable formats so that users understand the information security need the icon provides in order for recipients to understand how to look after other people's information. Also it enforces a machine-readable format through a unified AC model that works just like SPIDER's AC model. This solution creates a common collaborative-driven policy and enforcing it in a single point-of-control that is stuck to the information as long as it is accessed through this specific platform. Also, it creates a logical perimeter that stretches across all domains within the collaborative environment. However, this solution, like SPIDER, develops a specific application for the implementation and deployment of this technique in the collaborative environment which may not be fully compatible with LIS. Also, although the classification scheme addresses the three information security goals in a collaboration, it is designed to meet the balance mainly in business application domains which makes it inappropriate for other domains like healthcare. For example, medical information has a longevity characteristic meaning it is highly sensitive and confidential at all times [70, 44, 45, 69]. The sensitivity of this information does not decay over time even after a patient's death, especially when it may be needed for homicide investigations. Therefore, it does not have a "time-limited" sensitivity as protected by the Controlled Until icon.

This group provides a platform either through a piece of stand-alone software or a plug-in hosted by a widely used application. Using this platform, these solutions create a safe environment for policy enforcement. The issue remaining, is that heterogeneous LIS are unlikely to be compatible with this piece of software. This makes these groups unfit for collaborative environments with a heterogeneous nature which include LIS.

Fig 2.5.4 summarises section 2.5 and highlights a direct relation between the security design hierarchy, and the misinterpretation of information security policies. The solutions at the upper level cause misinterpretation of the security because the foreign organisation will have to interpret the policies with lower technology- and application-constrained levels of the information security design for the enforcement. Whereas, solutions at the lowest levels do not cause these problems, but on the other hand, they are inconsistent with LIS because a dedicated application is needed to make it work and their common information security policy only suits the information sharing and security contexts of limited types of collaborations.

Table 2.3: Protective Commons Icons [7].

Icon Name	Icon Image	Usage
Restricted Access icon		Information is very sensitive and is only to be shared with specific named persons, as defined by the information owner
Organisation Only icon		Information is sensitive and should not be shared outside the company
Community Access icon		Information is sensitive, but can be shared within a defined group of people. An information sharing agreement will be in place
Authorised By icon		This information is digitally signed, and a reference will be made to the organisation's electronic signature policy
Personal Information icon		Information relates to an identifiable person and sharing is controlled according to need and as declared under the Data Protection Act
Non-Disclosure icon		Information is owned by another organisation and is used by agreement and as defined within the Non-Disclosure Agreement (NDA)
Corporate Governance icon		Information is required for corporate reporting purposes
Safe Disposal icon		The information must be disposed of securely, such as by shredder, burning, or by use of a specialist contractor
Controlled Until icon		The information has time-limited sensitivity

		Information security design levels								
		Traditional (None of the levels) 	Upper Level Approaches 		Lower Level Approaches 			Holistic Approaches (Targets all levels) 	
		Clinical Portals deploying Traditional AC models	**Sticky Policies**	**Policy integration**	**DRM**	**Welsh Clinical Portal**	**CaNISC**	**Usage Control**	**SPIDER**	**Information Labelling Palette**
AC elements		Moves none	Moves P_A	Creates P_N	Moves all AC_A elements	Uses a unified PEP_N, PDP_N, and moves PSP_A		Moves PEP_A	Creates P_N (common policy) And uses a unified AC_N	
SCE Challenges	Common policy	**N**	**N**	**N**	**N**	**N**	**N**	**N**	**Y**	**Y**
	Single Point-of-control	**Y**	**Y**	**Y**	**Y**	**Y**	**Y**	**Y**	**Y**	**Y**
	Stretching logical perimeter	**N**	**N**	**Y**	**Y**	**Y**	**Y**	**Y**	**Y**	**Y**
	Legacy compatibility	**Y**	**Y**	**Y**	**N**	**Y**	**Y**	**N**	**N**	**N**
Misinterpretation		**N**	**Y**		**N**				**N**	
Ownership delegation		**Y**	**N**		**N**				**N**	

Figure 2.3: Summary of the comparison between related work.

2.6 Achieving an SCE

Although each of the solutions in section 2.5 is appropriate for the information security problem it tackles, none actually fully meets all the challenges in securing collaborative environments incorporating LIS identified in section 2.4.2 to achieve an SCE. This makes the approaches not applicable in collaborative environments with multiple inconsistent points-of-control, and thus, not sufficient and flexible enough for the achievement of an SCE. Therefore, based on the strong points of these proposals, this section suggests a general roadmap towards achieving information security in collaborative environments that would meet all the challenges in securing collaborative environments to bridge the gap in the literature, and this defines the term SCE.

2.6.1 Bridging the Gap in the Literature

In order to meet all four challenges, a solution needs to be holistic and targeting all levels of information security design. The upper levels help understanding of the information sharing and security contexts that are reflected in a common collaborative-driven information security policy to meet the first of the four challenges. Whereas, the remaining challenges are met at the lower levels of the information security design.

1. **Common collaboration-driven information security policy.** Initially, Mense *et al.* highlight that:

   > *"one of the biggest challenges is to define and maintain an organizational framework to ensure an appropriate, agreed, and sustainable security level for such a multi-organizational (cross-organizational) information security context"* [22].

   Proposals in group four tried to define an information security policy that meets the needs of the new information sharing and security contexts. In this thesis, we suggest a more comprehensive approach than the one developed by that group. The first stage in doing this is to gain a better understanding of the information sharing context in a collaborative environment with a defined scope. The second is to use that well-defined sharing context as a foundation to develop a risk-based information security policy that meets the needs of the information security context within it. Therefore, this research aims to implement a risk assessment on the defined information sharing context to identify all threats that can impact on the sharing to deliver the right information security balance that meets the needs of the information security context. This would deliver an information security policy that would fit both, the information sharing and security contexts of the collaborative environment.

Wasson *et al.* [28] predict that the combination of collaboration-driven and local organisation-driven policies is "an important area of research and will be more difficult than simple combination" [28]. So, the key question is, how to use this defined collaborative-driven policy along with local organisation-driven policies? According to Mense *et al.* [22] the best way to protect the information resources in this collaborative context is by providing an interoperability framework at a technical, semantic, and organisational level [22] where every participating information system implements a security level based on a common overarching information security policy, while keeping its own local information security policies [22]. This research investigates an approach which uses this collaborative-driven policy with the local organisation-driven ones. On the one hand, the aim of the collaboration-driven policy is not to meet an organisation-specific information security need (the $P_{B \cup A}$ of traditional approaches, nor the $P_{A \cup B}$ of Sticky Policies, Welsh Clinical Portal, CaNISC, DRM, and Usage Control), an integration of organisation-specific ones ($P_{B \cap A}$ of policy integration solutions), nor a domain-specific (holistic approaches). This collaborative-driven policy is a neutral P_N that does not conflict with either P_A or P_B, intended to govern only neutral information in the new sharing context and is not for the domains' local use. The local organisation-driven policies are domain-specific policies. Therefore, the research suggests using the organisation driven policies to govern information as long as it is used locally, and once it leaves the local domain, the collaboration-driven policy should take over the control of the information wherever it resides within the collaborative environment. This would guarantee that each policy enforces the balance of information security in its targeted domain in harmony without interruption.

2. **Compatibility with LIS with a level of autonomy and heterogeneity.** Solutions to modernising information systems can be either evolutionary, revolutionary, or somewhere between these two ends of the spectrum. Bisbal *et al.* [17] classifies them into three categories: wrapping, migration, and redevelopment. Wrapping is at one end of the solutions spectrum, as it is a widely used evolutionary approach [17, 62]. It provides a loosely coupled integration approach to link these systems through a new interface to make them more accessible by other systems through the wrapper [17, 62]. Redevelopment is at the other end of the spectrum and is a revolutionary approach that rewrites existing applications within the LIS [17]. Migration is a middle ground, that moves the LIS to "a more flexible environment, while retaining the original system's data and functionality" [17]. However, solutions proposed in the literature, falling into group three and four, fail to accommodate LIS because of their reliance on platform-specific solutions. Therefore, in order to address this, solutions must be application independent. In collaborative environments with discrete LIS, the LIS are not moved to a new environment as they still need to serve a local organisation, and thus, the safest approach to deliver a solution in this con-

text is system-independent by incorporating the solution in the "wrapper" then linking it to the LIS without revolutionising them. In addition, this wrapping approach enables a loosely coupled integration approach with any information system within the collaborative environment regardless of its heterogeneous nature. This integration approach can provide new functionalities through the wrapper while embracing the local functionalities without interruption, and this, meets the compatibility challenge with LIS.

3. **Single authority point-of-control.** In order to meet the third challenge, where a single obvious point-of-control is needed, this research suggests developing a neutral security domain that is common to all participating organisations within the collaborative environment, and using it as a single neutral point-of-control to enforce the collaboration-driven information security policies defined earlier. The wrapper is meant to provide a linkage between all information systems within the collaborative environment, and thus represents a perfect environment for this neutral domain. Therefore, it can be used for policy-enforcement once the information leaves an autonomous systems without interfering with the policy enforcement points used locally.

4. **Stretching logical perimeter.** The fourth challenge requires a solution that stretches the policy-enforcement point across organisations anywhere within the collaboration. Since the wrapper is a neutral policy-enforcement point linking all information systems within the collaborative environment, it can be used to stretch the logical perimeter to be equivalent to the boundaries of this wrapper. This means that the AC elements interact in this wrapper without interruption to meet all the logical rules.

These approaches can meet the SCE challenges (see section 2.4.2), and thus, they are selected by this research to bridge the gap in the literature, and hence, will be adopted for the creation of a SCE.

2.6.2 Defining an SCE

This thesis defines an SCE as:

> *A collective achievement- accomplished by different actors, at different times, and in geographically distributed locations- forming a new information sharing context that meets the overall collaboration goal, and is secured using common collaboration-driven information security policies attaining the right balance of information availability, integrity, and confidentiality; without interrupting the information security contexts of local information*

> *systems. These information security policies are enforced using a single neutral point-of-control with a logical perimeter that retains the balance of information security at the same level cross-organisations any where within the collaborative environment. So that local information is protected using local rules but once it leaves and moves anywhere within the collaboration logical perimeter it is governed using the collaboration policy.*

The main challenge lies in trying to achieve this in an AC model implementation to create an SCE that meets the needs of the information sharing and security contexts of a specific collaborative environment.

2.6.3 SCE Creation in Healthcare Collaborative Environments

This chapter has identified a gap in the literature of secure collaborative environments with multiple autonomous information systems deploying inconsistent points-of-control, and suggested an approach towards achieving an SCE to bridge this gap. This approach is studied in the remaining chapters to assess its applicability, highlight its strengths and weaknesses, identify its limitations, and suggest improvements. However, achieving an SCE requires studying the balance of information security in a well-defined context, and evaluating the balance to address the aspect of information security problems in that particular context. Therefore, in order to study the application of this approach, we chose modern healthcare collaborative environments as the application context. The main reason behind this selection is that this particular form of collaboration is needed to support an PC care treatment approach, where the patient follows a treatment pathway and the information needs to flow with the patient between different healthcare providers. Many countries, including the UK, are modernising their national healthcare systems by shifting from a traditional disease-centred treatment approach towards a PC one. Most of these countries have no option but to choose an evolutionary approach to achieve this, because of the large volume of LIS currently being used in this domain that cannot be left behind in this movement. This means that modern healthcare pursuing patient-centred care are autonomous LIS; making integration of the multiple points-of-control in harmony one of the key information security issues in the collaborative environments of current modern healthcare. In addition to the complexity of this domain, there is the challenge in emergency cases where the balance of information security needs resilience. This is a crucial requirement in this domain that adds more complexity than other applications like business and government collaborative environments providing services to clients and citizens. Finally, towards achieving an SCE in PC healthcare, it is hypothesised that by interviewing healthcare professionals and leading personnel at healthcare organisations, we can define the right collaboration driven balance of information security (availability, confidentiality, and integrity) required to establish a PC treat-

ment approach where information is held in LIS, identify threats in LIS that can breach the balance, and implement an PCAC model to achieve that balance of information security, which also addresses the threats.

2.7 Conclusion

Information is an extremely valuable asset in any organisation due to the fact that it plays a key role in executing its business operation and making critical decisions. Therefore, it is crucial for a business continuity to protect it using three key steps. First, to carefully balance between information confidentiality, integrity, and availability; to make sure the information is kept from unauthorised users, accurate and complete at all times, and has timely availability for decision-making processes. Second, to attain the right balance by creating an information security policy that defines the rules for access to the information, and prevents any threats from breaching this balance. Finally, to enforce this security policy in an information system using the three AC elements: PEP, PDP, and PSP. Maintaining the interaction between these elements without interruption creates a point-of-control. Discrete information systems have a single local point-of-control for policy enforcement to keep information under its control, which makes them autonomous by definition. However, enforcing information security policies in collaboration is another story. This chapter identified the characteristics of these environments, which makes the enforcement a lot more challenging than in discrete information systems. It highlighted four challenges resulting form the complexity of such environments. First, these environments lack collaboration-driven information security policies with the right balance of information security that best meets the protection needs in this new security context. Second, there is no single obvious authority in these environments for policy enforcement. Third, the logical perimeter needs revisiting to stretch across information systems to cover the whole collaborative environment. This chapter also studied the limitations in existing proposals in the literature to meet these challenges, and finally, most of these collaborative environments are of a heterogeneous nature and contain LIS. Furthermore, four groups of proposed solutions in the literature are discussed in the chapter to highlight their limitations with respect to the four SCE challenges. The notion of an SCE was introduced that identifies the best approach to securing collaborative environments with inconsistent information security policies to bridge the gap in the literature and facilitate cross-organisational information sharing. This suggested approach towards an SCE will be studied, implemented, tested, and evaluated in the context of healthcare in this thesis.

Chapter 3

Research Methodology

3.1 Introduction

The research aims to achieve an SCE in PC healthcare collaborative environments for care continuity between different healthcare providers, to address information security in a collaboration as a result of information flow between distributed information systems. Traditionally, most information security problems are addressed at a physical level. In such cases, information security is focused on the physical development aspects of information security as part of a particular system's requirements. This physical security shows "how" the security can support the system to achieve its aim. Other security solutions, that give more consideration to information security as an essential element contributing to the business' success, address security at a logical level that feeds into the physical level. Logical information security is more focused around "what" is needed to reduce the impact of risks threatening an existing system and their definition is independent of the implementation technology. Logical security is normally developed independently from the physical considerations of the implementing systems, and thus, a logical representation of the needs is created and interpreted in the transition from a logical to physical representation of such needs. However currently, security concerns are usually considered in both logical and physical information security as an afterthought to the software being developed as they are usually fitted into pre-existing working systems [71]. Consequently, they may be limited by the software functionalities or even jeopardise them [71]. This can produce additional vulnerabilities [71] and constrain any expansions reflecting emerging requirements in the future.

SCE, on the other hand, adopts a more comprehensive and holistic approach, which is based on a security design that meets the business goal at the conceptual level then builds an information system that can achieve it and not vice versa. This information security design approach has three levels: conceptual level defining the information security goal, logical level identifying *"what"* is needed to achieve it, and a physical level identifying *"how"* to achieve this goal. Thus it not only covers both logical and physical information security development, but also goes bey-

ond them to consider the conceptual level of security design, as the basis for the development of both logical and physical security levels. The top conceptual level is important in ill-defined security problems as it helps gain a better understanding of the situation, and defines new concepts for complex real-life situations. Quantitative research methods emphasise quantification in the collection of data, and thus, are mostly concerned with statistical analysis and direct measurement of research elements [72]. While qualitative research methods are best used to gain an understanding of complexity as they emphasise interpretations rather than quantification in the data collection [73, 72, 74]. Therefore, qualitative research methods [72] and soft system methodologies [75] are essential to gain an understanding of complex and rich situations. Examples include, but are not limited to, documentation, observations, interviews, questionnaires, systems dynamics, domain analysis [25], and advanced conceptual modelling. Logical security is better in more defined situations when designing the security. At this level soft systems methodologies and qualitative methods are also mostly used to design security. Examples of tools include risk assessment, threat modelling, entity relationship diagrams, data flow diagrams, business process modelling, and relational database schema. Finally, physical security best suits well-defined mostly straight-forward situations with a predefined set of requirements. Hard systems methodologies are normally used at this end of the spectrum to develop well-defined systems requirements. Software engineering approaches, prototyping, simulation, software engineering, and WfT are all methods used to develop information security requirements in information systems. The aim of this chapter is take the reader through the process of choosing the appropriate approach, methods, tools and techniques for the achievement of the research aim.

3.2 Research Methodology

This interdisciplinary research did not have a well-defined problem on which to build theoretical considerations in relation to both the information security and health informatics for the achievement of the SCE. Therefore, it required an empirical study to collect further information to clearly define the problem. This investigated the current situation in healthcare collaboration using observations, and interacted with healthcare care professionals and senior personnel in cancer care using interviews. Towards achieving the research aim in this interdisciplinary research the researcher forms a set of research questions that help drive the process of data collection and analysis for the design and implementation of an SCE in cancer care. According to Bryman [72], this requires a deductive approach. Consequently, the conduct of this research followed a scientific research methodology using an empirical study that is based on deductive theory [73, 72, 74].

The research methodology followed in this research is conducted at a high level in four main

stages: research problem identification, research question formation, SCE design and implementation, and research evaluation. The design and implementation of the SCE at each of its three levels needed different approaches, namely: data collection to define the high level information security goal; data analysis and synthesis to identify "what" is needed to achieve the defined goal at the middle level; and the proof of concept (SHarE) development to achieve the "how" at the lowest level. These stages need different design approaches and utilise a mixture of qualitative research methods to accomplish the research's main aim. These research stages are illustrated in Fig 3.1, and explained briefly below and in more detail in the following sections. The aims of the stages are:

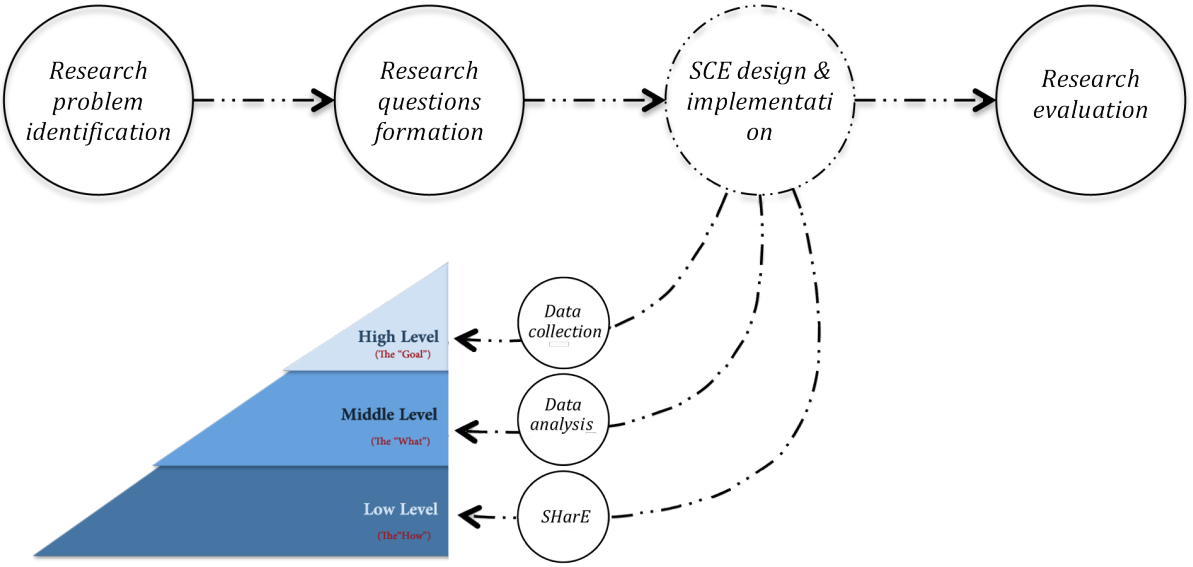


Figure 3.1: The different research stages following a qualitative research approach.

1. ***Research problem identification:*** to understand the background and research foundations used in both information security and health informatics domains, and to identify the research problem with aims and objectives.

2. ***Research questions formation:*** to form a set of research questions based on the research aim and objectives that can drive the data collection and analysis to define information security design in a collaboration.

3. ***SCE design and implementation:*** to design the information security at each of the three levels in Fig 3.1 to achieve an SCE in healthcare. This included the following substages:

   3.1. ***Data collection:*** inform the upper-level information security goal definition,

   3.2. ***Data analysis and synthesis:*** to identify the information security threats and controls.

This defines "what" is needed to achieve the goal at the middle level, and

3.3. ***SHarE development:*** to design the lower-level implementation of the controls in the prototype proof-of-concept system that defines *"how"* to achieve this goal.

4. ***Research evaluation:*** to evaluate the outcomes of the information security design at all the levels and assess whether the SCE approach addresses the research questions and achieves the research aim and objectives, as well as, to understand the implications of the research achievements.

3.3 Stage #1: Research Problem Identification

This identifies the problem in different steps using a mixture of methods including: domain analysis, conceptual modelling, observations, and interviews. Initially, there is a domain analysis which uses conceptual modelling to study PC care in the three cancer treatment pathways representing cancer care information sharing contexts. Also, there is a need to gain a better understanding of treatment in a disease-centred manner and how it is currently carried out using LIS. This will determine more fully the gap. Three currently used LIS and their usage in cancer care are investigated in this process to inform the design and implementation of the SCE.

3.3.1 *Domain Analysis and Conceptual Modelling*

Initially, there is a need to fully understand PC healthcare and its complexity, in general, and in cancer care in particular. Therefore, a qualitative tool or method is required to collect the information needed to gain that understanding. Soft systems methodology [75], domain analysis [25], interviews [76, 77], observations, questionnaires are all potential qualitative research methods that can be used [73, 72, 74]. However, PC care is best investigated through study of a real-life treatment pathway, and Map of Medicine (MoM) [6] publishes clinical guidelines for most diseases and conditions. These maps aim to improve the quality of care as part of the modernisation process of healthcare systems in the UK [6]. The pathways illustrate how treatment should be given by healthcare providers across a patient journey [6]. On the basis of the availability of these treatment pathways, there is neither a need to define root definitions for PC care, nor to conduct any interviews or questionnaires to collect treatment information from healthcare professionals as this is already reflected in the published pathways. The MoM probably used some of these methods to build the rich treatment pathways, which are accepted in the profession. This leaves us with pathways that requires intensive analysis, and thus, domain

analysis [25] was selected to gain a good understanding of how treatment should be performed in a PC way.

To study the various complexities in cancer care due to different treatment pathways, three different types of cancer were studied: Hepatocellular (HC), Upper Gastrointestinal (UGI), and breast cancers. The treatment pathways, also known as Integrated Care Pathways (ICP), were analysed for these three areas.

1. **HC Cancer:** HC cancer has a fairly simple one-page ICP (Fig G.1).

2. **UGI Cancer:** UGI cancer has a more detailed two-page ICP (Figs H.1, and H.2).

3. **Breast Cancer:** Breast cancer is the most complex of these three cancers as it has a six-page ICP in the MoM [6] (Figs I.1, I.2, I.3, I.4, I.5, I.6). Due to the complexity of the breast cancer ICPs, it was studied in more detail using conceptual modelling to understand each treatment point.

The cancers' ICPs show how treatment is done in a PC manner by showing each treatment point and they do not take account of any healthcare organisational boundaries. This is because these maps ignore any security domain boundaries which exist for the healthcare professionals following these pathways. It is important not to take these boundaries into account at the conceptual and logical levels as they are a physical feature that should only be considered at the physical level. In other words, the ICPs are ideal for understanding the information sharing context in cancer care independently from the information security context. Breast cancer is the most complex pathway of these cancers and can not be studied through its ICP alone. There is a need for enrichment details, which require further investigation. A comprehensive conceptual model of the breast cancer ICPs was created as shown in Fig I.7. In the creation of this complex diagram, each treatment point was investigated to identify the healthcare professional's role, information collected and recorded at that point, and healthcare information system and health record used to store this information. The development of this conceptual model gave a good understanding of how breast cancer treatment is achieved in a PC manner. Appendix I gives more details about this conceptual model. However, although the studied treatment pathways are fundamental for understanding the information sharing context in PC care, they are poor in illustrating how these treatments are currently performed using LIS, which is needed to identify the gap. Therefore, further investigation was needed to define the problem of the gap between the two treatment approaches.

Table 3.1: Observed MDT Sessions.

Cancer Type	MDT review	Total no. of hours	Total no. of patients
Breast Cancer	4 Normal Breast Cancer MDT reviews	8 hours 30 minutes	average of 35-40 patients per session reaching 50 sometimes [78]
	1 Metastatic Breast Cancer MDT review	1 hour	8 patients
UGI Cancer	1 UGI MDT review	1 hour	9 patients
HC Cancer	1 Hepatobiliary MDT review	1 hour 30 minutes	20 patients

3.3.2 *Observation of Current Practice and System Usage*

The investigations carried out on the three cancer ICPs highlighted that MDT reviews are essential elements in PC care, and that some cancers have more than one MDT review. These reviews are the most intensive points for sharing information throughout the treatment pathways. According to a General Practitioner (GP) [16], the MDTs were introduced in the UK less than a decade ago as an essential step towards PC care. An MDT review consists of healthcare professionals from different specialities who meet regularly (mostly on a weekly basis) to make shared decisions about the patients' care plans [9, 16]. They are fundamental in most treatment pathways [16] and represent a major information sharing point as they create and monitor the care management plans. The literature lacks sufficient information about MDT reviews and how current systems support it, and thus, understanding MDT reviews is best done by attending them in person and observing the interaction between the healthcare professionals during this fundamental sharing point, the information being shared, and how the LIS currently handles that. Therefore, to get a better understanding of the information security context in PC care, a total of seven different MDT review sessions in the selected cancers' pathways were observed (see details in Table 3.1).

MDTs help in understanding the role and limitations of LIS in supporting decision-making processes at MDTs. The outcomes from these observations massively helped in the design and implementation of the SCE. Moreover, although LIS's support for MDTs can be absolutely determined, further understanding of the architecture of these LIS and the information layer structure is needed to understand how they are used to record and retrieve information outside the MDTs at the various points of treatment. The use of three of the main information systems currently used in cancer treatments in the Welsh Cancer Centre were studied using observations inside and outside MDT meetings. These systems were:

1. **CaNISC** the stand-alone support system providing information to health professionals treating Welsh cancer patients across different NHS trusts in Wales [79]. It is designated as the central repository of breast cancer data across Wales [80].

2. **Centricity** the radiology system at Velindre NHS Trust.

3. **Clinical Portal** the web-based support system providing test results and letters to healthcare professionals at different NHS Trusts or hospital. Each hospital has its own separate implementation of the Clinical Portal to view local clinical information within the hospital's perimeter, and although they all have a similar idea, look, and feel they are local implementations with some differences [18].

These observations and studies helped the researcher gain a good understanding of these LIS's structure, limitations and weaknesses, and their usage for information sharing to support PC cancer care. However, this did not fully cover the information security context outside the MDTs, and so, the information security context is investigated next and linked with the information sharing context using a different more direct method of inquiry.

3.3.3 *Semi-Structured Interviews and Personal Communications*

A different research method is needed to collect information in order to gain an understanding of the information security context and link it to the fully investigated information sharing context in cancer care. Questionnaires, surveys, and interviews are all possible methods that can be used to achieve this. However, the aim at this stage was to fully understand, within the information sharing context in cancer care, the security policies and procedures deployed in each LIS to govern local information, as well as, the policies and procedures LIS follow to share cancer-related information between the systems across the patient's journey. This is undertaken to fully understand the information security context within the information sharing context. This information can only be collected from carefully selected healthcare professionals, information governance personnel, and senior employees in the NHS who have knowledge of information governance and healthcare systems in the UK in general, and in particular the treatment pathways used in cancer care. This is a very limited number of people and to avoid bias the design of questionnaires and surveys must not consider the respondent's role or views. This means they are less effective in this stage than interviews. Therefore, direct communication methods were chosen using interviews and various personal communications including email and face-to-face communication methods. The interviewees were chosen because of their knowledge, covering the 18 different roles in Table 3.2. These interviews and personal communications covered how PC care was supported by the current security-related and managerial procedures linking to LIS from the interviewees' perspective and what would improve this support. The interactions were based on both the role of the interviewee and the problem being investigated.

Table 3.2: Requirements interviews and personal communications.

Category	Role(s)
Senior roles in the healthcare organisation	Chair of the Cancer Service Management Board
	Clinical Director of the Velindre Cancer Centre
	Head of the Software Service Unit at Velindre Cancer Centre
	Head of Information Management & Technology (IM&T)
	IT Lead at Velindre Hospital
	Head of Clinical Information Unit (CIU) at Velindre NHS Trust
Information governance and support personnel	Cancer Centre Caldicott Guardian
	Information Governance and Security Specialist
	Information Governance Support Manager
Care team members	GP
	Breast Cancer Nurse Specialist
	Breast Cancer Consultant Clinical Oncologist
	UGI Cancer Consultant Clinical Oncologist
Care team-support personnel	Normal Breast Cancer MDT Coordinator
	Metastatic Breast Cancer MDT Coordinator
	UGI cancer MDT Coordinator
	HC cancer MDT Coordinator

These communications helped to identify the lack of information flow with the patient between the different healthcare providers as the key research problem. This was then set as the main aim and objective of the research.

3.4 Stage #2: Research Questions Formation

The collected data from the interview transcripts was manually analysed by identifying key parts. Then a full synthesis was performed to identify and group key information security requirements and concerns. Three main areas of concerns were identified and each of these three areas is associated with a level of security development: the right balance of information in collaborative cancer care at the conceptual level; threats that can breach it and the controls to mitigate them at the logical level; and the development that can implement that at the physical level. Therefore, towards achieving the research aim to achieve an SCE in PC collaborative care the following research questions were formed to achieve an SCE at each of the levels of information security design:

1. Can we define the right collaboration-driven balance of information security goals (avail-

ability, confidentiality, and integrity) required to establish a PC treatment approach where information is held in one or more LIS and the information has appropriate protection?

2. Can we identify threats in using LIS that can breach the balance?

3. Can we implement a PCAC model to achieve the identified balance of information security, which also addresses the threats?

3.5 Stage #3: SCE design and implementation

Chapter 2 identified a general roadmap towards achieving an SCE that would meet the four challenges in securing collaborative environments which bridge the gap in the literature. This roadmap is a comprehensive approach that targets all levels of information security design: the upper level where the information security goal is defined, the middle level which identifies *"what"* is needed to achieve the goal, and the lowest level which identifies *"how"* to achieve this goal. Implementation of this SCE approach initially requires defining an information sharing context as a foundation for the study of this information security context. The research narrowed the scope by choosing cancer treatment journeys as the information sharing context to study the implementation of an SCE in PC care. The main reason for this choice is that the different types of cancers and their treatment journeys are well-studied, documented, and published by MoM [6]. Studying these journeys identifies the different treatment points and these are studied to gain a better understanding of the information sharing needs among CT members across healthcare organisations for continuity of a patient's cancer care. Secondly, the Velindre Cancer Centre [81] is one of the largest cancer communities across Wales, and the study can be assessed by its staff. Finally, Velindre [82] is the home of CaNISC, which was developed at the Velindre's CIU, and is the LIS supporting cancer treatment across Wales. Therefore, developers at the CIU can evaluate the integration of CaNISC with the proof of concept SHarE.

After defining the information sharing scope, the information security context is studied at each level of the information security design using a mixture of qualitative methods and tools. This is to design and implement an SCE in the defined information security context. This was achieved through different research stages that included data collection for high-level goal identification, data analysis and synthesis for threats and controls identification, and a hard systems methodology for the development of a prototype system that implements these controls. Fig 3.2 shows the outcomes for each of the stages described below:

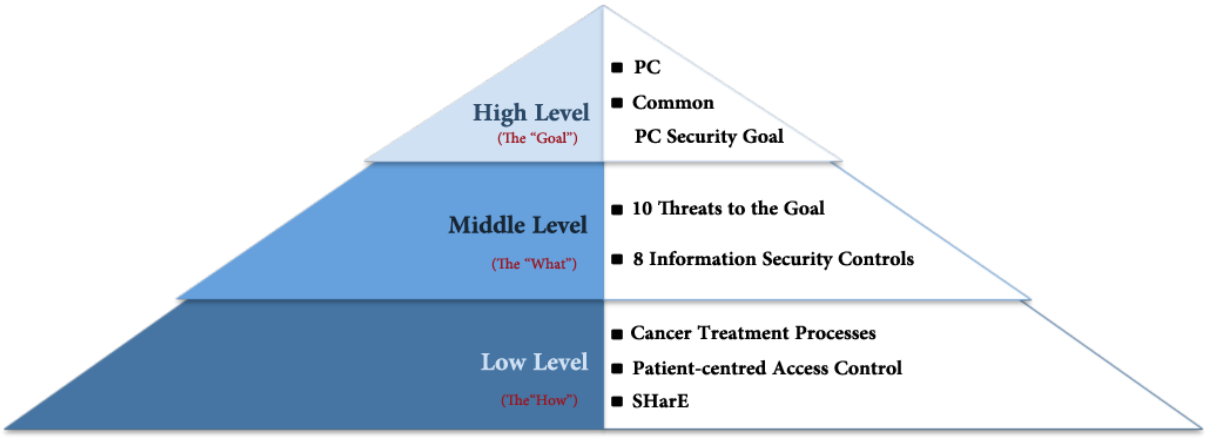


Figure 3.2: SCE design and implementation stages.

3.5.1 Stage #3.1: Data collection

This stage aims to identify the right balance of information security required in cancer treatment and the information security threats that can breach that balance. Data collection was essential to define the high level information security goal as it could not be defined without relevant data. Risk assessment is a comprehensive approach towards achieving this, which is recommended by international standards [21]. However, a risk assessment involves a number of tasks which must be carried out as part of achieving a systematic and comprehensive risk assessment process. This includes, but is not limited to, identifying all assets falling within the well-defined scope of the information sharing context. According to ISO/IEC 27002:2005 [21], there are six different types of assets: information, software, physical, services, people, and intangible assets. Therefore, to conduct a risk assessment in this research covering cancer treatment collaborative environments, an identification of every application software, system software, communication equipment, computer equipment, development tools and utilities, removable media, even furniture, and general utilities (including heating, air-conditioning, and lighting) must be carried out all the organisations involved. Also, all people working within the healthcare organisations taking part in this scope, must be interviewed to identify their skills, and qualifications. Finally, one of the most important intangible assets that needs to be considered is reputation and public image. However, this research is mainly concerned with information security in cross-organisational information sharing contexts like the cancer treatment domain, and hence, many of these assets do not fall into the scope of this research which means they are not of interest. Nevertheless, a systematic risk assessment should consider all asset types falling within the identified scope to be able to identify any information security issues within it, otherwise it will render it inappropriate since it will be incomplete. According to Calder and Watkins [21], until a complete asset-based risk assessment is conducted, it won't be clear whether the scope has

any information security issues [21]. It was decided not to carry out a risk assessment in this research as it is beyond the research scope, cannot be implemented in a time-constrained project, and not all of the risk assessment aspects are of interest to or affect this research. An alternative method that can give access to the observations of others was needed. Therefore, a qualitative interviewing form [76] was selected to conduct open-ended interviews with those who are in charge of carrying out risk assessments within the identified research scope to identify the information security balance within cancer collaborative environments and the threats that could breach them.

Hence, Dr. Tom Crosby [69], the Velindre Cancer Centre's Caldicott Guardian [69], was interviewed. His role as a Caldicott Guardian is itself part of the broader Information Governance at Velindre [83]. He is also Medical Director of the South Wales Cancer Network and plays a number of other leading roles including: Clinical Director of the Velindre Cancer Centre, Chair of the Cancer Service Management Board, and is a Consultant Oncologist treating UGI cancer [69]. This interview's aim was to identify the right balance of information security in information systems supporting cancer treatments pursuing a PC care, and the threats present in current information systems that would breach that balance. The full interview transcript is in Appendix A. The synthesis from the Caldicott Guardian's interview was confirmed by a second interview with Dr. Crosby [84] (see Appendix F), then assessed by the former head of the CIU [18] (see Appendix E), and an IT Lead at Velindre NHS Trust [85] (see Appendix F). Also, breast cancer was selected to assess the results from the initial interview with the Caldicott Guardian. This was done by interviewing a Breast Cancer Oncologist [86] (see Appendix D), Clinical Nurse Specialist in Breast Care [8] (see Appendix C), and the Normal Breast Cancer MDT Coordinator [78] (see Appendix B). In the remainder of this chapter, a synthesis from all the interviews regarding information security issues in LIS is presented.

3.5.2 Stage #3.2: Data analysis and synthesis

The qualitative interviews used to collect data are analysed to identify information security threats to treatment information as they flow with the patient between the various healthcare providers. Using ground theory methods [76], these threats were categorised based on the information security goal on which the threat was most likely to have an effect. This helped identify requirements in LIS for each category to help address the issue as a middle stage towards identifying the information security controls needed in the wrapper-based prototype that would reduce the impact of these threats. These controls represent what LIS would need to meet the goal and address the problem. Although the threats and controls are mainly identified from the interview with the Caldicott Guardian, more details around limitations in LIS were gathered from the analysis done of other interviews and personal communications with health-

care professionals and holders of senior roles in the healthcare organisation. This provided different perspectives on the same problem which were more specific to the interviewee's individual role. These interviews and personal communications collectively helped paint the bigger picture. Identifying the threats and controls at this middle level, defines *"what"* is needed to achieve the defined goal. The outcomes of this stage are used as the basis for the implementation of these controls in a prototype system.

3.5.3 Stage #3.3: SHarE Development

The implementation of the information security controls at the machine level required building a prototype proof of concept system, SHarE. The design and implementation of SHarE was conducted using a hard systems methodology. This was achieved by the following steps:

Real-Life Treatment Scenario

Any selected information sharing context need not be representative for the design of a prototype system that implements the controls. Therefore, one cancer had to be selected for an initial design and implementation in SHarE as a first step. This step is based on the analysis outcome of the three cancers' treatment pathways, and in making this choice, a real-life treatment scenario for each of the three cancers was selected and extracted from the full ICP published by MoM [6]. These scenarios were then checked by healthcare professionals involved in these scenarios.

1. **HC Cancer:** A treatment scenario mentioned by Dr. Tom Crosby [69] was selected (see interview transcript in Appendix A, and scenario details are in Appendix G).
2. **UGI Cancer:** A UGI cancer treatment scenario also mentioned by Dr. Tom Crosby [69] was selected (Scenario details are in Appendix H).
3. **Breast Cancer:** The breast cancer treatment scenario was mentioned and double checked by a Breast Cancer Oncologist [87] and a Clinical Nurse Specialist in Breast Care [88] in two separate interviews (see Appendix I for breast cancer scenario). However, due to the complexity of this cancer's ICPs, a decision had to be made regarding which route of the alternative routes the scenario could follow would be studied. Surgery was selected as the first treatment option and chemotherapy as the second. This is justified in Appendix I and this decision does not bias the results.

However, although PC care and information sharing needs were studied along each of these three cancer's ICPs and treatment scenarios, breast cancer is more complex than the other types,

and it was selected for the design and implementation of SHarE, as it would cover more situations and so lead to an outcome which gave more information when defining the next steps to be taken.

Business Process Modelling (BPM) and Entity Relationship (ER)

BPM was chosen to design SHarE. A key reason for this choice is that information flow is natural in healthcare systems and designing treatment as a business process is a perfect fit. Moreover, BPM is one of the the recommended risk assessment approaches and is based on an organisation's business processes. This is where the creation of an information security policy should start by identifying critical business processes covering the information sharing scope, then list all assets used by these processes [37]. Since one of the fundamental objectives of this research is to define a collaboration-driven information security policy across organisations in cancer care, the breast cancer treatment scenario is treated as a business process. This enables the BPM to be used to model and visualise the treatment scenario extracted from the breast cancer conceptual model as an essential business process in cancer care among different hospitals. This will clearly show the information needed and recorded at each treatment point, as well as, the physical boundaries of each hospital's security domain. This limits the point-of-control for the local organisations policies being applied to the information. However, in order to control access to information at each treatment point in the process, an ER diagram was created to design the relationship between the key elements in both the information sharing and security contexts which link them together. Chapter 6 discusses the use of ER in this project.

1. **HC Cancer:** the treatment scenario is extracted from the HC cancer full ICP (see Fig G.2) to build a business process model using the OmniGraffle application [89], which is a free available tool which was replaced with Stateframe, a more advanced software after it was installed and set up by software developers for the purpose of this project (see Fig G.3). Details are presented in Appendix G.

2. **UGI Cancer:** the UGI cancer treatment scenario is extracted from the UGI cancer ICP (see Fig H.3) to build a business process model using the OmniGraffle application (see Fig H.4). Details are presented in Appendix H.

3. **Breast Cancer:** To build a business process model of breast cancer like the other cancers, this real-life treatment scenario was extracted from the ICPs of breast cancer and the conceptual model shown in Fig I.8. This scenario was used to build a business process model drawn using the Visio application [90], and because it is an extremely lengthy and complex model, it had to be broken into 12 figures to fit the pages in this thesis. Visio

is a BPM tool supported by Stateframe Business Process Management System which was used to implement SHarE and this is why Visio was preferred over OmniGraffle for the breast cancer business process model (see Figs I.10, I.11, I.12, I.13, I.14, I.15, I.16, I.17, I.18, I.19, I.20, I.21). These figures clearly show the different hospitals, information systems, and physical perimeters, of where the information is collected, recorded, and shared. The details are presented in Appendix I.

Data Flow Diagrams and Use Case Scenarios are other possible tools available to demonstrate the information sharing and security contexts. However, while the former is perfect for data flow demonstration between different system elements (i.e. healthcare providers), it is poor at showing the security boundaries surrounding these elements to which this information belongs across the whole treatment. While the latter is good at illustrating these boundaries between different system actors (representing CT members), it is limited when it comes to demonstrating the information flow between the different actors.

Workflow Technology (WfT)

SHarE is the SCE created for use in PC collaborative healthcare. It is a proof-of-concept security system. BPM was used to design the treatment as a business process model, and WfT implements the business process models to bring SHarE to life. As cancer ICPs are a flow of information, WfT was selected to implement the prototype. This is a rational choice as WfT is a widely used tool for business process automation [ref]. It helps manage the collaboration in a manner suited to PC treatment in the information sharing context throughout the selected breast cancer treatment business process, and provides a suitable environment to implement the information security controls into these processes to control the security of the information following this pathway. These controls help achieve an SCE at the lower levels of information security design for the information security context through this wrapper-based system. WfT was selected as it provides control over each stage a patient goes through along their treatment pathway. It involves three elements: process designer, workflow engine, and workflow database. The process designer models the processes, which the workflow engine manages and executes, storing progress information in its database. WfT creates the cancer care information sharing context by modelling the beast cancer treatment process, and representing and coding the different treatment stages as: webpages, automated tasks, and prompts. In addition, the users responsible for each treatment stage and their roles are represented and tasks are assigned to each user according to their role [91]. WfT allows mapping of the treatment process using the business process designer. This includes all possible tasks and routes a patient can pass through on the care pathway. Also the management includes customising the treatment flow to meet

each patient's needs according to the decisions of the patient's CT [11]. The workflow database stores the model logic (i.e. predefined treatment stages with all possible routes) and the progress of each patient (i.e. the patient's specific route based on the treatment plan). The information tracking for a particular patient is held by creating a patient instance in the database. This is used to serve the workflow engine and is different from the databases used by the local cancer support systems. The WfT does not require the security rules to be set in advance but allows these rules to build up as the patient progresses along their treatment pathway. This flexibility is needed to achieve the balance required for an SCE in modern healthcare, supporting PC care. The details of the implementation are covered in Chapter 6.

3.6 Stage #4: Research Evaluation

This final stage aims to assess the outcomes of the SCE approach at each level of the information security design. This stage needs an evaluation method that can confirm the research problem, the presence of the information security threats identified from the interview with the Caldicott Guardian, and the controls implemented in SHarE as a solution to eliminate the impact of these threats. This assessment needs an evaluation approach where a set of questions can be asked regarding the problem and threats, then a full demonstration of SHarE along with its main eight controls can be given before another set of questions reflecting the evaluation criteria and the interviewee's role can be asked to assess the controls. Face-to-face semistructured interviews with carefully picked interviewees were chosen as the evaluation method of SHarE based on the evaluation criteria, mentioned in Section 7.2.2. The researcher had to conduct both assessment of the research problem and SCE outcomes in the same interview session. This is not ideal, since the evaluation process is most effective if the same sample assesses both these aspects, and there was a risk of not achieving this due to the limited time available for the interview and tight schedule of interviewees, it was decided to undertake both aspects in the same interview Therefore, as much information as possible is collected from the interviewees in a session. However, if the interviewee was to disagree with the research problem, then that interview would terminate for reflection on the interviewee's view and justification for the disagreement.

3.6.1 *Semi-Structured Interviews*

Interview is an essential qualitative research method that gives access to the observations of others [76]. There are different forms of interviewing in the literature [76, 77]. According to Gubrium and Holistein [76] they include survey, qualitative, in-depth, the life story, and focus ground interviewing. Each of them represent a different way of how the interviewing process

Table 3.3: Evaluation interviews.

Evaluation Category	Name	Role(s)
Usefulness and acceptance	Ms. Mital Patel	The Normal Breast Cancer MDT Coordinator
	Ms. Helen McGarrigle	A Breast Cancer Nurse Specialist
	Dr. Annabel Borley	A Breast Cancer Oncologist
	Dr. Tom Crosby	An UGI Oncologist
Setup and integration	Dr. Dave Morrey	The former Head of the developers' team in the cancer centre's CIU at Velindre Hospital
	Ms. Ann Marie Stockdale	An IT lead at Velindre Hospital
Information governance	Dr. Tom Crosby	The Caldicott Guardian at Velindre NHS Hospital
	Ms. Ann Marie Stockdale	An IT lead at Velindre Hospital

is designed and organised. First, survey interviewing is the traditional face-to-face conversion between two individuals mostly based on specific close-ended questions that direct the conversation. Second, qualitative and in-depth interviewing are more flexible with open-ended questions that can move in new related directions that emerges in the interview process, where qualitative interview is more focused on the qualities of interviewees' experiences, while in-depth interviewing takes this into "the emotional realm" [76] to understand the hidden feelings and most heartfelt views and values. Third, the life story interview is a more therapeutic form that uses narrative approaches. Finally, focus ground interviewing is a more recent form that moves in the other direction. It is a modification to the traditional face-to-face conversation form by expanding the number of interviewees. It does not aim to gather experiential facts but to explore the range and depth of shared meanings in an area.

However, this research chooses flexible qualitative interviewing as it is more theory driven and flexible with open-ended questions [76]. This form supports an interview design that meets the evaluation aim and criteria that is driven by the formed research questions and the study. Furthermore, it choses an interview analysis strategy that is based on ground theory methods [76, 77]. Five different interview sessions were conducted in the evaluation of SHarE and they are presented in this chapter in chronological order. Four of the sessions were conducted with a single interviewee, while one was conducted with two interviewees and the lead research supervisor present. The evaluation was based on three criteria: usefulness, integration and setup, and information governance. The interview design and analysis were based on these three criteria. The sample of interviewees included six personnel having the roles shown in Table 3.3.

The interviewees' roles and their total number in the chosen sample is believed to be representative for the following reasons. Initially, it is important to be selective when it comes to

the roles. This is mainly because a semistructured interview was the chosen method to define the right balance of information security in cancer care with the Caldicott Guardian in the first instance.

Consequently, the roles played by the interviewees cover the three evaluation criteria. The sample choice of interviewees' roles was made for the following reasons. Firstly, the breast cancer scenario is the cancer implemented in the prototype system, and thus, the usefulness of SHarE will be best assessed by people already familiar with the scenario and the information needs in this scenario. Therefore, three different healthcare professionals involved in the breast cancer treatment scenario were interviewed: a Breast Cancer Oncologist, a Breast Cancer Nurse Specialist, and a Normal Breast Cancer MDT coordinator. To assess the generality of the proposed system, an oncologist from another type of cancer (UGI) that was studied but not implemented in SHarE was also interviewed. Secondly, the systems' development team at the CIU where CaNISC was developed and maintained. CaNISC is the LIS used in cancer care across Wales. It is an LIS with which SHarE could be integrated. Therefore, the former head of this team was interviewed to assess the possibility of adopting SHarE and integrating it with CaNISC and other LIS, along with the IT lead who is aware of the informatics needs in cancer care and the systems used to support these needs. Finally, information governance can only be assessed by the Caldicott Guardian who understands fully the information governance needs in cancer care and the fine line between information availability and confidentiality in a healthcare collaborative environment, and this is the same person whose initial interview was used to identify the threats.

Furthermore, the small number of interviewees selected for each category is also considered representative since most of the key roles for the evaluation of the research are undertaken by one person and this is the only person who has a full understanding of the role, in order to assess SHarE from the perspective of that role. There is only one Caldicott Guardian for each hospital but there are other Caldicott Guardians supervising them. The Caldicott Guardian in the Velindre Hospital, Dr. Tom Crosby, was interviewed and when we tried to ask him to introduce us to his superior Caldicott Guardian, he highlighted the fact that this person has a very busy schedule and even the local Caldicott Guardian finds it very hard to get hold of him, which would make it almost impossible to meet him for the purpose of this research. The normal breast cancer MDT coordinator is only undertaken by one person, Mital Patel, although some other cancer MDT coordinators may cover for her in cases of sick leave. Mital Patel was the most suitable person to provide a full picture of that role for the breast cancer scenario selected in this research. The head of developers is also a unique position, and since this person was interviewed in the early stages of research when the research problem was under investigation, he was also included in the evaluation sample although at the time of the final stage he had recently retired. There are only two oncologists in the breast Cancer Centre, and one of them

was in our sample. However, an UGI cancer oncologist who also plays the role of Caldicott Guardian was also interviewed to evaluate information needs and to assess the generalisation of SHarE. The order of interviews was based on the availability of the selected people for an interview.

3.7 Conclusion

This research was conducted using a scientific research methodology that is conducted at four main high-level research stages: research problem identification, research question formation, SCE design and implementation, and research evaluation. A mixture of carefully selected research qualitative tools and methods were used at each research stage. First, domain analysis, conceptual modelling, observations, and interviews were used to identify the research problem. This is understanding the background and research foundations used in both information security and health informatics domains, and to identify the research problem with aims and objectives. Second, data analysis and synthesis were used in research question formation based on the research aim and objectives that will drive the data collection and analysis to define information security in the collaboration. Third, these research questions helped direct the data collection and analysis for the SCE design and implementation at each of the three levels for the information security design. Finally, semi-structured interviews were used to evaluate the outcomes of the information security design at all the levels and assess whether the SCE approach addresses the research questions and achieves the research aim and objectives, as well as, to understand the implications of the research achievements. These research stages achieved an SCE in PC healthcare and met the research aim.

Chapter 4

Patient-Centred Healthcare

Overview

This chapter introduces Patient-Centred (PC) care and the associated collaborative environments of modern healthcare needed to deliver this care. It highlights its main characteristics and compares it with traditional disease-centred care, explaining the global movement towards PC care, and why the adoption of this treatment delivery model will affect information system support as it will enable the sharing of information currently held in autonomous information systems into the created collaborative environments. The initial steps towards the achievement of a SCE by defining a common collaboration-driven information security policy in PC healthcare using LIS is explained.

4.1 Introduction

"Population ageing is a demographic revolution affecting the entire world" [2] due to medical advances, increased child survival, and improved health care. This is evidenced by figures published by the UNFPA [2], see Fig 4.1, which shows the increasing number of people aged 60 or over between the years 1950-2050 in the world's developed and developing countries [2]. However, this does not mean that older persons should be a burden [2]. Older people's health condition requires a more holistic care as comorbidity is more common in older patients than in younger ones [8]. Patients with comorbidity suffer from more than one condition at a time, and so they follow multiple treatment pathways. It is clear that healthcare delivery systems need to cope with this emerging need, and be ready for the ageing population, with modern integrated healthcare services that can cope holistically with a patient with more than one health condition.

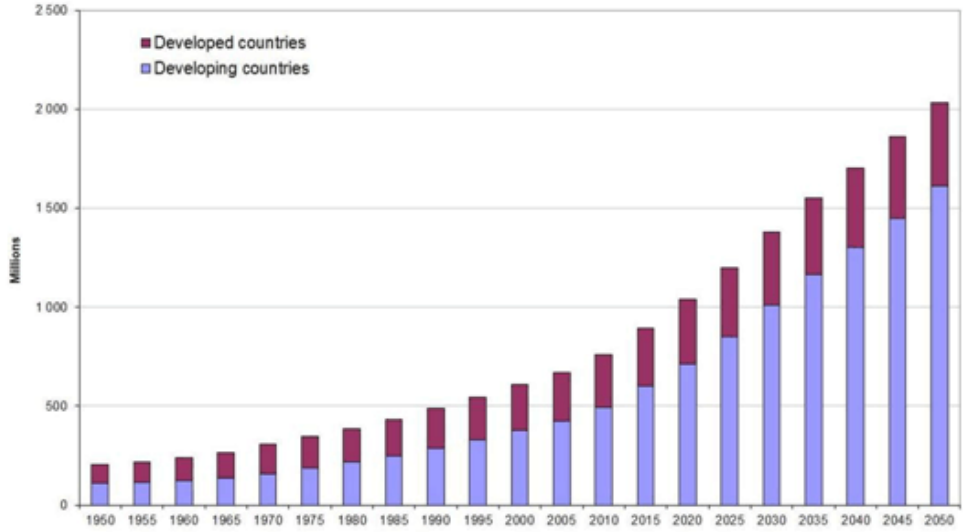


Figure 4.1: Number of people aged 60 or over: World, developed and developing countries, 1950-2050 [2].

The delivery of healthcare in many countries has been shifting from a traditional fragmented disease-centred approach towards an integrated PC approach. This is where care provision is tailored to meet an individual patient's needs holistically. PC care is the basis of healthcare collaborative environments today, which require the flow of medical information with the patient between different healthcare providers as they follow a treatment plan. Many countries are using an evolutionary approach to shift towards PC care by building integrated systems based on the sound foundations of the current LIS to support the PC care. Achieving an SCE in PC healthcare, which allows all carers of a patient access to required information held in different LIS, demands attaining the right balance between information availability, integrity, and confidentiality at the collaboration level that meets the overall care goal, while retaining the balance of

local information security for shared medical information among the care team. However, LIS fall short of achieving an SCE due to the compromises they have to make in terms of information availability, integrity, and confidentiality. Thus, LIS require additional security features to cope with this emerging need if they are to participate in SCE. Chapter 2 discussed a general roadmap towards achieving a SCE that would meet all four challenges in secure collaborative environments. Therefore, achieving an SCE in PC care using LIS requires the implementation of a comprehensive approach that targets all levels of information security design for these LIS. The upper levels achieve a collaboration driven information security policy that defines the right balance of information security meeting the needs of the new information sharing and security contexts. This requires defining the information sharing context that is the scope of the information security context, and identifying any threats within that scope that would breach the balance of information security. In this chapter the information sharing and security contexts are studied to identify the balance of information security needed. This high level task meets one of the SCE challenges. The lower levels meet the remaining challenges by enforcing this policy to retain the balance of information security in these systems in harmony using a wrapper. This is achieved by identifying the requirements needed in this wrapper to eliminate the threats' impact, and enforce the balance of information security. This low level task meets the remaining challenges to achieve an SCE that meets the needs of this collaboration.

4.2 PC Healthcare Movement

Modern integrated healthcare services are an essential part of e-health [92]. They use ICT to enhance collaboration, communication, and coordination in the health sector [27, 92]. At the heart of this integration of care lies PC healthcare [13], defined as:

> *"A collaborative effort consisting of patients, patients' families, friends, the doctors and other health professionals . . . where patients and the health care professionals collaborate as a team, share knowledge and work toward the common goals of optimum healing and recovery"* [93].

In the global adoption of PC care [31, 14, 9], patient treatment is shifting from a traditionally fragmented disease-centred approach towards an integrated PC one [93, 13, 14, 9, 11]. Disease-centred care is also known as traditional healthcare [70], doctor-centred [93], hospital-centred [93], location-based, and clinic-centred healthcare [44]. In a disease-centred approach healthcare professionals use a treatment approach reflecting the needs of the disease diagnosis. Care for the patient focuses around the needs of the professionals treating the patient [9, 10]. This leads to each professional using an information silo to store information about patients with the

same disease, and this is held in their organisation and managed by an independent stand-alone system not integrated with any other disease silo [10]. Access to patient information is limited to the physical boundaries of the provider [10]. Any decision-making process is fragmented and based on limited available information, as each healthcare provider keeps patient information "hidden" from care providers in other areas [9].

PC care has a more holistic view that considers the patient's condition as a whole in contrast to different healthcare professionals treating each diagnosed disease separately [11, 12]. The patient is kept at the heart of these healthcare services and care is integrated and tailored around the patient's needs and current state [13, 14, 10, 15]. It encourages healthcare professionals to adapt to these needs [15] by collaborating as a Care Team (CT) [11] and using shared decision-making processes in regular MDT reviews [9, 16], mostly on a weekly basis [16]. Also, each CT member collects and shares relevant information with other members. This collectively forms a complete patient record about the holistic condition of the patient, covering all the patient's multiple conditions in cases of comorbidity. This encourages using appropriate information-sharing mechanisms among CT members while still preserving information confidentiality. Thus, central to PC care is the appointment of a "Guardian" of person-based clinical information in each healthcare organisation to oversee the sharing arrangements and make decisions when it comes to the use and sharing of clinical information and patient identifiable information [83]. Therefore, each healthcare organisation, with access to patient records, is mandated to have a Caldicott Guardian [94], who is a "senior person responsible for protecting the confidentiality of a patient and service-user information and enabling appropriate information-sharing" [94]. Each Caldicott Guardian plays a key role in ensuring the organisation satisfies the highest practical standards for handling patient identifiable information [83, 94]. There is also an overarching lead Information Governance Caldicott Guardian whose role is to make sure all local Caldicott Guardians are consistent [69]. The treatment delivery approaches have different attributes, the key emphasis in traditional disease-centred care is on record keeping [10], while the PC approach creates a "culture of open information" [15] emphasising accessibility to patient information [10], teamwork and collaboration [11], and shared decision-making [9, 15]. This led to PC treatment being called "shared care" of a patient [70].

4.3 Towards PC Care Adoption Using LIS

Movement towards PC healthcare is occurring in many countries. In the UK, it is taking an evolutionary approach in most of its regions due to LIS [13, 14, 9, 95]. Therefore, it is not a surprise that the transformation from LIS supporting a traditional disease-centred approach to systems supporting PC care is a concrete challenge the UK NHS is facing whilst modernising

Table 4.1: NHS Information Principles.

NHS Principle Number	Description
NHS Principle #1	information is person-based
NHS Principle #2	systems are integrated
NHS Principle #3	management information is derived from operational systems
NHS Principle #4	information is secure and confidential
NHS Principle #5	information is shared across the NHS

its health services [9, 96]. Data in the old format is stored in stand-alone information silos, and needs to be converted into the format required by the new integrated support systems [96]. The evolutionary movement in the NHS is based on the principle of "keeping what works and discarding what has failed" [14] as it believes that what is working effectively should not be discarded. This means the new integrated systems are built on the foundations of the fragmented LIS [14]. Thus for the time being, the LIS will not be discarded [14, 9, 95] but will be interfaced with the new support systems [96]. Nevertheless, the NHS strategy towards integrated healthcare specifies that healthcare systems used by healthcare professionals working patient-centrically (whether totally new or combined with LIS) should have the five information principles in Table 4.1 [9, 97]. These principles support integrated care in which the needs of patients, not the needs of healthcare support systems are at the heart of the health services. However, meeting the above information principles in an integrated healthcare system needs a supporting collaborative environment [98] that provides holistic records of a patient's health in which all CT members treating the patient can incorporate their contributions and the record is shared by the CT [99]. This environment should operate effectively, ensuring accessibility and flexibility of healthcare services across the organisational boundaries of the NHS healthcare organisations providing the care, to ensure that individuals experience healthcare that is well integrated with smooth transitions between health services in different settings [9, 99]. Nevertheless, such an environment raises key information security concerns that are barriers to the implementation of integrated healthcare using LIS and require a more secure collaborative environment. This is caused by the LIS being designed to meet the needs of traditional treatment models [14, 42], and not fully supporting the secure cross-organisational information sharing needed in collaborative environments generated by PC care. Therefore, LIS hinder the realisation of PC care in modern healthcare, and require enhancing to create an SCE where CT members can seamlessly access all relevant information at the point of treatment of a patient without losing control over it.

4.4 Achieving an SCE in PC Care with LIS

There are a number of generic solutions in the literature proposing integration mechanisms in heterogeneous systems improving LIS. These include, but are not limited to, federated database [100, 101, 102], meta-search-engine integration [103], application-specific solutions and frameworks, and metadata repository integration [104]. However, these solutions do not address information security at a high level as they are aimed at a technical build of a system that is suitable for LIS linkage that is loosely coupled databases, by embracing their local context while enforcing the collaboration and after they do not involve active LIS. Nevertheless, most of these solutions use metadata for the achievement of the federation of the data base management system and they do not address the information security in the system but deal with information security using an external information security management system to manage access to the database management system itself. This means they are suited to meet the information sharing context in the collaboration, but do not address the information security context in the collaboration at the upper levels of the information security design. This renders them unable comprehensively to address the cross-organisation information sharing in collaboration identified as the gap in the literature and ensuring security at a holistic level. Therefore, a more comprehensive approach using the SCE approach is needed.

Achieving an SCE in PC care using LIS requires the implementation of a comprehensive approach that targets all levels of information security design of these LIS. The upper levels must achieve a collaboration-driven information security policy that has the right balance of information security meeting the needs of the new information sharing and security contexts. This, however, requires defining an information sharing context that represents the scope of the information security context, and identify any threats within that scope that would breach the right balance of information security. This has not been addressed in the federated database approach to date.

4.4.1 Meeting the High-level SCE Challenge

The Right Balance of Information Security in Cancer Care

In very broad terms, according to Dr. Crosby [69], information security implementation in healthcare must aim to carefully balance between access to clinical information and patient identifiable information by those people who need to see it to support clinical decision-making, and the need to protect the clinical and patient identifiable information from those who do not treat the patient, while maintaining the accuracy of this information. He emphasised the need for this balance in information security to be at the level of an individual case record basis, and

Table 4.2: Caldicott Guardian Principles.

Caldicott Guardian Principle Number	Description
Caldicott Guardian Principle #1	Justify the purpose(s) for using confidential information
Caldicott Guardian Principle #2	Only use it when absolutely necessary
Caldicott Guardian Principle #3	Use the minimum that is required
Caldicott Guardian Principle #4	Access should be on a strict need-to-know basis
Caldicott Guardian Principle #5	Everyone must understand his or her responsibilities
Caldicott Guardian Principle #6	Understand and comply with the law

also on a more population wide group basis [69] and that it was an area that was hindering the provision of the best possible care.

Therefore, at one extreme, his role as clinical director of the cancer centre is to ensure when *"clinicians and staff see patients they have the right amount of clinical information available,"* [69] and at the other extreme, as the Caldicott Guardian he needs *"to ensure that as much security is put in place that is reasonable and practical to ensure that that is done safely"* [69]. This indicates that the balance of information security that Dr. Crosby is enforcing in the Cancer Centre is on a "need-to-know" basis as highlighted in the NHS Plan to modernise its healthcare system [45, 83, 69], while complying with the Data Protection Act 1998 [45, 83] and a long list of other legislations [83]. This includes but is not limited to - the Human Rights Act 1998, the Freedom of Information Act 2000, the NHS Code of Practice on Confidentiality 2003, the inception of NHS Information Governance 2003 [83]. The Caldicott Guardian must ensure the implementation of this information access need by making sure the *"use or flow of patient-identifiable information should be regularly justified and routinely tested against the principles developed in the Caldicott Report"* [83], see Table 4.2.

4.5 Information Security Issues Threatening the Balance

As a matter of fact, the "need-to-know" access rule has been the norm balance of information security in healthcare for decades even in autonomous discrete information systems supporting traditional disease-centred care, each with its own information security rules deployed. A discrete LIS's local information security balance is enforced within their physical perimeter already on a "need-to-know" basis. However, as each discrete information system has interpreted this high-level information access rule from the national guideline into their information security design and expressed it differently at the lower levels of the design to enforce it at the machine level. This situation, of inconsistent interpretations of the information access rule, is

causing an information security issue that threatens the implementation of PC care using these systems. This was clearly highlighted by the Caldicott Guardian, when he said:

> *"on a very high level I think because of varying interpretation of the guidance around information security, clinicians are often blocked from having the right information to treat a patient and I do not think enough weight is put on that (i.e. patients' rights of access to the best healthcare available because of variation in the interpretation of security rules)"* [69].

Therefore, moving towards PC care where the medical treatment follows a treatment pathway with care at a number of locations, requires an overarching balance of information security that implements the "need-to-know" access rule at the collaboration level without interfering with the inconsistent local implementations of this rule. This interpretation inconsistency is threatening the stability of the local balance once the information leaves the discrete LIS by compromising one or more of the security goals in many ways, along with other threats as described in the interview and discussed fully in the next section.

4.5.1 Threats to Information Integrity

LIS supporting cancer treatment are raising integrity issues as they fall short of preserving the accuracy of clinical information in that context. Among the causes of this situation are:

- ***Human error.*** The integrity of patient information can be hard to preserve once human error has occurred in the recording of the information for a patient being referred to different healthcare providers. If an oncologist at one organisation receives an incorrect code for the diagnosed cancer type (i.e. a code referring to a different cancer type) current systems do not allow him or her to change it. This is because the owner who recorded it works for a different healthcare provider, and edit access right is not granted to a consultant who works in a different organisation. Another major weakness in the current system is that it is not possible to track back to the owner of information at the point where the information was compiled. In addition, even if there is a need to write to the information originator (if known) to request an alteration, it cannot be changed remotely by the current system [69].

- ***Inconsistent results in different systems.*** Regular MDT reviews are essential to cancer treatments as the most crucial information sharing point among CT members, as critical shared decision-making processes occur at the MDT. However, the use of different hospitals' discrete information systems in geographically distributed collaborative care affects

the accuracy of information. This was highlighted by an MDT coordinator [78] who expressed extreme concern about information accuracy, which she finds difficult to preserve in the context of collaborative cancer care. She mentioned an incident in one of the MDT reviews, when the pathologist did not have some patients' results but the breast care nurse did. In such a case the consultant who examined the patient is normally at the MDT review and she/ he makes the decision as to whether the results from the nurse should be considered or the patient's case should be rescheduled to the next review awaiting the pathologist's results. However, the consultant's absence in this case made it worse, and because patients cannot be left hanging, the MDT Coordinator had to make the decision but she did not know what to do in this very confusing situation. Eventually, she put the patient on next week's MDT list, although this delayed the patient's treatment, if the diagnosis is reconfirmed, but this decision has less risk for the patient than considering wrong results. Although such cases are very rare, they still happen and it is critically important to deal with them professionally. However, the systems could help in these cases if information is organised in a chronological order, to show the treatment points and compare the date when the nurse and the pathologist saw the patient with the date of the test results. This would help the coordinator make an informed decision.

LIS compromise on the integrity of PC information, and need the following requirements to restore the right level of information integrity to suit PC cancer care.

1. Information organisation in chronological order to help track the information to the information owner and treatment points.
2. Remote information update after dissemination to allow information owners to update the information in the case of a human error incident.

4.5.2 Threats to Information Availability

Information availability is extremely critical in patient care management. According to the Caldicott Guardian, more harm is done to the patient through lack of access to relevant information, as it prevents informed clinical decisions using it, than by misuse due to the risk of information falling into the wrong hands [69]. However, LIS supporting PC care compromise on the availability of patient information for a number of reasons.

- ***Disconnected systems at major sharing points.*** MDT reviews are one of the most sensitive sharing points in a treatment journey for most conditions and diseases not only for cancer. However, in the context of cancer care a patient's case is normally discussed at

several MDT review points - the initial diagnosis of the cancer, and at key treatment points like chemotherapy and surgery. Normally before an MDT review, consultants or nurses based on the patients care, request the patient to be added to the MDT list with a note as to why the patient's case needs discussion and what information needs to be ready to enable the discussion. The MDT Coordinator prepares a list of all patients to be considered, who will come from several organisations. The relevant Cancer Service Departments are then responsible for listing reports on CaNISC in the MDT Summary ready for the meeting, and the coordinator is responsible as overall coordinator for ensuring images and other information are available [105]. However, some MDT reviews are not very successful in achieving this goal because some systems are not connected. According to an oncologist [86], this results in the MDT patient list that the MDT coordinator, surgeon, and pathologist have being totally different. So the results of patients in the list the surgeon had expected and the results that the MDT coordinator and pathologist were expecting were not there, *"so it was all a bit hopeless"* [86]. Moreover, in one of the observed MDT reviews twelve of the patients were not discussed because the information was not there at that point in time, although the patients had been referred, the information did not flow with them, and hence, was not available on time. In such a case all the MDT members said was: 'we don't know why, so we're going to investigate why this is happening and come back next week.' But a week's delay makes a huge difference to the patient's treatment as *"the clock is ticking and the patients wouldn't understand that delay"* [18].

- ***Inconsistent information security policies.*** Many LIS in the UK were designed in 1948 when the NHS was established [14] to meet the requirements of a disease-centred approach. All NHS Trusts and hospitals working under the NHS umbrella adopted the NHS national high-level policies and practice guidelines for the implementation of information access on a "need-to-know" basis, and each system adapted the policies and guidelines to achieve an organisation-driven implementation of this access need locally [106] and implemented locally. This was achieved by interpreting high-level policies into lower-level ones, which can result in different inconsistent information security policies and rules at this level. Once information is shared, the different healthcare providers can have varying interpretations of the guidance around information security [69] (See Fig 4.2).

  The Caldicott Guardian at Velindre [69] explained this in an example:

  > The South Wales service for hepatic surgery (liver surgery) is run here for patients with secondary cancers in their liver, the surgical service is based in Cardiff and the oncology is largely based here but we take patients from all over Wales. Patients are referred from West Wales to the surgeon who considers the case. Using their films and x-rays sent electronically or by disk to Cardiff.

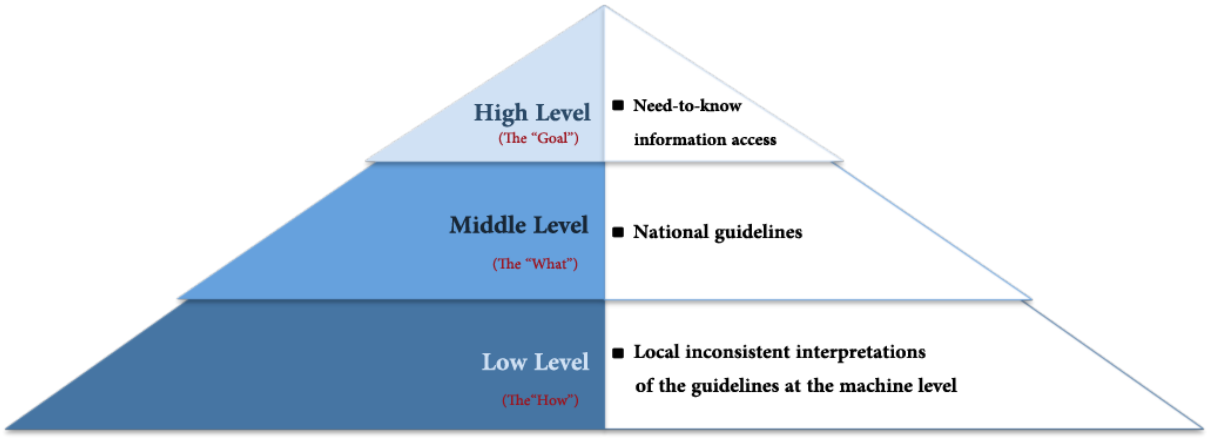


Figure 4.2: Inconsistent interpretation of the "need-to-know" information access need among various hospitals working under the NHS umbrella.

> They are discussed here by the MDT that you came to, or a similar one. But Cardiff does not have direct access to those images because West Wales are only holding on to them as... the statutory owner of the information is the patient and the original healthcare organisation. Darren Lloyd who is the Head of Information Governance has said basically that it is a wrong interpretation of the rules, clinical information should be allowed to follow a patient. He concluded: *"on a very high level I think because of varying interpretation of the guidance around information security, clinicians are often blocked from having the right information to treat a patient and I don't think enough weight is put on that (i.e. patient's rights of access to the best healthcare available because of variation in the interpretation of security rules)"* [69].

Also, current systems cannot override access permissions locally to allow access in such cases, so CT members must contact the originator to ask for relaxation of security rules [69]. This interrupts treatment continuity, causes delays, and hinders effective communication of information.

- ***Inflexible balance of information security in emergency cases.*** The big challenge in information security solutions in healthcare systems is that life threatening emergency situations require resilience, most importantly when the patient is unconscious and decisions can mean life or death. In such cases, there is a need to access any information stored about the patient, at very short notice, in the hope that it will help save the patient's life. This may require "trusted" CT members to access information not normally required for their regular treatment role [69] and, therefore, there is a need to relax already assigned access rights to enable immediate access to information when every second counts, and then restore these levels of information security. A major weakness in current LIS is the

inability to deal with such cases when the CT member's access is blocked, and writing to the original organisation requesting access [69] may delay or prevent the treatment happening in a timely fashion.

- ***Inconsistent user-hostile information layers' structure.*** LIS supporting PC healthcare today have inconsistent information structure design. Two widely used LIS in cancer care across Wales are: CaNISC and Clinical Portal.

  – **CaNISC** is a disease-centred information system. It is a stand-alone system developed as part of a bigger Information System for Clinical Organisations (ISCO) [3, 4].

  > *"ISCO is a clinical information system developed then continuously expanded and improved since 1991 by a small team in the CIU at Velindre Hospital. It allows any number of organisations to record assessments, treatments and follow-up care into a common patient casenote, which any health care professional caring for that patient can access, thus giving a full picture of each individual's care wherever that person happens to be treated"* [3].

  Since CaNISC is designed to create just one set of casenotes holding cancer-related information per patient to be used for all organisations and groups across Wales [4], these casenotes are structured into three information layers: Patient, Diagnosis, and Provider [3, 4] (see Fig 4.3).

  > "The ISCO casenote is designed to protect patient data from inappropriate use whilst allowing legitimate access. It also supports clinical audit by organisations and teams providing patient care [3]. The layers are:
  >
  > 1. **Patient Information Layer:** this has one casenote per patient. Once a patient is registered, information from any Provider is added to the patient's casenote.
  > 2. **Disease Episode Information Layer:** after registration, a disease episode can be added for the patient. A patient can have more than one disease episode (primary disease) and each disease episode is added into the system separately.
  > 3. **Referrals Information Layer:** after the disease episode is specified, a provider must add their referral to the appropriate disease episode to assist continuity of care and clinical audit" [3].

  Although CaNISC is an effective system for information sharing across systems, it is a disease-centred system that holds cancer-related information. Therefore, it was not designed to provide a holistic view of the patient's condition, especially if

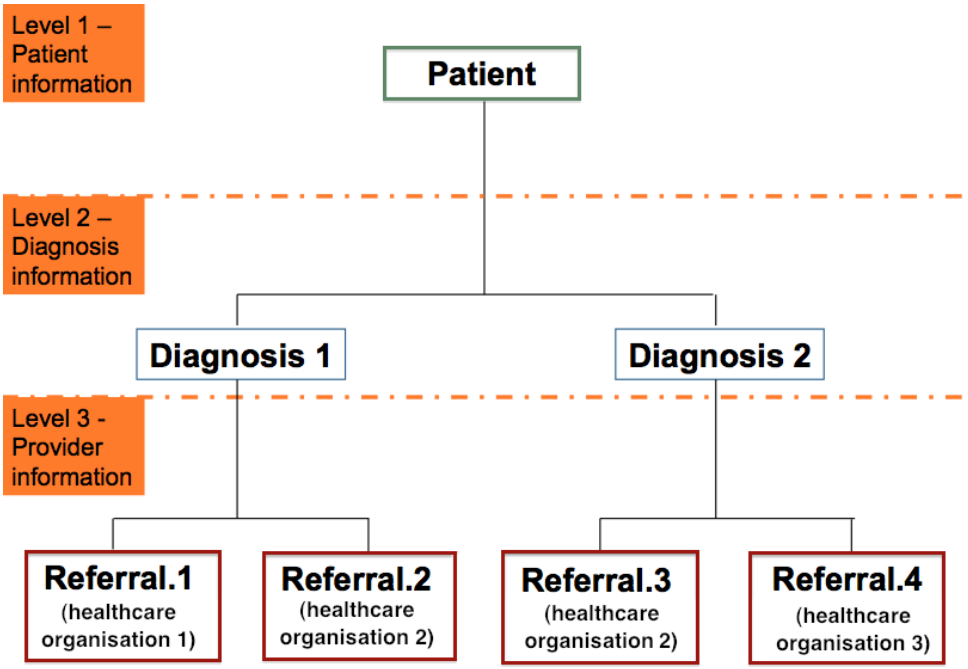


Figure 4.3: ISCO Structure [3, 4].

the patient has comorbidities. Also, the patient information is partitioned per each individual hospital [3, 4, 107]. The Caldicott Guardian stated that:

> *"the design of CaNISC is not intuitive; it's on a provider level and not a patient level. So you have to find your way around it"* [84]. He explained this in an example: *"in Cardiff and Vale, if the surgeon puts in information, even if they put it into CaNISC, they'd put it under their provider episode. And you have to have a fairly good knowledge to navigate around the casenote to find that if you were say a Velindre person"* [84].

This disease-centred information structure makes CaNISC a slow user-hostile system, that requires intensive training to be properly used to locate relevant information [8]. This was confirmed by a Clinical Nurse Specialist in Breast Care who said:

> *"we are very simple people. You know, we are nurses and we are doctors, and none of us is stupid, but that's not our priority. This is supposed to be a tool for us. Need to be able to just help us do our job, not learn somebody else's job and we do not have much time to learn how to make it work"* [8]. She summed CaNISC up as very difficult to find information, and hard work. She complained, *"CaNISC is not easy!"* [8].

– **Clinical Portal.** The Clinical Portal is an organisation-centred information system

providing test results and letters to healthcare professionals at different NHS Trusts or hospitals. Each hospital has its own separate implementation of the Clinical Portal to view local clinical information within the hospital's perimeter, and although they all have a similar idea, look, and feel they're local implementations [18]. It has a similar but different structure to CaNISC [8]. It has layers but not in the same order, as they are organised into [8]: Provider, Patient, and Diagnosis Information layers (see Fig 4.4). These layers are:

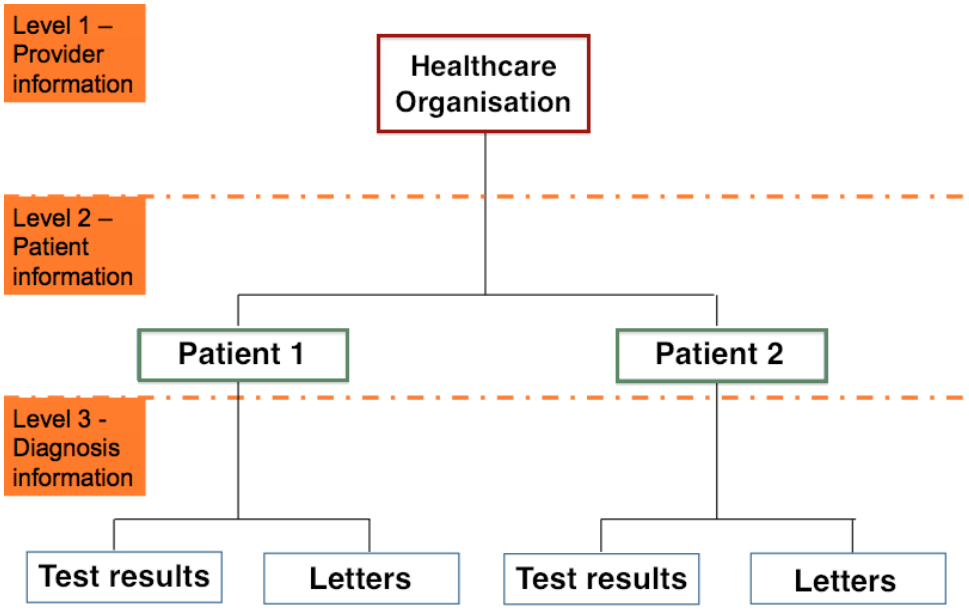


Figure 4.4: Clinical Portal Structure.

1. **Healthcare Organisation Information Layer:** access is based on the hospital number, to all the information about a patient being treated in the particular hospital.
2. **Patient Information Layer:** there is one casenote per patient, and after registration in the Clinical Portal, information from any healthcare organisation can be added to a patient's casenote.
3. **Diagnosis Information Layer:** a patient can have more than one disease or condition, therefore information added by all healthcare professionals caring for that particular patient in the hospital is categorised based on its type: as letters, test results, and so on.

Users have to log into the system using the hospital number which gives access to all the test results done in the hospital for that patient [8]. Thus, CT members may

have to do several log ins to different hospital portals to collect relevant information about a particular patient if the tests have been done in several hospitals. This is another issue for CT members, as explained by the Clinical Nurse Specialist: *"the biggest problem [with] Clinical Portal is getting into it in the first place"* [8]. This is mainly *"because if you don't have the hospital number, it doesn't like letting you in just with a name. It will sometimes, and you have to find out the right address"* [8]. Although the Clinical Portal is a more user-friendly system in comparison with CaNISC, according to the same Clinical Nurse Specialist who said: *"Portal is OK. Portal is quite quick,"* [8], however its structure makes it an organisation-centred system which is unable to provide a patient-centred view, like CaNISC.

- ***Untraceable shared information.*** To guarantee patient care continuity, systems supporting healthcare should reflect the *patient's care management* occurring in a number of healthcare organisations, and the flow of their information following the treatment pathway [69]. This means these systems should not reflect the needs of an *organisation* the patient is treated in (Clinical Portal is an organisation-centred system), nor a *disease* the patient is being treated for (CaNISC is a disease-centred system). Developing systems that reflect the patient's treatment pathway helps track patient treatment as a single business process. Currently, enhanced LIS supporting PC healthcare are designed to organise patient casenote data in parallel on a healthcare-provider basis and not in sequence on a treatment-point basis [69, 78]. Thus information management is based on the healthcare provider and each patient's casenotes are split into parallel partitions where each provider holds relevant information for a disease or part of the treatment in their partition [69]. Each provider owns and controls their part of the information [69], and they give direct access to it by listing the CT member's names as having access [69]. If a CT member happens not to be listed for access to the information (normally caused by the interpretation of security rules), he/ she will have no access until the other provider grants permission [69]. This can only make it difficult to find relevant clinical information but may also cause information duplication in the different partitions [69]. For example, when each provider submits a stage of diagnosis with obvious differences revealing a mistake, this can cause data inconsistency issues directly affecting the patient's clinical care, making it harder to locate and track relevant information at a point of care [69]. Also, these problems can lead to losing track of patients and their information at some point in the treatment pathway. For example, it may be unclear which CT member is responsible for patient follow-up after treatment [108, 106] leading to the patient not receiving this necessary health service. Additionally, care management may be interrupted when information does not flow with the patient from one provider to another on the clinical pathway (for example, when patients are referred to Cardiff from Swansea but their scan images do not follow, this can

make critical information unavailable at a treatment point and cause incorrect treatment [69]).

- ***Manual management of referrals between healthcare providers.*** According to a Breast Cancer Nurse Specialist [8], current systems do not automatically refer the patient to the CT member in charge following a treatment plan. Early referrals in the treatment pathway come from the GP, and are normally faxed to the hospital. Some GPs fill a pro forma with all the needed information including the last 10-15 visits to the GP, medical history, and medication they are on. The surgeon then looks at any of this information that is relevant to the cancer, mostly medical history, and ignores what is not relevant. Although the faxed referral stays in paper-format, relevant information is added to the cancer record in the surgeon's local information system. Any referrals happening after the initial GP referral are dictated letters that are transcribed by secretaries using a dictation system for example from an MDT review to an oncologist. The Breast Cancer Nurse Specialist explained:

  > *"At the moment... the doctors see a patient, they dictate into a machine and say: 'I have just seen this lady...' and then the secretaries pick up the tape, and they put it into a machine and they play it back, and they type it in"* [8]. She complained that although the dictation systems are as accurate as typing, they are *"causing the secretaries trouble when they dictate the letters and that is not the word they said at all"* [8].

  This ineffective referral approach may cause delays in information delivery, as well as, exposing the information to human error resulting in the information being inaccurate [8]. It is clear that current systems are incapable of handling referrals and both means used today for referrals are not practical and this aspect needs improvement. Therefore, an automated referral to a CT member's role that is picked up by the recipient with all information needed is also a key requirement in PC care.

LIS compromise on the availability of PC information and the requirements below will help restore the right level of information availability to suit PC cancer care.

1. Common collaboration driven information access needs to overarch the local organisation-driven policies.
2. Consistent information organisation needs that provide a PC holistic view which gives easy access to a patient's clinical information
3. Automated referrals among different healthcare providers with the right information for the person.

4. Gathering and filtering of relevant information, to avoid overwhelming CT members with irrelevant information. This increases the chance of finding the right information at the right time.

5. Resilience in emergency cases. This is a crucial requirement which speeds access to information for decision making in a life or death situation.

4.5.3 Threats to Information Confidentiality

- ***Improper disclosure of medical information.*** Information confidentiality is essential due to the movement towards a culture of open information, in which information access is a priority to healthcare professionals [9, 15]. A higher degree of information sharing is needed in PC care than in a traditional disease-centred approach [27, 9, 69]. Confidentiality can be breached in PC care if information is improperly disclosed to unauthorised people [69]. There are two factors increasing the risk of improper disclosure of information: the number of people having access to the information, and the value of this information [41]. PC care has a higher risk of medical information being disclosed to unauthorised people than in a traditional approach. This is due to the NHS planning to integrate separate systems run by 100 Health Authorities, around 3,500 GPs and over 400 NHS Trusts, in the modernisation of UK healthcare systems [14]. Also, there is a direct correlation between valuable information and the risk of its disclosure [41], mainly because if it is valuable to its owner, it will be valuable to someone else [21]. There are many reasons why systems supporting healthcare store highly valuable information. First and foremost, clinical information has value as a basis for healthcare professionals' decision-making processes [69], and its corruption can lead to incorrect decisions, which may harm or even kill a patient [41]. The systems hold extensive information about a patient, which may contain personal, embarrassing, and critical medical information [108]. This information has a longevity characteristic meaning it is highly sensitive and confidential at all times without decay even after the patient is dead [70, 44, 45, 69]. Therefore, the nature of medical information means it should only be disclosed for permitted medical purposes [45]. This puts PC information at great risk of improper disclosure [41] and stresses the need to keep information protected from those not needing it, while ensuring availability of life-critical information about the patient's medical condition on a "need-to-know" basis at the time of care [45, 83].

- ***Hospital-wide AC.*** CaNISC has a security model that reflects its information layer structure (see Fig 4.3). Dr. Morrey explains the security model developed in CaNISC:

> *"the way that CaNISC operated it, was to say that once you got a referral into the organisation, then anybody in the organisation can actually see it, and the way we enforced that was there's a security log, so any time anybody reads anything or changes anything, it's recorded in the database. And everybody knows there is that full audit trail"* [18].

This security model has a hospital-wide AC model that is causing some issues. Dr. Morrey highlighted these issues:

> *"the problem we ran into was when you implement that then in terms of the security model, medical secretaries for an example, or sometimes maybe a nurse, would actually have wider access than the consultant... the reason is that the consultant belongs to his firm, and he sees patients about his firm. The nurse or the medical secretary may need to cover for another medical secretary, who works in another consultant firm. So, you end up with a situation where the medical secretary or maybe the nurse in their role which spans consultant firms... have wider access than individual consultants"* [18].

The following requirements paint the full picture of a PC collaboration-driven information security which restores the right level of information confidentiality.

1. Common collaboration-driven information access needs. Although this requirement helps with information availability, it also preserves its confidentiality as it defines the fine line between these two conflicting information security goals.
2. Information security policies awareness in a culture of open information. This requirement raises the awareness of CT members as to how to look after other member's information within the collaboration to help preserve the confidentiality of shared information especially in emergency cases.

4.6 Requirements for a Common Collaboration-Driven Balance of Information Security in PC Care

These threats to PC information highlight the fact that LIS fall short of achieving an SCE, due to the compromises they have to make in terms of information availability, integrity, and confidentiality. Although threats target all information security goals, there is more weight on the compromises on information availability in the PC information sharing context. Interviews

showed that the current balance of information security in LIS used in cancer care is more concerned with information confidentiality and this may be working well locally, within its physical and logical perimeters, as this meets these systems' information sharing and security contexts. This is because information security implementation in discrete LIS focused mainly on information confidentiality and integrity as they were the information security issues at that time [19], whereas information availability was not. Pfleeger and Pfleeger recognise this phenomena in LIS and they add that it is not clear that a single point-of-control can actually enforce availability [19]. Therefore, the key reason why LIS fall short of attaining a security balance in PC care is because information availability issues were only raised by the movement towards collaboration making this information security goal a challenge in collaborative environments. So, when this information leaves these autonomous LIS, there is a need for these systems to rebalance the information security to address the compromises it makes on the availability of information for the collaboration without interrupting the local balances of information security. To cope with this emerging need, LIS need additional requirements to define a collaboration-driven information security policy that can attain the new balance of information security that has more weight on information availability. The requirements are summarised in the following points:

1. Consistent information organisation needs that provide a PC holistic view which gives easy access to a patient's clinical information

2. Common collaboration-driven information access needs to overarch the local organisation-driven policies. This requirement helps with information availability, and at the same time preserves its confidentiality. This means it is the key requirements that defines the fine line between these two conflicting information security goals.

3. Information organisation in chronological order to help track the information to the information owner and treatment points.

4. Gathering and filtering of relevant information, to avoid overwhelming CT members with irrelevant information. This increases the chance of finding the right information at the right time.

5. Automated referrals among different healthcare providers with the right information for the person.

6. Resilience in emergency cases. This is a crucial requirement which speeds access to information for decision making in a life or death situation.

7. Remote information update after dissemination to allow information owners to update the information in the case of a human error incident.

8. Information security policies awareness. This requirement raises the awareness of CT members as to how to look after other member's information within the collaboration to help preserve the confidentiality of shared information especially in emergency cases.

These eight requirements aim to reduce the impact of the threats discussed in Section 4.5, and attain a common collaboration-driven balance of information security. This achieves one of the challenges in a SCE targeting the higher levels of LIS's information security design. These requirements are used to achieve the remaining challenges at the lower levels to implement this high-level balance of information security. They present the foundation for defining information security controls for the wrapper, which will be developed as a top layer linking all LIS to enhance them in order to implement PC care safely. This wrapper is a proof-of-concept prototype system named SHarE in this research.

4.7 Conclusion

There is a global shift in healthcare delivery towards an integrated PC treatment approach to cope with the emerging needs of an ageing population worldwide. The adoption of PC care in many countries is achieved through an evolutionary approach using existing LIS, which were developed at a time when the sharing of information was not common. In collaboration with Velindre Cancer Centre this research defines a common collaboration-driven balance of information security in PC care, and identifies weaknesses in LIS used today in cancer care and uses them to achieve an SCE. Results show that the threats they present compromise on information security goals. Initially, a human error in shared information, and inconsistent results at different systems; compromise the integrity of clinical information. While, inconsistent information security policies, inflexible balance of information security in emergency cases, untraceable shared information, and inconsistent user-hostile information structure; compromises on the availability of PC information among CT members. Finally, improper disclosure of medical information, and a hospital-wide AC compromise on the confidentiality of patient information. Moreover, results show that most of the information security issues are around the availability of clinical information. This means that information security implementation in discrete LIS focused on the confidentiality and integrity of medical information as they were a key issue while availability was not. Thus, the key reason why LIS falls short of attaining a security balance in PC care is because information availability only became an issue with collaboration. These threats led to the identification of eight requirements needed to assist LIS to reduce the impact of the threats and attain a common collaboration-driven balance of information security. This achieves one of the challenges in a SCE by targeting the upper levels of LIS's information security design. The remaining challenges at the lower levels are achieved in the next chapter

to implement this collaboration-driven balance of information security to assist LIS safely implement PC care without being totally discarded.

Chapter 5

A Secure Healthcare Collaborative Environment in Patient-Centred Care

5.1 Introduction

The achievement of an SCE in PC care using LIS requires the implementation of a comprehensive approach that targets all levels of information security design of these LIS. This comprehensive approach meets all the challenges in creating an SCE, see Chapter 2, to bridge the gap identified in the literature. In Chapter 3, the higher-level challenge was met via the identification of eight requirements in LIS to achieve a collaboration-driven information security policy, that reduces the impact of threats that can breach the attainment of the right balance of information security meeting the information sharing needs in cancer treatment. This chapter presents the core of this research by introducing the concept of SHarE, which at the low level enforces the common collaboration-driven balance of information security in a wrapper-based system, to meet the remaining challenges in creating a secured collaborative environment. Therefore, the eight requirements for the high-level collaboration-driven policy are used to define eight information security controls in SHarE to be implemented via a wrapper. An information security control is a synonym for safeguard or countermeasure [48], defined by the ISO/IEC 27002:2005 [48] as a:

> *"means of managing risk, including policies, procedures, guidelines, practices or organisational structures, which can be of administrative, technical, management, or legal nature"* [48].

These controls eliminate the threats impact, and enforce the balance of information security for an LIS supporting PC care in harmony. SHarE is the implementation of these controls in a wrapper-based prototype system which allows LIS to be used from the collaborative environment without affecting the LIS local security.

5.2 Meeting the Low-level SCE Challenges

In Chapter 2, four challenges were identified to achieve an SCE, one is high-level, and the remaining three are lower level. The high level challenge was achieved in Chapter 3, which identified the high level requirements for an LIS to attain the common collaboration-driven information security policy without affecting its local security. This chapter concentrates on meeting the three other challenges, which are:

1. Single authority point-of-control.
2. Stretching the logical perimeter.
3. Compatibility with LIS with a level of autonomy and heterogeneity.

The eight identified requirements, in Chapter 3, led to the identification of eight controls to manage both the information sharing and security contexts in PC at the low level. To achieve that, a "wrapper" must be developed and directly linked with the LIS. From a software engineering point of view in this project, the wrapper is implemented in a prototype system called SHarE. SHarE manages the flow of information based on a patient's treatment pathway to meet the information sharing context, and deploys a unified AC model dedicated for PC care, called the PCAC model, which controls access to this information throughout the treatment to meet the information security context. SHarE is neutral to all heterogeneous LIS and is linked to them in a loosely-coupled layer throughout the wrapper to enforce the controls equally in all systems in harmony to create a single neutral point-of-control designated for the collaboration. This point-of-control is a PCAC model that enforces the common collaboration-driven policy while allowing the local organisation-driven AC models to function locally without interruption. This layer defines a new boundary for the PCAC model's logical perimeter to cover the whole collaboration environment without any interruption, without being limited to any of the discrete LIS's physical or logical perimeters. This will achieve all the low-level challenges of securing collaborative environments using LIS.

5.3 Secure Healthcare collaborative Environment (SHarE)

The eight identified requirements are high-level requirements whose implementation at a lower level, will give SHarE control over the information security of shared cancer information across healthcare LIS loosely linked to its environment. Based on these requirements, the following eight controls have been identified, see Table 5.1.

Table 5.1: SHarE's information security controls.

Control Number	Control Description
Control #1	A consistent information layers structure should be provided throughout the collaboration that reflects PC care.
Control #2	A PCAC model should be deployed to govern information in the collaboration, where access decisions are based on the patient's condition and treatment stage.
Control #3	The information should be organised in chronological order (timeline) with a stamp that includes: date and time of care point, and who saw the patient.
Control #4	The information should be gathered and filtered from the different LIS at each point of care based on the PCAC access decisions.
Control #5	Referrals should be automated to a CT member's role and picked up by the recipient with all information they need.
Control #6	If speedy access to information is needed in an emergency, trusted CT members in the circle-of-trust should be able have access to all information they need and justify it, and this should automatically alert everyone involved, when it happens.
Control #7	Information may only be edited after sharing by the originator and such editing shall be notified to all who have access to the information.
Control #8	The sensitivity level of patients information should be labelled and communicated to all healthcare professionals as a technique to raise their information security awareness.

5.3.1 *Control #1*

- **Control:** A consistent information layers structure should be provided throughout the collaboration that reflects PC care.

- **Description:** One of the key reasons why LIS fall short of fully serving cancer care in a PC manner is their anti-PC information layers structure. CaNISC is a disease-centred system meaning that, first, it is designed to serve all patients with cancer-related diagnosis, which makes it limited for usage within the cancer care community and unfit to serve other healthcare professionals beyond cancer. Second, it was designed to meet the needs of this disease-centred treatment approach, and thus, it has clearly defined partitions for each patient's casenotes allocated to separate providers' information (see Fig 4.3). However, it aims to provide information to healthcare professionals caring for all the patient's diagnoses with any type of cancer across a wide geographical area, which makes it an ideal system for cross-organisational information sharing, but not for a holistic view about the patient's condition especially for patients suffering from more than one disease or condition. The Clinical Portal, on the other hand, is an organisational

centred system aiming to provide information to healthcare professionals based on the hospital where treatments are located (see Fig 4.4). Although it may be a good system in which to view all test results and referrals for a particular patient reflecting more than one disease, it is limited to a particular healthcare organisation. In other words, it is incapable of cross-organisational sharing and referencing, and thus, it hinders the provision of a holistic view. Consequently, both models do not support a PC healthcare treatment approach and are unable to provide a holistic view of the patient.

However, according to the Clinical Nurse Specialist in Breast Care [8], all healthcare providers in cancer care are moving towards CaNISC. Therefore, SHarE aims to address the issues raised by current systems (Clinical Portal and CaNISC) by taking advantage of their strengths and improving them to provide a PC system that best serves a PC healthcare treatment approach. First, although the Clinical Portal is limited to a single hospital's test results, it can reflect more than one disease, as shown in the structure of its information layers (see Fig 4.4). Hence, SHarE can use this functionality and extend it to include all healthcare organisations involved in these test results. Second, CaNISC's information layers' structure (see Fig 4.3) is ideal for cross-organisational sharing of information, apart from the partitions it builds to separate different organisation's information, which hinders access. SHaRE can improve CaNISC by generalising it to accept and consider any condition by removing and breaking all boundaries between the different healthcare providers. Therefore, SHarE can use the CaNISC and Clinical Portal information layers structures and apply a number of modifications to include all hospitals, and all patient's conditions and diseases. This will make it a PC system, and not an organisation- or a disease-centred system. The new structure (see Fig 5.1) consists of three information layers: Patient, Problem, and Treatment Information Layers.

1. **Patient Information Layer:** there is only ever one casenote per patient within SHarE as in ISCO. Therefore, once a patient is registered in SHarE, information about that patient from any healthcare organisation can be provided.
2. **Problem Information Layer:** to generalise the diseases and conditions, SHarE deals with a problem rather than just a disease. This includes diagnostic and non-diagnostic conditions. A patient can have more than one disease episode and each disease episode must be added to the system as a separate problem.
3. **Treatments Information Layer:** so that SHarE can remove all boundaries separating each healthcare provider caring for the patient, the system organises the information based on the treatment points for each problem or disease the patient has. Therefore, each healthcare provider should add information and record it against the treatment point where it is used. This assists continuity of care, and the provision of

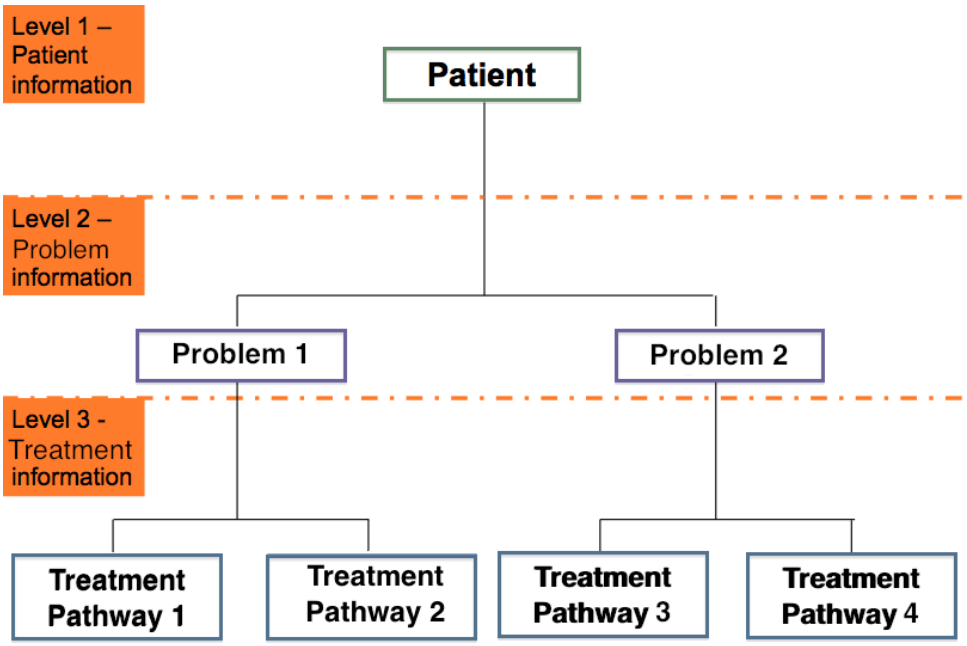


Figure 5.1: SHarE Information Layers Structure.

a holistic view.

5.3.2 *Control #2*

- **Control:** A PCAC model should be deployed to govern information in the collaboration, where access decisions are based on the patient's condition and treatment stage.

- **Description:** It is important that access to PC information in cancer care reflects PC care, and hence, there is a need for an AC model that reflects the new PC information layers structure introduced by SHarE. This means the implementation of a "need-to-know" information access rule at the collaboration level needs to be revisited to attain the right balance of information security for the collaboration. However, implementation of a "need-to-know" access rule relies heavily on the access decisions made by the system's AC model to reflect the interpretation of the high level information security policy, and this is the key difference between an information system supporting a traditional disease-centred care and one supporting PC care.

  At one extreme, LIS usually make access decisions on the basis of whether the healthcare professional works at the hospital or not [8]. Hence, access is granted from organisation-driven information security rules which reflect the healthcare professional's position and role in the organisation and not the patient's treatment [8, 78]. Consequently, if a pro-

fessional has the right privileges, the system grants them a coarse-grained access to the whole system [78], so they can see any information about any patient within the hospital [8, 78]. Whereas, if local information needs to be shared with another healthcare professional at another hospital following a treatment plan, then there are two cases: first if the hospitals use the same system such as CaNISC and they have been trained in using it [69], then this information is stored in a designated partition in CaNISC, and the named recipient is granted remote fine-grained view access to only that particular piece of information without the ability to alter the information and without any rules and governance around it [78, 69]. They are then trusted to act responsibly in accessing this information, and CaNISC audits the access [69]. Second case, if the systems are not linked and often an organisation uses a different system, for instance a referral from the GP to a specialist, then a copy of that information is taken out of the live system and faxed to the other organisation. This means they own it so even if they did alter that information, it wouldn't have any implications on the original version [69], which will be unchanged

At the other extreme, based on the new PC information layers structure introduced by SHarE, PC care needs access decisions to PC-wide information resources, and enforces these decisions anywhere within SHarE based on the treatment status and not the hospital. These access decisions are an implementation of the "need-to-know" access rule which helps attain the right balance between information integrity, availability, and confidentiality discussed in Chapter 3. Therefore, the new PC information layers structure introduced by SHarE introduces a novel PCAC model, that addresses information security issues in modern healthcare collaborative environments, and restores the harmony of information security goals once the information is shared outside a local LIS. Therefore, SHarE protects the information recorded and shared at each treatment point in this environment using the PCAC model. This model makes and enforces the decisions around information security based on four conditions:

- The patient being treated,
- His/ her condition,
- The treatment point, and
- The role of the CT member treating this patient with that condition.

This suggests the need for a role-based fine-grained access control as a foundation for the PCAC. Most security solutions have an "all or nothing" property [109, 32]. In other words, these solutions either grant access to the full requested resource or not at all [109, 32]. This explains why LIS mostly grant a coarse-grain access to all healthcare professionals working at the hospital. However, privacy violations can be expected if all

members in the healthcare environment can see every patient's records [41]. Furthermore, implementation of the PCAC access decisions means that in cancer care collaborative environments, different roles will have different information access needs based on the treatment. Thus it is key to have fine-grained access control that enforces security rules within a resource at different granularity levels by moving information security controls from a coarse-grained to a finer-grained level (with more varied information ranges) [32]. This gives LIS the flexibility to provide different protection levels for different parts of the information resource based on the access needs at each treatment point. Granular access to certain parts of the information should correspond to a healthcare professional's role(s) in the patient's treatment. Thus, access privileges are assigned to a role instead of a user, and users are assigned to roles. This is key to preserve the confidentiality of both clinical and patient identifiable information.

Finally, SHarE represents a wrapper-based neutral domain independent from all other domains containing LIS, which creates a healthcare collaborative environment where a number of discrete information systems from geographically-distributed hospitals, healthcare professionals playing different roles, and pieces of information recorded at different points of treatment are collectively used in the treatment of a single patient following a cancer treatment pathway. This makes SHarE a platform for the enforcement of this balance which avoids having various interpretations of the policy, so preventing any misinterpretation, while not interrupting the local information security policies of the LIS.

5.3.3 *Control #3*

- **Control:** The information should be organised in chronological order (timeline) with a stamp that includes: date and time of care point, and who saw the patient.

- **Description:** One of the key issues with current LIS supporting PC cancer is their inconsistent information structure, which implies that these systems organise information differently. CaNISC for example, organises information on an information provider basis [3] (see Fig 4.3). The patient's casenote is divided into partitions in which each provider stores treatment-related information. This system was not designed to show this information based on the history of treatment points, therefore it is harder to locate the most recent test results or treatments, unless the user is well-trained and very familiar with the system, and computer literate [69, 8].

  While the Clinical Portal organises information based on its type [8] (see Fig 4.4), once a healthcare professional is logged into the system, different lists appear at the right side of the screen: results list, letters list, and so on. Each of these types of information is presen-

ted in the Clinical Portal in a chronological order, with normally the latest information at the top, and CT members work their way down. This organisation is preferred by the Clinical Nurse Specialist, who said: *"I think the good thing about this is that normally they would be in chronological order. So, as it happens, it looks like almost everything that's been done recently"* [8]. This organisation is preferred because it is comorbidity friendly, which is fundamental to PC care. The list of test results can show if the patient has other conditions, as each test result is labelled with the particular condition. This is a more holistic view than CaNISC. For example, if the patient was also going to a diabetic clinic at the same hospital in between cancer treatment points, then the Clinical Portal will show this clearly, as it would read: breast, breast, diabetic, breast, breast, diabetic, renal. However, although each category is listed chronologically, it still does not show the most recent treatment points that do not have any test results to be listed. Thus for CT members to figure out the most recent treatment point to understand the patient's current health status, they have to be familiar with the treatment pathway. This is normally limited to the CT member's speciality, and the interviewed Clinical Nurse Specialist pointed out it is extremely difficult when it comes to other conditions, and in such cases an assumption is made regarding what happened to a patient receiving treatment for another condition. She commented about current systems *"in current systems, you have to go and find the information,"* [8] and even then their structure makes it very difficult to find information mainly because the systems do not show it in an obvious way.

It is crystal clear that some LIS were designed and developed before the concept of sharing and collaborating. Therefore, the design model meets the needs of the traditional disease-centred treatment approach, where the information is stored in partitions, each owned and managed by an independent healthcare organisation. This disease- and organisation-centred structure can make these systems slow and user-hostile [8]. They require intensive training to be properly used to locate relevant information [8]. However, PC care cannot be achieved without supporting systems meeting these needs, and thus, information provision to clinicians should be PC which means information is organised based on the patient's condition and treatment stage and not on a healthcare organisation basis. Therefore, based on SHarE's information structure (see Fig 5.1) and the PCAC model, it is best if a LIS can organise information in chronological order (representing a treatment timeline) with a time stamp at each completed treatment point. This stamp shows the date and time of each care point, and who saw the patient and recorded the information at that particular point. This would help track the information along with the patient, information ownership, and treatment stage.

5.3.4 *Control #4*

- **Control:** The information should be gathered and filtered from the different LIS at each point of care based on the PCAC access decisions.

- **Description:** Although it is very critical to share information in cancer care for patient care continuity, it is equally important neither to overwhelm CT members with loads of information nor summarise the information in a way that leads to misinterpretation of its meaning. Therefore, to carefully balance the fine line between these two needs, this research suggests gathering the information from the different discrete systems, filtering it based on the access decision in the PCAC model, and then organising it in a chronological order. This provides a safe way to serve the purpose of easy access to foreign information and making sense of it in a busy collaborative environment without information overloading, which may overwhelm the CT. This requirement is most important in complex sharing points such as the MDT in the context of PC care.

5.3.5 *Control #5*

- **Control:** Referrals should be automated to the CT member's role and picked up by the recipient with all information they need.

- **Description:** Legacy systems do not automate referrals, as they are managed manually. This is one of the reasons why information is sometimes delayed, and inaccurate. An automated referral using a CT member's role that is picked up by the recipient with all the information needed is a key requirement in PC care. However, according to the Breast Cancer Nurse Specialist [8], generally when referrals happen, they are to a named person and not a role [8]. This is because of the small number of people playing that role. The nurse explains this by an example:

  > *"going from perhaps surgery to oncology, then it is to the consultant oncologist, but there are only two of them, so they put somebody, stroke, then the other one. So as put both their names on them,"* [8] and whoever is free would pick it up. Helen also said: *"we usually know when she's on leave. That's because it's quite a small unit, so we will know what's happening with each other"* [8]. However, she commented: *"it might be better not to have a specific name, but just to have a role"* [8]. This is because the referral may go to a named person, like Annabel who plays an oncologist's role in cancer care for example, but the patient sees Helen, the nurse specialist, instead if Annabel is on leave. She explained: *"if we sent out a letter directly to the oncologist that is the first person*

> *that does contact, and then that's perhaps handed out, that might be delegated to one of the other doctors or to a nurse then"* [8]. She justified: *"so they are still under the auspices of the oncologist. So Annabel would still be in charge"* [8].

This makes this functionality more effective in bigger communities where the CT includes a large number of members and it is hard to keep track of who is on leave and who has delegated their tasks to other members of the CT.

5.3.6 *Control #6*

- **Control:** If speedy access to information is needed in an emergency, trusted CT members in the circle-of-trust should be able to have access to all information they need and justify it, and this should automatically alert everyone involved, when it happens.

- **Description:** Urgent emergency cases need LIS to be more resilient. Since referrals are managed manually, if a CT member unintentionally refers the patient with incomplete information, there may be a need to access the missing information remotely, especially in patients with urgent cases when it is time-consuming to get back to the originator and request the missing information to be resent. Another example is, if the patient suffers from a serious life-threatening injury and is rushed to A&E. In this case, there may be a need for speedy access to information to allow a life or death decision to be made. In both cases, however, there may be a need to force the system to allow access outside the routine access decision making processes by enabling a "break-glass." Therefore, the concept of "break-glass," is introduced that allows trusted CT members, who need immediate access to information to care for the patient, to actually access the information. Once the CT member accesses the information and the urgency element is over, he/ she must justify the need for breaking the glass, and this should alert other CT members that their information has been broken into. Finally, the system should log all CT activities on SHarE, including break-glass incidents.

  The break-glass feature lies right at the heart of the fine line between information availability and confidentiality. According to Beale [44] and Anderson [110], these two information security goals are in direct conflict [44], which makes it hard to achieve a balance, even using the current traditional computer security mechanisms [110]. This research uses trust management techniques to achieve this. According to Alfarez and Hailes [109] "trust is a notion central to secure distributed systems communications and transactions" [109]. This is because if something is secure, it is "trusted," and what the security solution does in distributed collaborative environments is ensure that systems are trusted [109]. In

addition, they state that trust is best managed in collaborative systems more than in local discrete systems [109] for two reasons:

First, trust is subjective [109] in that each rational domain involved will take responsibility for its own fate [109], and second, since each LIS has its own information security policy, it is better that each domain makes decisions for itself that best suits its local policy [109]. Whereas in complex information-intensive collaborative environments, like cancer care, the fine line on which a trust decision is based on whether to allow access or not can be blurry sometimes [8]. Hence, there is a need for a mechanism to differentiate between authorised users who need immediate access to information in an emergency (the CT members trusted to break-glass) and other authorised roles that do not [70] by labelling the former as "trusted." This research achieves this using the "circle-of-trust" concept. A conceptual circle is assigned to each treatment pathway and used to include all healthcare professionals treating the patient with that particular condition (i.e. CT members for that condition). Therefore, it stretches across the security domains of all collaborating health providers, like the logical perimeter concept, to include all CT members no matter where they work. Once an emergency occurs, information security is relaxed only to those in the circle-of-trust so they can break into the information.

However, since trust relies on assumptions made regarding who can be labeled as "trusted" in a system [109], "trusted" labels can be misleading as they imply that "nothing can go wrong" [109]. This is definitely not the case [109] as there is no such thing as a flawless security system [109]. This returns to the fact that information security cannot be absolute [39, 21, 40], as it is not statically simple, but highly dynamic [39, 22]. Therefore, Alfarez and Hailes [109] recommend that trust assumptions must be explicit in securing a system, and thus, this research explicitly assumes that CT members in this circle are trusted to access information on a "need-to-know" basis in emergency cases to save the patient's life when decisions mean life or death.

5.3.7 *Control #7*

- **Control:** Information may only be edited after sharing by the originator and such editing shall be notified to all who have access to the information.

- **Description:** Clinical information has a value as a basis for healthcare professionals' decision-making processes, and its corruption can lead to incorrect decisions, which may harm or even kill a patient [41]. However, a key threat to the integrity of PC information results from human error. If the shared information contains an error, it is crucial to correct misleading information. Nevertheless, according to the Cancer Centre's Caldicott

Guardian [69] it is worrying if any CT member wants to come in and edit his records without my knowledge [69]. Therefore, only the information originator should be able to do so remotely. The organisation of information in chronological order helps track the information originator, and this control gives him/ her the ability to update the information that has been already shared from his/ her local system. However, it is as important to notify all CT members who might have made their decisions based on misleading information that this has happened. Therefore, once the information is amended everyone involved in the treatment is alerted so they can check their decisions.

5.3.8 *Control #8*

- **Control:** The sensitivity level of patient information should be labelled and communicated to all healthcare professionals as a technique to raise their information security awareness.
- **Description:** Protecting PC information needs CT members to think patient-centrically. The core of this research is to bring PC information together from different discrete autonomous systems each with its local information security. This PC information (containing clinical and patient identifiable information) is confidential [69, 45], and may have different levels of sensitivity [69]. Examples include systems recording details about social services, HIV positive results, and paediatrics systems recording child abuse information [69]. This information can be labelled as being more sensitive. In such an environment it is important to communicate the protection needs to all CT members at the different hospitals in an easy to understand language at the human-level. This research uses an icon-based labelling scheme to achieve this. These icons are seen as visual labels and carriers of meaning to communicate information security needs in collaborative environments, especially in modern healthcare. Although it is important to define a classification scheme that best suits PC care, this requirement is linked to the human-readable information security policy that is already out of the scope of this research. Therefore, the idea is proposed using a simple widely used information classification scheme for illustration purposes. This classification scheme is called Traffic Light. It is used in SPIDER [7], where it creates a common policy for sharing. This research uses it to communicate the sensitivity level of information shared and information security needs in the collaborative environment with multiple users in a visual manner. Each of the colours represents a different sensitivity level (see Table 5.2).

  The idea is that the information originator is the person who can decide how sensitive the information he/ she is recording. Therefore, once a CT records information, he or she can choose the right icon. This icon is stuck with the information anywhere it is accessed

Table 5.2: Traffic Light Information Classification Scheme Usage in SHaRE.

Classification Name	Label	Targeted Information Resource	Protection level
Red		highly sensitive	is used for information classified as "super sensitive" that should only be handled with care, usage example could be high-risk patients with HIV positive results
Amber		sensitive	used for "sensitive" information with limited distribution requirements, usage example could be for local use within the physical boundaries of the hospital
Green		normal business	used for "Care Team Wide" information for CT members' usage for the patient treatment at a specific condition
White		public	this class targets "public" information that does not require any sort of control, and can be accessed by any professional working at any of the hospitals

within the collaborative environment. For example, a patient with breast cancer has cancer related information collected about her case as she goes down her breast cancer treatment pathway. Now this cancer-related information is labelled Green to every CT member playing a role in that treatment pathway. Any non-cancer related information like HIV positive diagnosis can be labelled Red to this same team, but Green to the haematologist. Generally speaking, they are useful and show the CT member caring for the patient at the next treatment point how sensitive the information is. Moreover, it is important to use these labels in alerts, such as in a break-glass incident, where an icon is stuck to the information that was broken into to show the sensitivity level of patient-identifiable information and communicating it to all healthcare professionals to raise their awareness is essential.

5.4 Conclusion

This chapter presents "what" is needed to create an SCE in PC care using LIS, in eight information security controls. These controls represent the requirements for SHarE, which will

be the low level enforcement of the common collaboration-driven balance of information security, to meet the remaining challenges to create a collaborative environments. Therefore, the requirements for this high-level collaboration-driven policy, identified in Chapter 4, are used as a base to define eight controls for SHarE. These controls will mean SHarE can achieve the lower level challenges of securing collaborative environments using LIS. First, SHarE represents a top layer, that is neutral to all systems, where the controls are implemented. This top layer is linked to all heterogeneous LIS to enforce the controls in all systems in harmony to create a single neutral point-of-control. This point-of-control in SHarE is loosely-coupled with the discrete LIS and not limited to their physical or logical perimeters, and thus, defines a new boundary for the PCAC model's logical perimeter to cover the whole collaboration environment without any interruption while not affecting any LIS's role in its local environment.

Chapter 6

SHarE Prototype Design and Implementation

6.1 Introduction

SHarE is a proof-of-concept implementation of an SCE in cancer PC care. This chapter covers the design and implementation choices made to create SHarE as a wrapper-based prototype system. The information sharing and security contexts are designed in SHarE using Business Processes, Business Process Modelling (BPM), and Entity Relationship (ER) diagrams. This is achieved by studying three cancer types' ICPs and a selected treatment scenario: HC, UGI, and breast cancer. For the complexity of its treatment process, breast cancer is selected as the exemplar for the design and implementation of SHarE. A selected real-life treatment scenario was extracted from breast cancer ICPs, designed as a business process, and modelled using BPM. An ER diagram was developed to show the relationship between the key elements of information sharing and security contexts and the linkage between these contexts in breast cancer care. Workflow Technology (WfT) is selected to implement SHarE as a wrapper-based system by automating the breast cancer treatment process, managing the flow of information, and controlling access to it at each treatment point. Workflow for Integrated Care Pathway (WffICP) is a Workflow Management System (WFMS) designed to support coordination between CT members in PC healthcare using ICPs. It was used to implement the breast cancer treatment process to create the information sharing context needed, but it falls short of meeting the needs of the information security context. However, WffICP is a location transparent system with an architecture that enables the implementation of the wrapper as a loosely-coupled system with a LIS. Therefore, it provides the perfect environment to implement the identified information security controls to control access to information throughout the treatment process. It is used to create the PCAC model that defines access decisions based on pre-defined users' roles, and information access rules, and links these rules to each treatment point in the process. Finally, this chapter covers how the eight controls are implemented in SHarE. This shows that SHarE meets the SCE challenges to secure cross-organisational information sharing in cancer care, and

ensure the right information is accessed by the right person at the right time in the care process.

6.2 SHarE Information Design

The design of SHarE has two stages, first, the design of the information sharing context represented in cancer care using Business Processes, BPM and ER diagrams. The second stage is the design of the information security context for cancer care using ER diagrams to model the security context on top of the treatment process. Both contexts' ER diagrams are merged into one, to link both contexts and meet the needs of holistic PC care.

6.2.1 Business Process

A business process is described by Alsalamah [5] as the flow of one or more activities that are undertaken to perform a certain task or service in an organisation [5], while an activity is:

> *"the piece of work that forms a logical step to perform the business objective"* [5]. These activities are *"usually restricted to a certain role in the organisation and each role is restricted to specific actions. Furthermore, activities in a business process usually require an input which gets processed through a method to produce an output"* [5].

One practical approach towards conducting a risk assessment to secure an information system, is based on the organisation's business processes [37]. This is where the creation of an information security policy starts by defining critical business processes covering the information sharing scope, listing all the assets used by these processes, and identifying threats to those assets [37]. Since one of the fundamental objectives of this research is to define a collaboration-driven information security policy cross-organisations in cancer care, this means, a treatment is the common business process for all participating healthcare organisations and care providers. The treatment points are the activities within this business process, and at each treatment point a specific healthcare professional having a particular role is responsible for carrying out care actions. A Business Process approach was selected for the design of SHarE as a treatment process can be automated by WfT to create a wrapper-based system. The relationship between the key elements of an information sharing context is shown in the ER diagram (Fig 6.1), where each activity must be undertaken by a specific role, and should be linked to one process, and each process represents one treatment.

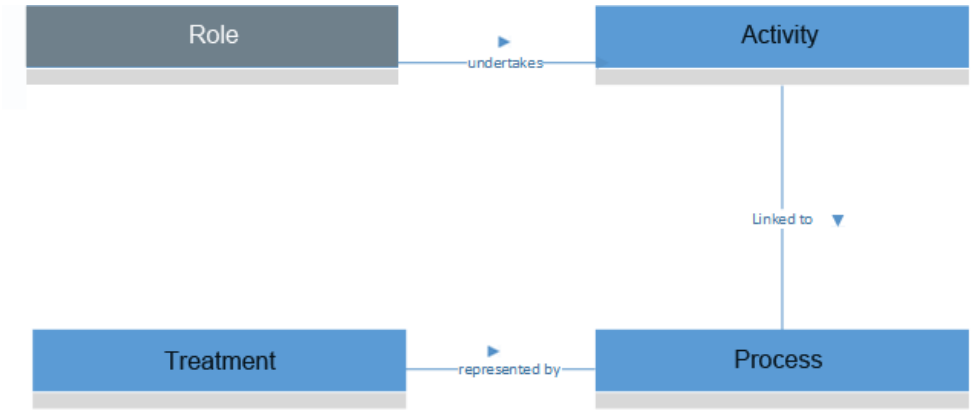


Figure 6.1: ER diagram for SHarE's information sharing context.

In order to design and implement SHarE as a treatment process, a type of cancer has to be selected as a first step. Three real-life treatment scenarios for HC, UGI, and breast cancers were considered initially. This showed breast cancer had more complexity than the other types considered which were fairly simple with a one-page ICP (see Appendixes G and H for HC and UGI scenarios, respectfully). Breast cancer has a six-page ICP (see Figs I.1, I.2, I.3, I.4, I.5, I.6). This means it is more likely to cover unusual situations. Therefore, the breast cancer treatment scenario was selected for the design and implementation of SHarE and is used in the remainder of this chapter. The breast cancer ICP was investigated to identify at each treatment point the healthcare professionals' roles, information collected and recorded at that point, and healthcare information system and health record used for storing this information. A comprehensive conceptual model (Fig I.7) of the breast cancer ICP was created as a result of this intensive study (full detailed are in Appendix I). However, due to the complexity of this cancer's ICP in comparison to the other straight forward cancer ICPs, there are a number of possible decisions that can be made about which route to follow. A common real-life scenario was extracted from this conceptual model for the implementation of the proof-of-concept system. In this scenario a decision had to be made regarding which route the scenario should follow, and so surgery was selected as the first treatment option and chemotherapy as the second. This choice was made based on the statistics published in the Breast Cancer Audit [80] report in 2012 which highlights the fact that

> *"45% to 81% (mean=61%) of patients aged 70+ have surgery as primary treatment for invasive breast cancer; the remainder may or may not have had primary drug therapy,"* [80] while *"67% to 100% (mean = 90%) of patients are receiving radiotherapy after breast conserving surgery for invasive breast cancer"* [80]

6.2.2 Breast Cancer Real-Life Treatment Scenario

A simple breast cancer treatment scenario in Wales starts with a patient seeing a GP at a surgery with worrying symptoms. The GP examines the patient, collects information, and stores it in his information system. If the GP is suspicious, then he refers the patient for a triple assessment. A specialist (i.e. surgeon) starts the triple assessment with further examination and a history check. Then a radiologist performs an ultrasound or a mammogram, and finally a biopsy is performed by a pathologist. The results from the triple assessment are discussed at an initial MDT review to decide a treatment plan. Most patient's undergo an operation as the first treatment option, and post-op another MDT review is arranged to decide on any further treatments. Finally, the patient may have further treatment with chemotherapy by an oncologist. This real-life breast cancer treatment scenario was checked by a Breast Cancer Oncologist [87] and a Clinical Nurse Specialist in Breast Cancer Care [88] in two designated interviews. This treatment scenario is a common straightforward route for breast cancer care, and it is referred to as the "Happy Pathway" in Velindre Cancer Centre. It was extracted from the breast cancer full ICP, and is shown in Fig 6.2. The flow of the patient between the different healthcare providers is illustrated in Fig 6.3.

6.2.3 Information Sharing Context Design

BPM is generally used to model and visualise business processes. One of the key benefits of BPM is that it can be used to communicate at a human level rather than a software engineering level [111]. However, it requires a notation to standardise the modelling among the people involved in the design. Business Process Modelling Notations (BPMN) developed by the Object Management Group (OMG) provides a simple and understandable mechanism for creating business process models [111] that is designed to cover many types of modelling. One of BPMN's sub-models is "Collaboration" which is able to model interactions between two or more business entities through the "Pool" and "Lane" elements [111]. Pool acts as a "swimlane" and is a graphical representation of an individual "Participant" in the Collaboration [111], and used as a graphical container for partitioning a set of activities from other Pools [111]. A Lane, on the other hand, is a sub-partition within a Pool that extends the entire length of the business process [111]. These featured elements are utilised in this project to define the physical perimeter dividing a healthcare organisation using a Pool and a healthcare professional's role within the healthcare organisation using a Lane. This is the main reason this notation was selected to design the above breast cancer treatment scenario as a business process for SHarE. BPMN was used to model and visualise the treatment process as an essential business process in cancer care among different hospitals. The above treatment scenario was used to build a breast cancer

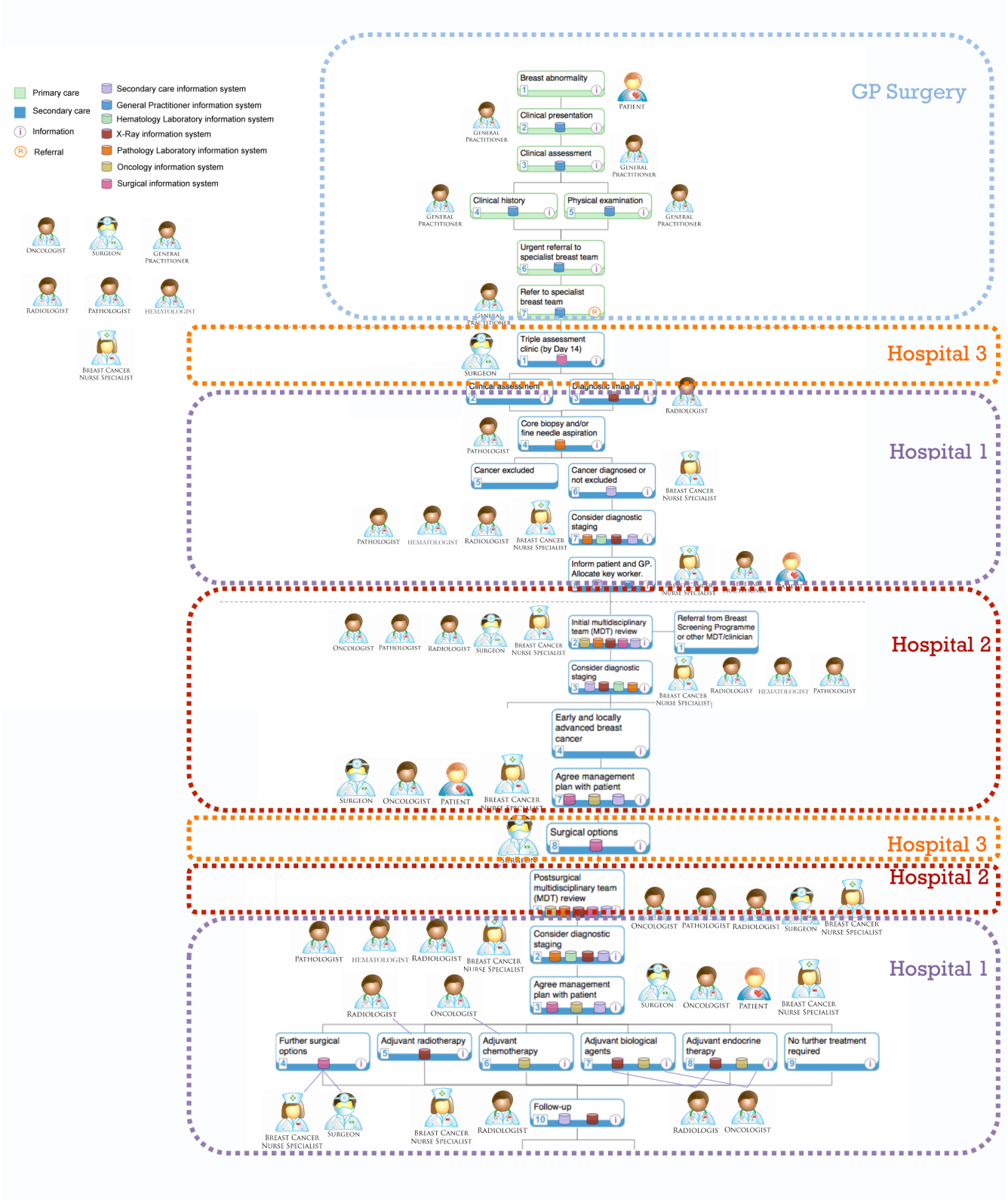


Figure 6.2: Breast cancer selected treatment scenario extracted from breast cancer ICPs.

business process model. For readability purposes, it had to be broken into smaller figures to fit the pages in this thesis, and only part of this model is shown in Fig 6.4 in this chapter, the full

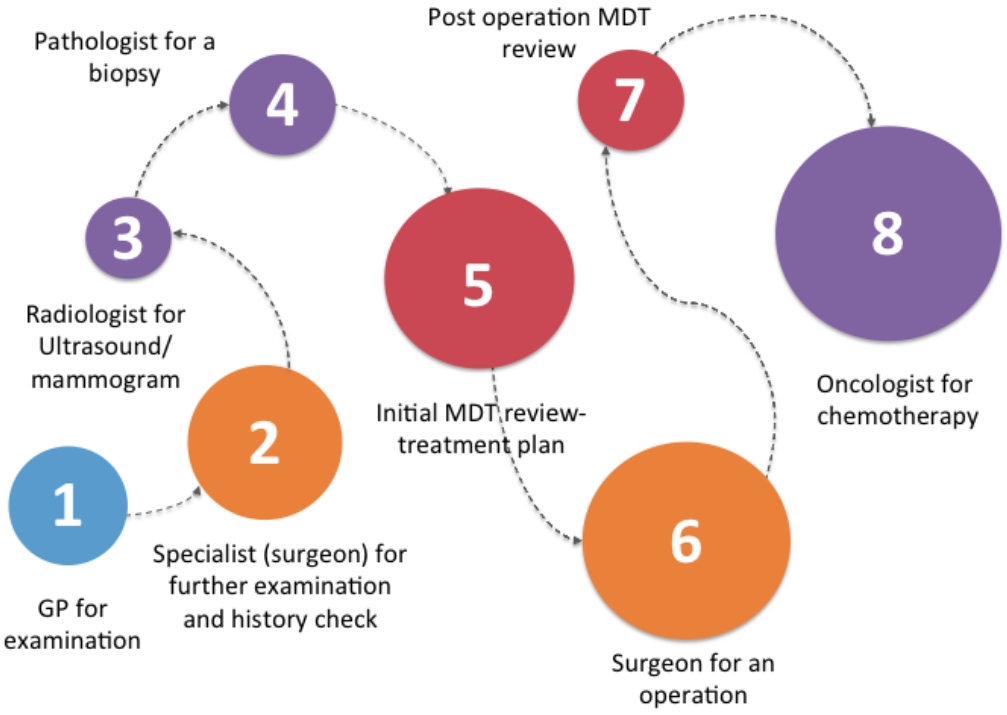


Figure 6.3: Patient and information flow among healthcare providers in breast cancer treatment scenario.

model is in Appendix I.

Fig 6.4 shows part of the model with four Pools: GP Surgery, Hospital 1, Hospital 2, and Hospital 3. Each of these Pools have one role except for Hospital 1 that has four Lanes for the BC Nurse Specialist, Radiologist, Pathologist, and an Oncologist. Different treatment points within the treatment process are undertaken by the various roles based on the patient's condition, and the care point.

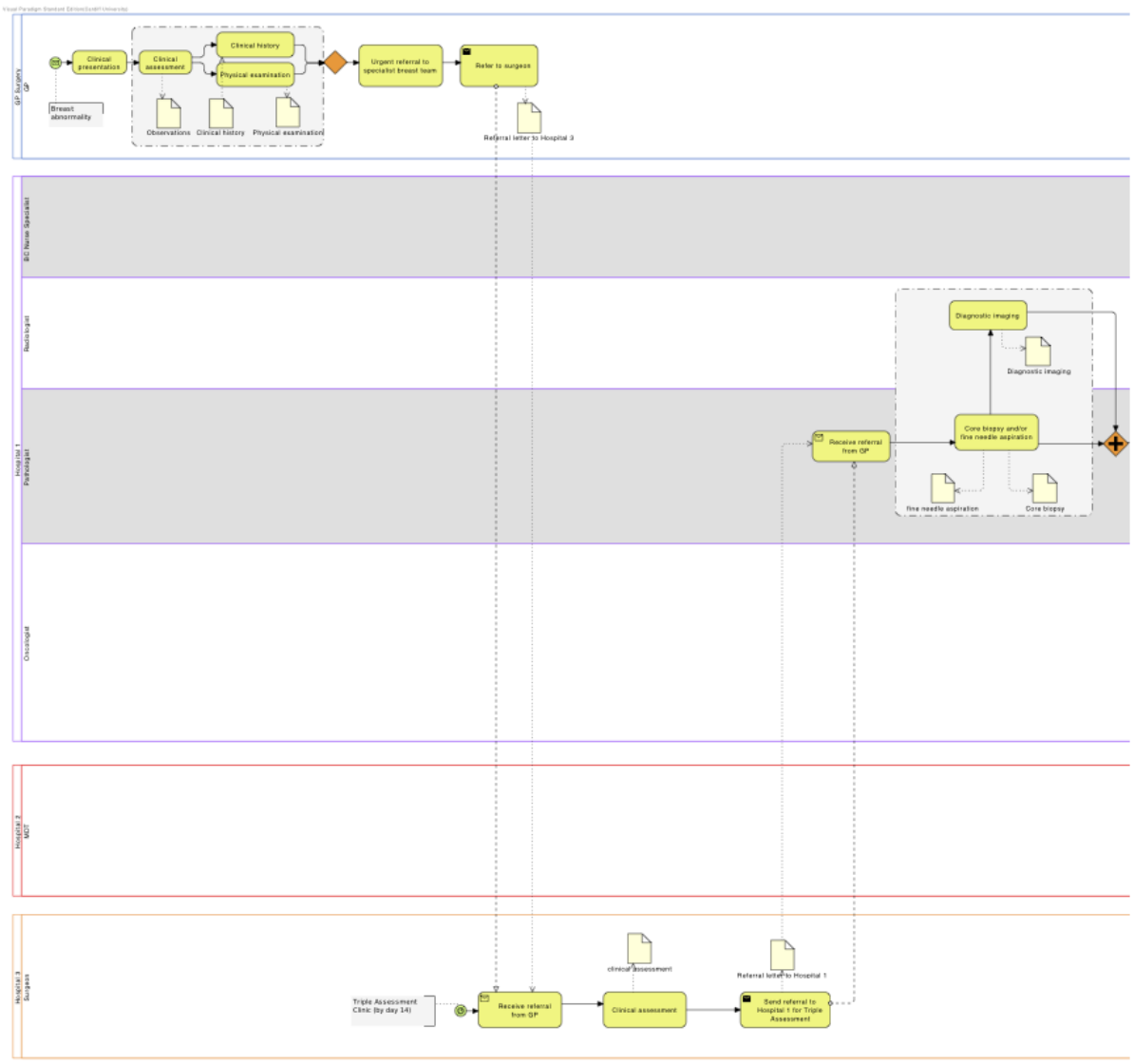


Figure 6.4: One page of breast cancer treatment process model.

6.2.4 Information Security Context Design

Once the treatment process has been designed, information access to the relevant information at each treatment point to meet the needs of the information sharing context has to be identified along with the controls for this access. A virtual patient record that paints the big picture can be accessed by one or more users, who each have a defined role in patient care. This role has to belong to one or more groups. These groups link the role to a healthcare organisation. Also each role can undertake one or more activities that must link to only one process that represents only one treatment. Finally, access to the patient record must be based on access decisions which have to be compared against one or more rules. These rules must be linked to a healthcare professional's role. The relationship between the key elements of the information security context is shown in Fig 6.5.

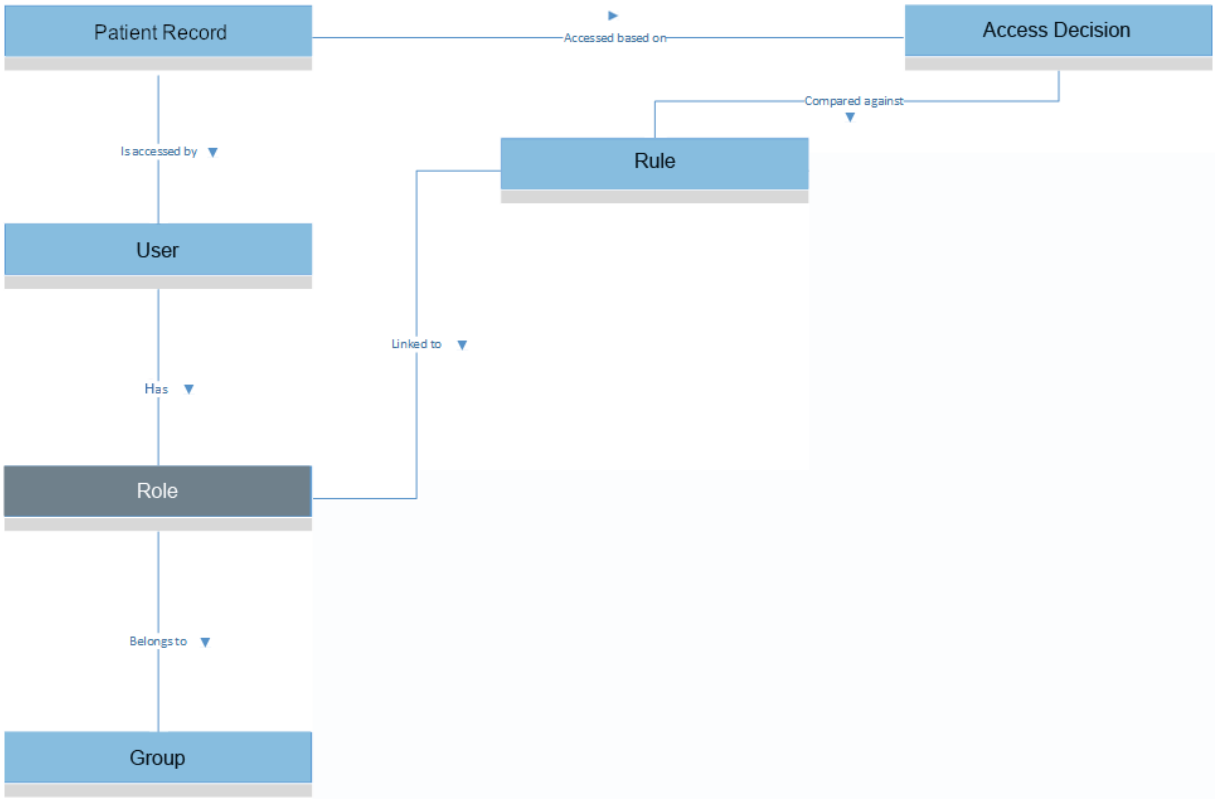


Figure 6.5: ER diagram for SHarE's information security context.

The "Role" element is common to this ER diagram and the ER diagram (Fig 6.1) for the information sharing context and it is the link between the diagrams. Fig 6.6 shows these ER diagrams merged into a single ER which paints the full picture of PC care needs.

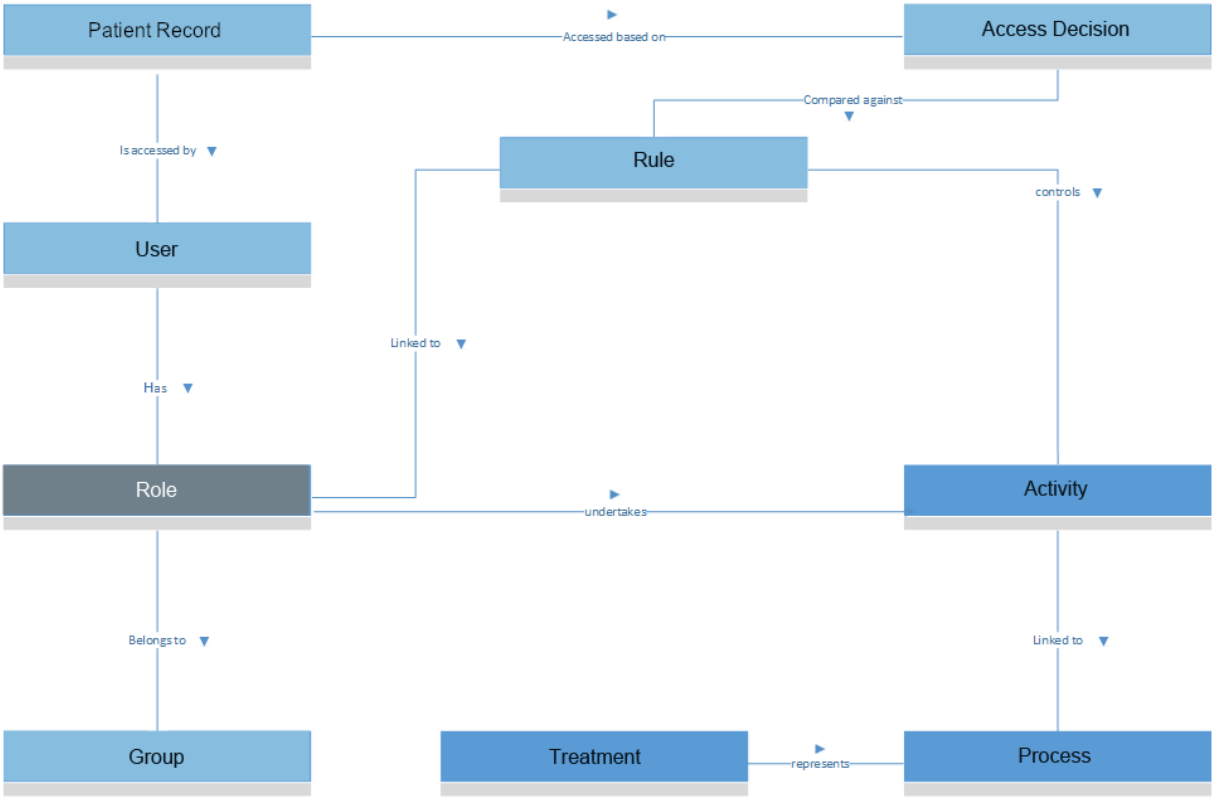


Figure 6.6: Holistic ER diagram for SHarE's information sharing and security contexts.

6.3 Implementation of the Controls in SHarE

The designed information sharing and security contexts are implemented in SHarE through the eight controls to achieve an SCE in PC healthcare. This section covers their implementation.

6.3.1 *Control #1*

- **Control:** A consistent information layers structure should be provided throughout the collaboration that reflects PC care.

- **Implementation:** SHarE's information layers structure has three layers: Patient, Problem, and Treatment Layers (see Fig 5.1). This structure helps SHarE access information through the cross-organisation system boundaries between each of the healthcare providers caring for the patient, and to organise the information based on the treatment points for each problem or disease the patient has. This allows each healthcare provider to add information processed and record it against the treatment point where it is used. In order for this control to manage the flow of treatment information WfT is used. This is achieved at the design and implementation stages: SHarE is designed as a treatment business pro-

cess, modelled using BPM, and implemented as a wrapper-based prototype system using WfT which automates this business process and brings SHarE to life [5].

- **WfT.** WfT has a number of components which help implement both the information sharing and security contexts. It automates the whole treatment process and controls each treatment point a patient goes through along their treatment pathway. This achieves two things. First, it provides the information sharing context for the collaborative environment by managing the collaboration in a PC manner throughout the selected breast cancer treatment business process. Second, it provides a sound foundation to build the PCAC model that achieves the right information security context. The PCAC model makes access decisions for each process activity which controls the security of information following this treatment pathway to achieve an SCE at the low level. WfT was selected as it has the following components that help achieve the above in SHarE:
  - *Workflow Engine* which automates a business process, in which documents, information, or tasks are passed from one participant to another for action, according to a set of procedural rules [5]; and
  - *WFMS* which is software used for the definition, creation, management, and execution of workflows [5].
- **WffICP WFMS.** According to Alsalamah [5], there are a number of WFMSs available today, some are commercial and others are open source. These WFMSs can be categorised into Scientific and Business Workflows. Alsalamah studied the different types of WFMS, justified the most suitable one for PC healthcare, and used it to build WffICP. WffICP was developed as part of a PhD project at Cardiff University [5]. WffICP is a WfT-based implementation of a healthcare ICP that uses a commercial WFMS, Stateframe [112], and modifies it to build a wrapper-based system dedicated to incorporating heterogeneous information systems to support PC care from an informatics point of view [5]. This WffICP system focuses on care management and the decision making process in healthcare collaborative environments to support communication and coordination among CT members [5]. The usefulness and effectiveness of WffICP was evaluated and approved by both healthcare care professionals at Velindre Hospital, Cancer Centre community, and WfT experts [5, 11]. Part of the breast cancer ICP was demonstrated in WffICP, this was used as a starting point to build the breast cancer scenario in SHarE since the novelty of this research does not lie in the tool used to build the wrapper-based system, but is rather focused on the information security controls identified to address the imbalance in information security resulting from cross-organisational information sharing. Hence, WffICP was selected for the implementation of the breast cancer

process as a wrapper-based system and the PCAC model to enforce the access decisions throughout the treatment process.

WffICP constructs an independent information layer that lies on top of the interface of the discrete information systems currently in use to simulate the wrapper where the designed breast cancer business process model can reside independently from all the discrete systems linked to it [5]. Its architecture is shown in Fig 6.7.

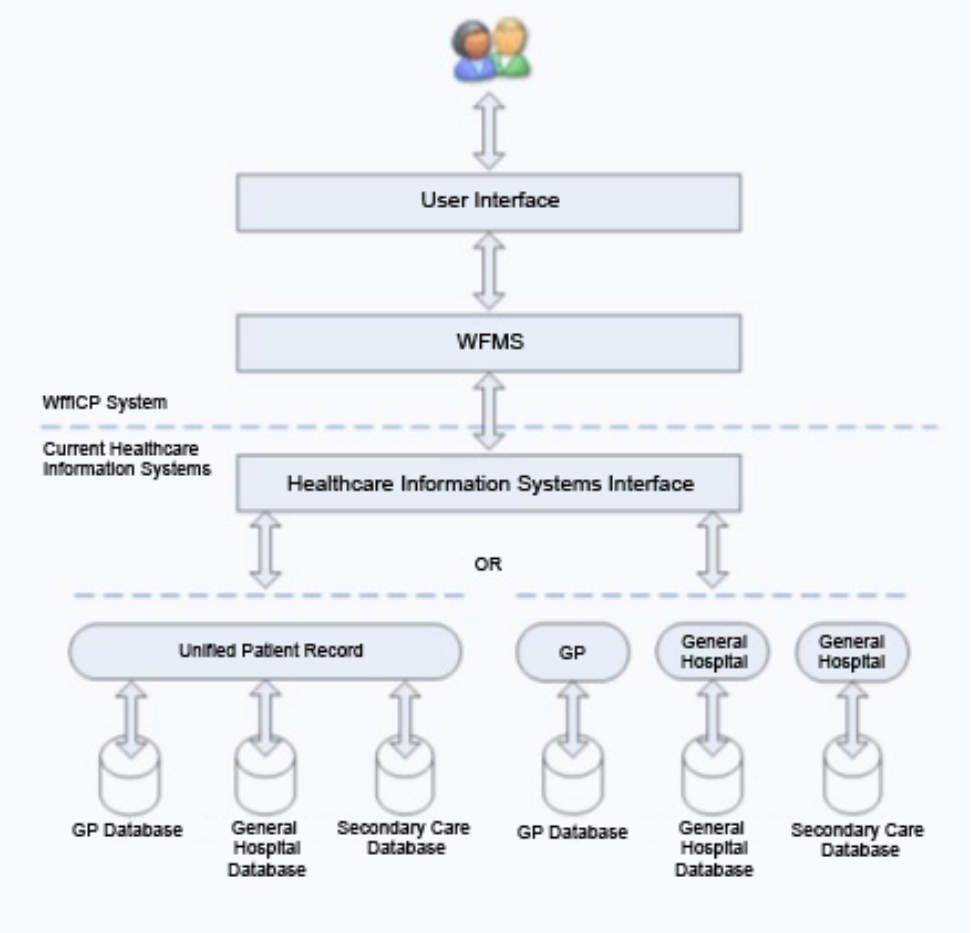


Figure 6.7: WffICP Architecture [5].

This independent layer interacts with the interfaces of discrete information systems no matter what structure, autonomy, or heterogeneity they have. Hence, this layer can interact with each of the geographically distributed healthcare information systems and databases required for each patient. This allows healthcare providers to keep up with the patient's progress from one visit to the next and as they move from stage to stage in their treatment. The two arrows with an "OR" in between illustrate the generality of WffICP to suit collaborative environments with either a unified health record with one user interface or discrete ones with each having a specific user interface. This makes WffICP a suitable tool for SHarE to use the selected

treatment process representing the sharing context in PC care. However, WffICP falls short of providing the controls identified in Chapter 4 and they need to be implemented in WffICP to create SHarE. Therefore, WffICP's components are used as follows to create SHarE:

* **Process Mapping tool** defines the business process logic (represented in the treatment journey) and stores it in the workflow engine [5];
* **Activities** these represent the treatment points within the treatment pathway, and WffICP defines four types of activities for treatment processes [5, 113]:
  1. *Prompt Activity* for a manual decision;
  2. *Referral* an automated step to a specific pre-defined role;
  3. *Active Server Pages (ASP)* activate a web-based display of relevant information to a specific pre-defined role; and
  4. *Automated Step* that runs transparently to users and do not require their interaction. An example of such an activity would be a patient's age calculation task, that the user might not be aware of its progress but its consequence becomes visible to them [5].
* **Security Administration Tool**: manages groups, users, roles, and rules [5],
* **Instance** "is a representation of a single enactment of a case" [5]. So that when a new patient case is created through WffICP, an instance is created for that patient that creates a unique journey based on her/ his needs. Therefore, "each instance represents a unique case which is executed and controlled separately" [5]. This is what makes WffICP a PC system.

– **SHarE Architecture.** (see Fig 6.8). WffICP enables SHarE to be loosely-coupled with LIS and virtually integrated with these systems. This allows SHarE to enforce the PC-driven information security policy on any information used for the collaboration and accessed through SHarE's unified user interface, while maintaining the enforcement of local information security policies on the information when used locally. This flexible architecture allows as many LIS as are needed to join the collaboration to meet the dynamism of modern collaborative environments, at the lower levels. However, before achieving that, these LIS should adhere to the high-level information security goals, and conform to the information security controls. This is to guarantee that all LIS are in harmony with each other to create an SCE that assists the collaboration to achieve the ultimate goal.

– **Mapping Treatment Process and Defining Activities.** The first step in the implementation of SHarE's information layers structure is mapping the breast cancer business process model onto the WffICP's workflow engine. In order to achieve this,

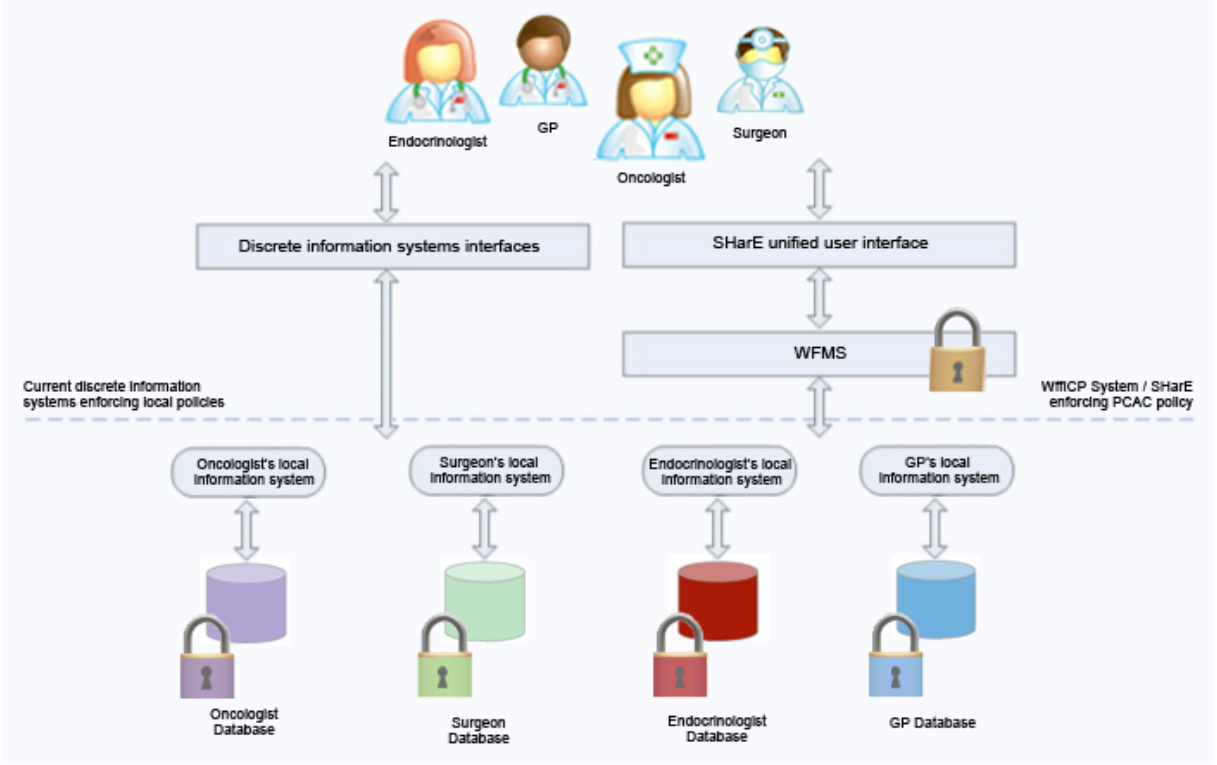


Figure 6.8: SHarE Architecture.

the process activities must be defined. These activities represent treatment points throughout the treatment scenario extracted from the breast cancer ICP, and each one of these activities is either manual or automatic in that it uses a data, web service and/ or a computer application resource based on its type (i.e. referral, prompt, etc) [5] to complete the task(s) necessary to care for the patient at that treatment point. Secondly, the mapped process has a number of routes as treatment options, different data input and outputs from each treatment point, different healthcare professionals undertake the responsibility of caring for the patient at the various treatment points. This requires the logic to be mapped into the process map to decide all "routing conditions, inputs and outputs, authorised users, data to be used, and the invoked IT resources of every single activity in the workflow" [5]. The workflow logic mapped into the workflow engine gets automatically stored in a dedicated workflow database [5]. The treatment process model was mapped into the WffICP. As this model is lengthy and complex, it was broken into 12 smaller figures to fit the pages in this thesis. The first of these figures is Fig 6.9 and the remainder are in Appendix I (namely I.11, I.12, I.13, I.14, I.15, I.16, I.17, I.18, I.19, I.20, and I.21).

A number of screenshots are used to show how SHarE creates and activates a breast cancer treatment process through a unique instance. This treatment follows the scenario shown in Fig 6.3 for a new patient named "Susan Smith", NHS number "123"

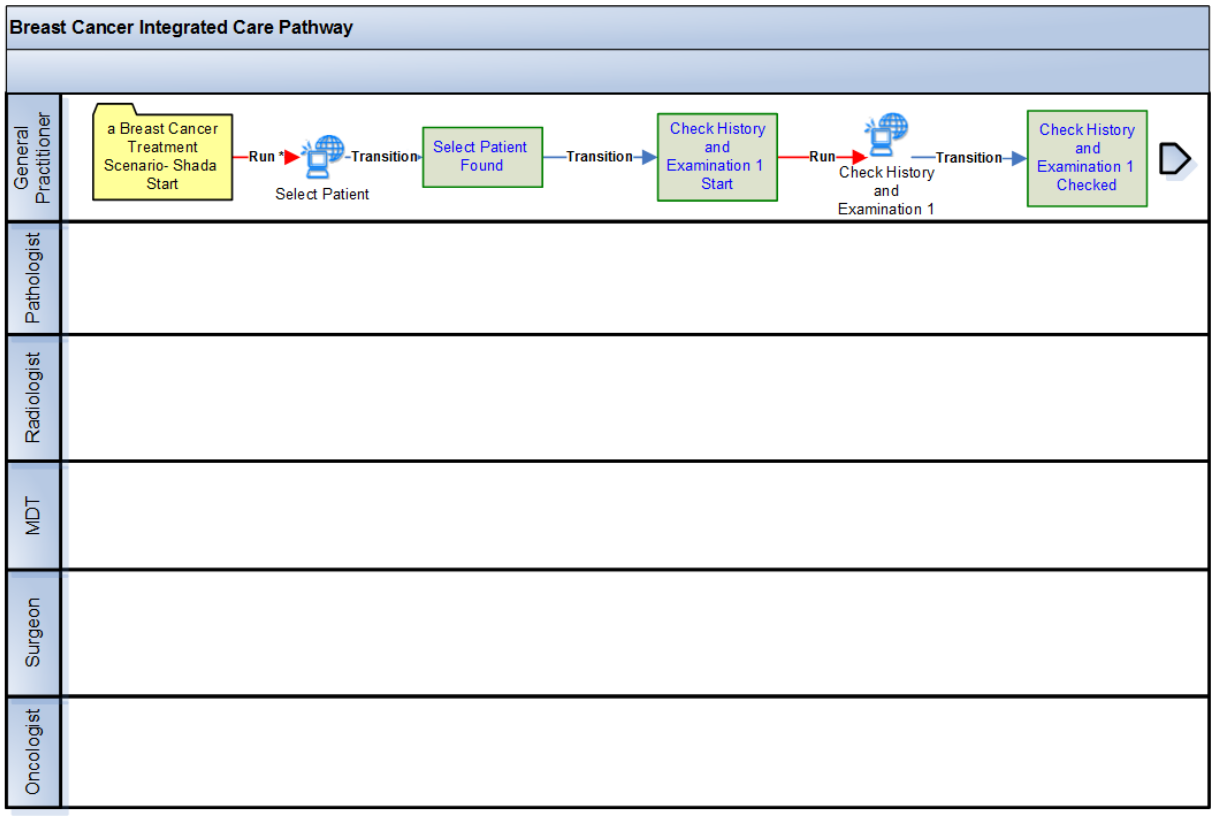


Figure 6.9: One page of the breast cancer treatment business process.

(see Appendix J).

This control uses the treatment scenarios extracted from MoM ICPs as basis for the information layer. However, this control may not be as straight forward if to be implemented in a different collaborative environment that is not treatment based. The challenge is to build the right information layer structure that reflects the information sharing and security contexts.

6.3.2 *Control #2*

- **Control:** A PCAC model should be deployed to govern information in the collaboration, where an access decision is based on the patient's condition and treatment stage.
- **Implementation:** This control creates the PSP, PDP, and PEP elements in the PCAC model. The PCAC model implements "need-to-know" access decisions throughout the PC information layers structure. Although WffICP falls short of implementing this control, it provides a perfect foundation to build the PCAC model that can achieve the right information security context. The PCAC model makes access decisions in each process activity to control the security of information following this treatment pathway to achieve

Table 6.1: Users and their Roles in SHarE.

CT member name	Role in treatment
Hessah Alsalamah	GP
Carl Passant	Surgeon
Kate Jones	Pathologist
Amal Ahmad	Radiologist
Annabel Borley	Oncologist
Claire Miles	MDT coordinator

an SCE at the low level. This access decision is based on four conditions: the patient being treated, his/ her condition, the treatment point, and the role of the CT member treating this patient with that condition. WffICP contains a Security Administration Tool that assist SHarE in achieving this control. This tool helps manage groups, users, roles, and information security rules. After mapping the treatment process and all of its routes, activities, and inputs and outputs involved, the next step is to define access decision rules for SHarE against which the access decision is compared for each patient once it is live through an instance. Therefore, to guarantee the availability of required information at each treatment point (i.e. process activity) in SHarE, authorised healthcare professional users, their roles, groups they belong to (i.e. healthcare organisations), and information access rules must be defined and linked to each activity throughout the whole process [5]. In the example here SHarE has six users each of them having a certain role in the treatment as shown in Table 6.1. Therefore, based on the information security context ER diagram (see Fig 6.5), SHarE uses WffICP's Security Administration Tool to define these users Fig 6.10, their roles Fig 6.11, the groups Fig 6.12, and access rules Fig 6.13.

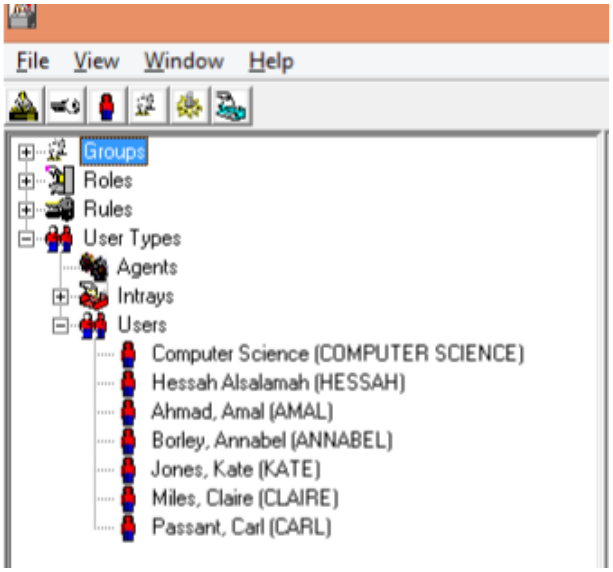


Figure 6.10: SHarE's Users.

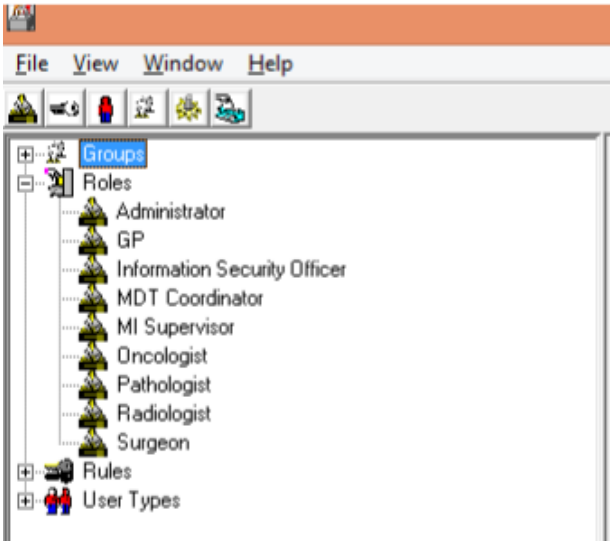


Figure 6.11: SHarE's Roles.

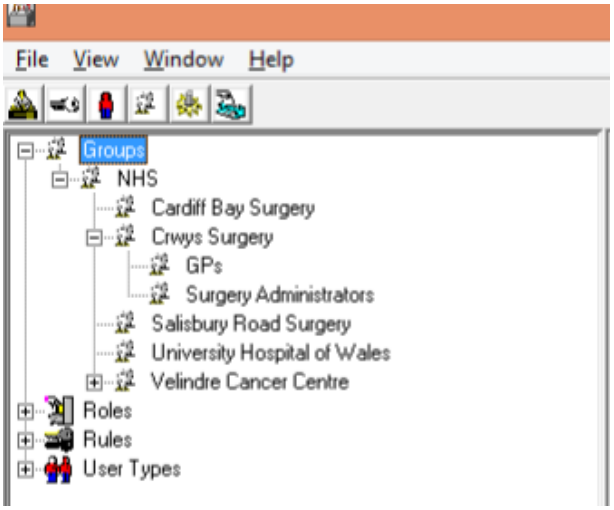


Figure 6.12: SHarE's Groups.

The relationship between the information security context elements shows that:

- Patient record can be accessed by one or more users: information in the patient record is collected and / or recorded in the LIS's database directly, and it is not stored in the WfT's database. Therefore, the only linkage is through an activity of type ASP. Fig 6.14 shows how a user is linked to information collected and/ or recorded by an ASP type activity;
- Each user can play a certain role in patient care: Fig 6.15 shows a GP role is assigned to Hessah Alsalamah;
- A role has to belong to one or more groups, and a group links the role to a healthcare organisation: groups in SHarE represent healthcare organisations, and in Fig 6.16

Figure 6.13: SHarE's Rules.

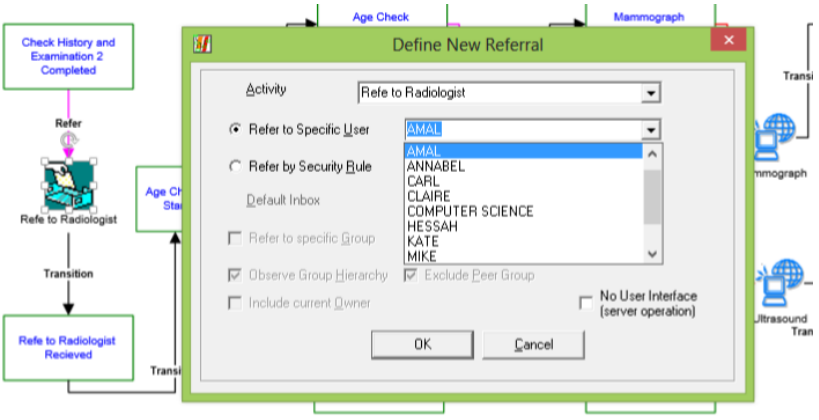


Figure 6.14: Linking role to activities in SHarE.

the list of roles belonging to Velindre Cancer Centre is shown. The group element can be used in comorbidities to group each condition's CT members together. This is a way to implement and manage a circle-of-trust for each condition;

– Each role can undertake one or more activities that must link to only one process that represents only one treatment, and access to the patient record must be based on access decisions which have to be compared against one or more rules: these are achieved in Fig 6.14;

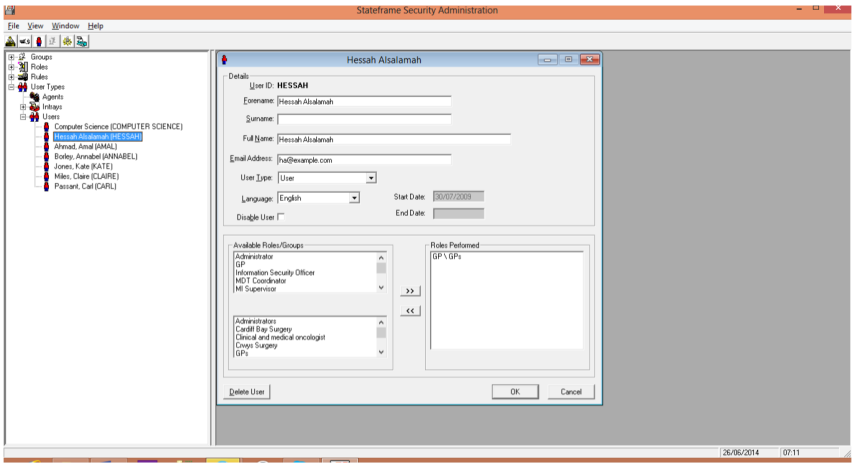


Figure 6.15: Roles assignment to users in SHarE.

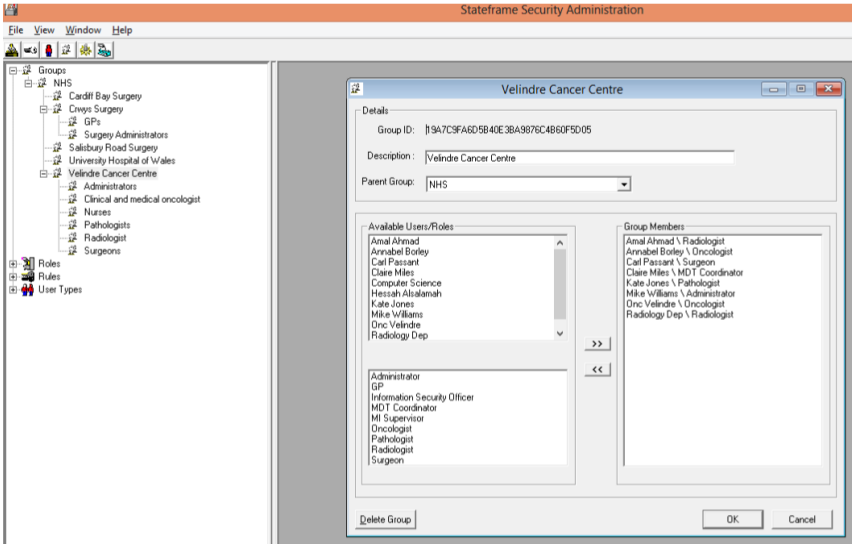


Figure 6.16: Roles belonging to groups in SHarE.

– Each rule must be linked to a healthcare professional's role: Fig 6.17 shows how to link roles to a rule, for example the "Breaking Glass to GP info" rule allows the listed trusted roles: MDT Coordinator, Oncologist, Pathologist, Radiologist, and Surgeon to break into the GP's information in case of an emergency. These roles are the trusted CT members in the breast cancer treatment scenario. Fig 6.18 shows the list of rules linked to the GP role.

These roles, users, groups, and rules create the PSP element, which helps maintain and support the execution of the workflow logic (the PDP) by a WFMS (PEP) [5]. The interaction between these elements is sustained throughout the whole process to create a single obvious point-of-control.

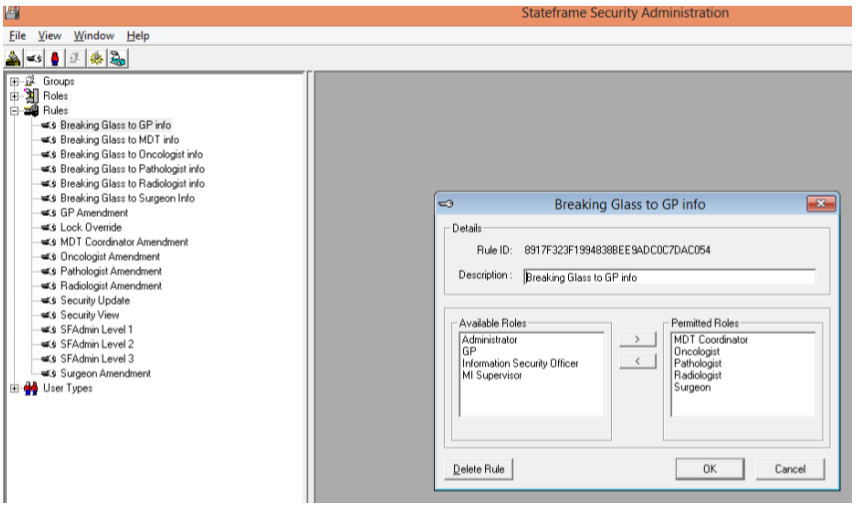


Figure 6.17: Linking roles to a rule in SHarE.

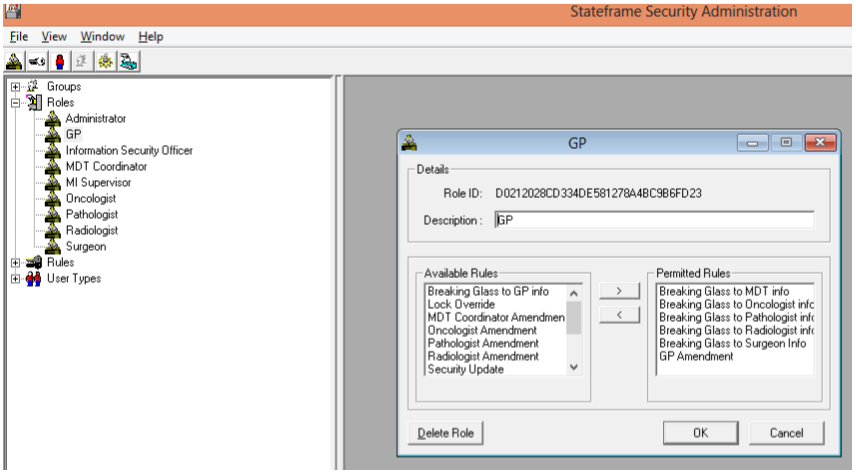


Figure 6.18: List of rules linked to a certain role in SHarE.

Finally, this control is at the heart of the information security design and contributes to its success. Moreover, it is linked with Control #1 as the access decision is based on the information layers structure. Therefore, they are specific to the type of collaborative environment in which it is implemented, and thus, it is crucial that these two controls meet the collaboration needs and implemented in harmony.

6.3.3 *Control #3*

- **Control:** The information should be organised in chronological order (timeline) with a stamp that includes: date and time of care point, and who saw the patient.
- **Implementation:** WffICP deploys Stateframe [112] that can develop a Case Hierarchy as part of case management, which is a natural way of providing a total view of the process to

all participating users [113]. This feature helps SHarE implement this control by viewing the patient's treatment points as a timeline in a hierarchal fashion. This is achieved by selecting the activities that represents them along with the date and time details, and the CT member processing this activity. Fig 6.19 shows the timeline of Susan's treatment plan. This timeline is unique to each patient, and builds up after each treatment point at the left side of SHarE's interface. It shows the treatment points in chronological order as a timeline with a stamp with minimum information displayed including: treatment point, status, and healthcare provider. However, if the CT member hovers the mouse over any of the treatment points, more information including the treatment date and time is displayed.

Figure 6.19: A timeline representation of treatment information in chronological order.

This information was built up as Susan was following her treatment pathway between different systems where her CT members work (see Appendix J for full screenshots).

6.3.4 *Control #4*

- **Control:** The information should be gathered and filtered from the different LIS at each point of care based on the PCAC access decisions.

- **Implementation:** This control is implemented through the PCAC model. At each activity (representing a treatment point) throughout the mapped workflow logic, a direct connection to the CT member's information systems's database is made using the programming language C# to gather relevant information, and filter what is needed based on national guidelines. Decisions were made based on the comprehensive study of breast cancer ICPs published by MoM using conceptual modelling (see Fig I.7). Fig J.19 shows the breast cancer MDT coordinator (Claire Miles), accessing all the information needed from the triple assessment for Susan. Collected from three discrete information systems. She selects the information she needs by clicking on the button which accesses the information which is ready for her to see. The first piece of information comes from primary care, if she needs to see any notes from the GP for example. The second piece is from secondary care from the specialist. Third is the biopsy results, and fourth the imaging report. So she clicks on the appropriate button(s) then she sees the information that she wants. The availability of this information supports the discussion of Susan's case at the initial MDT review. Finally, it is important to agree on the criteria on which the information is filtered when implementing this control as any misunderstanding in the implementation can have a consequence on the effectiveness of Control #2.

6.3.5 *Control #5*

- **Control:** Referrals should be automated to the CT member's role and picked up by the recipient with all information they need.

- **Implementation:** This control is implemented using the Referral Activity type, and Intray in WffICP. At the end of a treatment point and before the next, a referral activity is added (see Fig I.20). It automates the next activity in the treatment process to the next specific pre-defined role. Once the recipient logs in, he/ she receives the patient's referred case in his Intray with an "outstanding" task status awaiting his action (see Fig J.8).

6.3.6 *Control #6*

- **Control:** If speedy access to information is needed in an emergency, trusted CT members in the circle-of-trust should be able to have access to all information they need and justify

it, and this should automatically alert everyone involved.

- **Implementation:** SHarE implements this control by first, creating a break-glass activity following each treatment activity where new information is recorded and linking them together. Second, defining a dedicated break-glass access rule for each healthcare provider (the information owner/ originator) and only adding trusted CT member's roles to this rule and not the healthcare professional's role because logically he/ she is not allowed to break into his/ her own information as it should be available anyway. This would allow SHarE to show the break-glass activity in the treatment hierarchy to everyone included in this access rule. Once they click on it, an instance of this activity is created as a sub-process and associated with the role who initiated it and time of break-glass incident. Finally, link all break-glass rules to all other treatment activities undertaken by the same user that involves information. SHarE draws the virtual circle-of-trust around all healthcare professionals caring for a patient with a particular disease or condition. In other words, any healthcare professional playing a role in the treatment process of a particular disease for a patient is trusted to break into information recorded and owned by another CT member also treating the patient for that disease. In cases of comorbidities, this could be managed more effectively by using Groups which could be hierarchical, so each disease has a dedicated group to identify those who are trusted to break into information related to the same disease. This could assist in managing patient cases with conditions that could interact, and so an overlapping group could be used to stretch the circle of trusted people across diseases. By achieving the above, SHarE allows any of those trusted CT members to break into other CT member's information from the treatment hierarchy as shown in Fig 6.20.

  This figure shows the surgeon's treatment hierarchy, and that she can only break into other CT members information (circled in red) but not her information as it is assumed to be accessible. Once a Breaking-Glass icon was pressed (GP information for example), the CT member must justify before accessing the information (see Fig 6.21). Then the GP information can be displayed along with its stuck sensitivity icon(s) as shown in Fig 6.22. Once the breaking incident is over, SHarE adds it to the treatment hierarchy to highlight it with a date and time stamp like any other treatment point but uses a warning icon to visually attract attention as shown in Fig 6.23.

6.3.7 *Control #7*

- **Control:** Information may only be edited after sharing by the originator and such editing shall be notified to all who have access to the information.

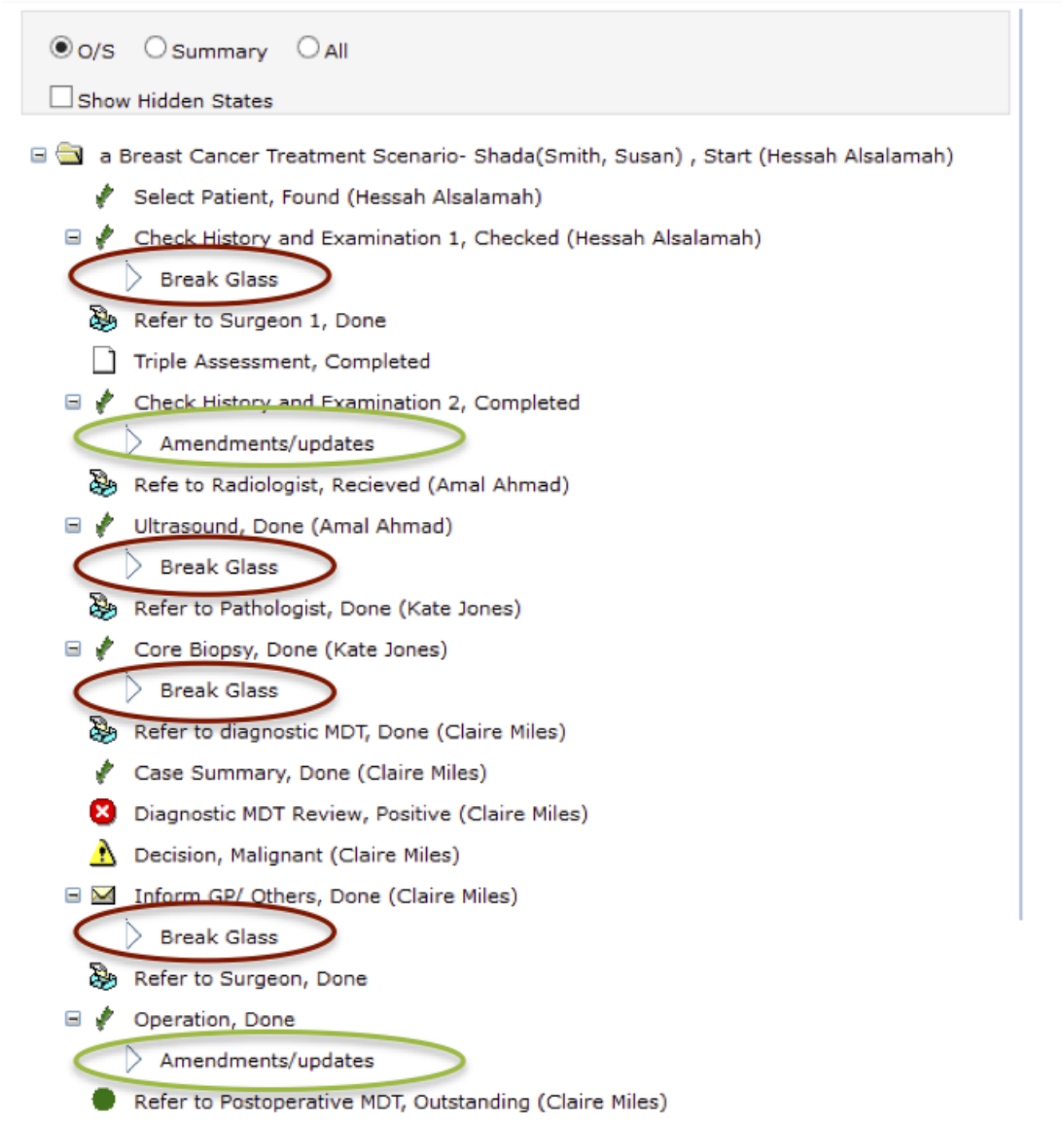


Figure 6.20: Breaking-glass and remote amendment features in SHarE.

- **Implementation:** This control is similar but opposite to the concept used in implementing Control #6 for the break-glass. The similarity lies in the fact that this control adds flexibility to SHarE and, at the same time, it alerts everyone in the hierarchy that the information has been amended so they can make any decision based on the change. However, it is opposite to the break-glass concept in terms of implementation, as it allows every CT member to amend his/ her information even after sharing but not other CT members information. This is circled in green in Fig 6.20. The figure shows the Surgeon's page (Carl) where she saw the patient twice, once early in the treatment for triple assessment, and second later on for the operation. Therefore, she is the only person who can amend her information in both points of care, but she can also break into the other

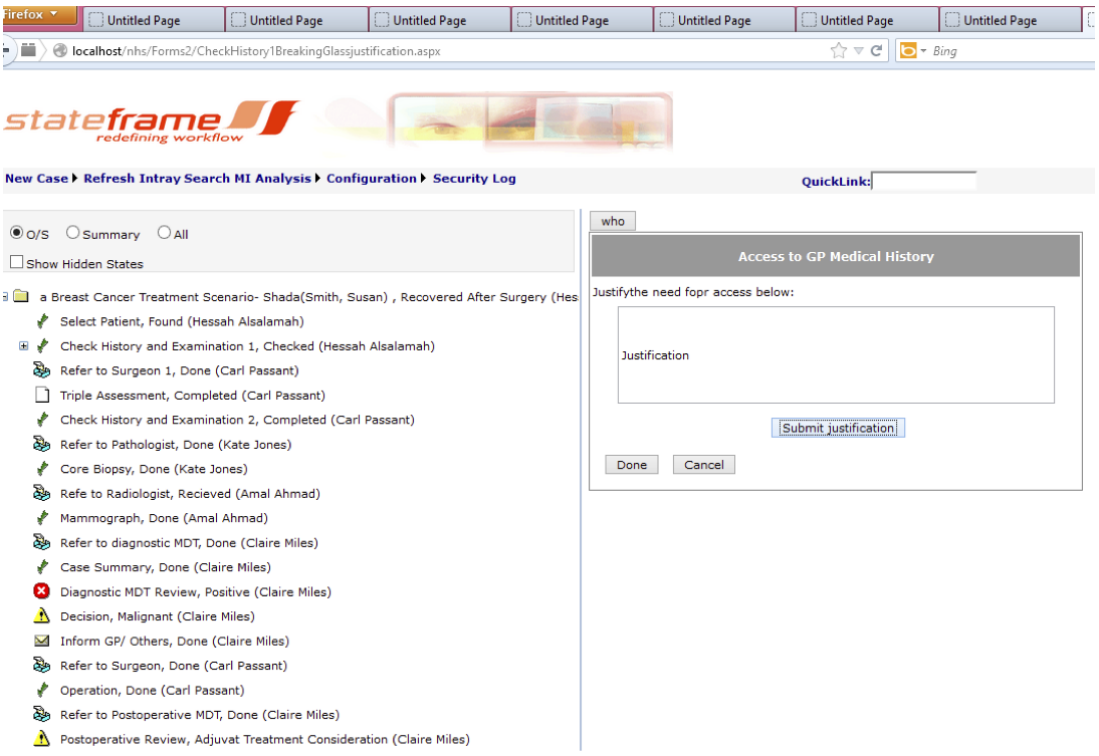


Figure 6.21: A timeline representation of treatment information in chronological order.

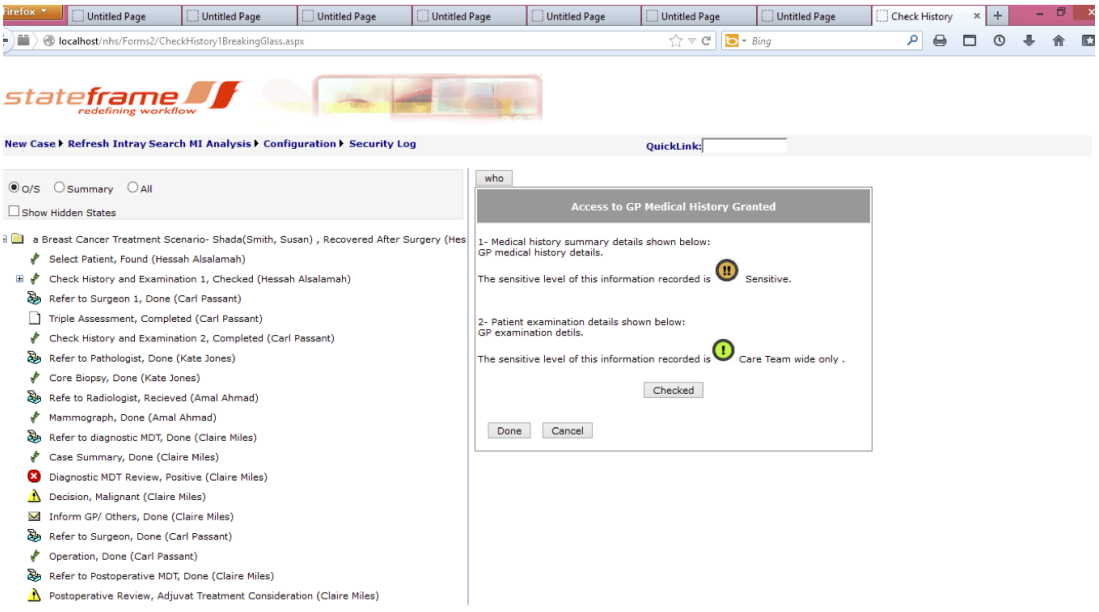


Figure 6.22: Breaking-glass incident in SHarE.

CT member's information if the information was not available for any reason. As for the implementation of this control, first, an amendment activity occurs for each point where new information is recorded and it links them together. Second, defining a dedicated amendment access rule for each healthcare provider (the information owner/ originator) and only adds him/ her and no one else. This allows only the information owner to visibly

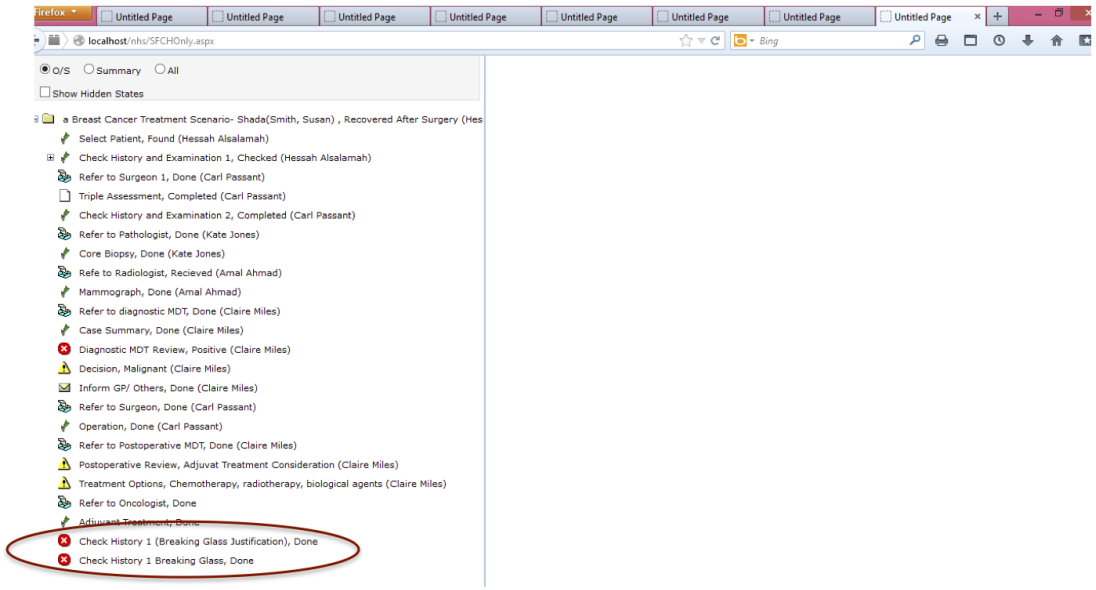


Figure 6.23: SHarE adds and highlights a break-glass incident in the treatment hierarchy with a time stamp.

see the amendment activity to their information in the treatment while no one in the CT does, and once they click on it, an instance of this activity is created and associated with his/ her role who initiated it and time. Finally, linking all amendment access rules to the activities undertaken by the same user.

6.3.8 *Control #8*

- **Control:** The sensitivity level of patient-identifiable information should be labelled and communicated to all healthcare professionals as a technique to raise their information security awareness.

- **Implementation:** This control aims to communicate the sensitivity level of information shared and information security needs in the collaborative environment with multiple users in a visual manner. It is implemented by viewing the Traffic Light Classification Scheme at each treatment point as icon-based radio buttons. This allows each CT member to select the right sensitivity level for recorded information, and attach the selected icon with the information to communicate the sensitivity level reflecting the owner's needs to all CT members. White for information that is Not Sensitive, Green is for Care Team Wide sharing (the default if the CT member does not have time to choose a level), Amber for Sensitive information, and Red is for Highly Sensitive information. Fig J.5 shows the GP treatment point, Fig 6.22 shows the icons attached to information that has been broken into. This scheme is selected in this research to demonstrate how to raise awareness about

security among CT members. Finally, it is more effective to use an information classification scheme that reflects the collaboration needs, and this was out of the scope of this research.

6.4 Conclusion

The design and implementation of SHarE, the proof-of-concept implementation of an SCE in cancer PC care, is discussed and illustrated in this chapter. Business Process Modelling was used to design SHarE as a treatment process using a selected breast cancer treatment scenario, this represents the information sharing context. Then BPM and ER diagrams were used to design both the information sharing and security contexts, while WfT was used to automate the treatment process and control access to information at each treatment point. WffICP is a WfT-based system and the most suitable WFMS to implement a wrapper-based systems that is loosely-coupled with LIS. Therefore, the breast cancer treatment process was mapped using WffICP process mapping tool, and access decisions were defined based on pre-defined groups, users, roles, and information access rules to create the PCAC model. WffICP linked access decisions to treatment points in the process to enforce the rules once the system is live. The chapter presented the implementation of the eight controls in SHarE with some screen shots with links to figures in the appendices. Eventually, through these controls, SHarE enforces the collaboration-driven information security rules at the machine level to achieve a SCE in cancer PC care to secure cross-organisational information sharing in cancer care, so the right information is accessed by the right person at the right time in the care process, and at the same time allowing each LIS to maintain their local security rules to meet their information sharing and security contexts in their home organisation.

Chapter 7

Evaluation

Overview

This chapter presents the evaluation of the SCE approach outcomes at both the high-level problem the goal addresses, and low-level implementation of SHarE. It starts with a description of the evaluation process and criteria. It also explains and justifies the evaluation method which uses interviews with the different healthcare providers and senior personnel in a number of healthcare organisations mainly involved in cancer care in Wales. Furthermore, the findings are presented in this chapter along with potential challenges identified and the limitations of the SCE approach at both the high-level problem the research addresses, and the low-level implementation of SHarE.

7.1 Introduction

This chapter describes the research evaluation stage as the final stage in the research methodology. This stage aims to evaluate the SCE approach outcomes, and in particular, the usefulness and acceptance of the proposal, the possibility of integration with LIS to achieve the research objectives, and the significance of the information security requirements identified and implemented. The chapter also explains and justifies the choice of method used to assess the outcomes of the SCE approach at all levels. Five semistructured interviews with six interviewees from different healthcare providers who are senior personnel in Welsh secondary and tertiary healthcare trusts involved in cancer care were conducted. Their roles in cancer care are:

1. Normal Breast Cancer MDT Coordinator,
2. Breast Cancer Nurse Specialist,
3. Breast Cancer Oncologist,
4. UGI Oncologist,
5. former Head of the developers' team in the cancer centre's CIU at Velindre Hospital,
6. the Caldicott Guardian at Velindre NHS Hospital, and
7. the IT lead at Velindre Hospital.

These interviews had two purposes: first to assess the research problem and threats highlighted by the Caldicott Guardian in the early stages of this research; and second to assess the controls and their implementation in the proposed system SHarE. The assessment involves evaluating the usefulness of the proposed system, the possibility of integration with LIS, and the significance of the information security requirements identified and implemented. Therefore, the evaluation of SHarE can be categorised into three main areas: usefulness, integration and setup, and information governance. This chapter describes how the interviews were designed and analysed. It also presents the key findings from these interviews, which fall into three categories. The information needs for each role, reflection on the eight controls identified to achieve an SCE in cancer care, and reflection on SHarE in general. Each interview is transcribed, and fully analysed for the findings which are presented in this chapter. For full details on each of the five interviews, see Appendixes B, C, D, E and F. Each of these appendixes outline details of a single interview session covering the interviewee's role details, interview aim and structure, list of questions asked during the interview session, and finally a full analysis based on the categorisation areas of the questions asked during the interview, and a full interview transcript.

Finally, this chapter goes beneath the surface by discussing the challenges SHarE may face for its adoption and integration, as well as, the limitations of the outcomes.

7.2 Evaluation Criteria

It is essential to assess the proposed system as part of this research, however, this task requires assessing the research problem as a first step. Therefore, the evaluation process of this research has two parts: research problem assessment (including the goal and threats), and research proposal assessment (which includes the controls and SHarE). The research problem was clearly highlighted by the Caldicott Guardian, when he said: *"because of varying interpretation of the guidance around information security, clinicians are often blocked from having the right information to treat a patient"* [69]. This results in the information not flowing with the patient between the different healthcare providers following a treatment pathway. This high-level research problem was identified at an early stage of this research from an initial interview with the Caldicott Guardian. It is a solution to this problem which is proposed in this research. Therefore, before assessing the proposal, this research problem statement is confirmed with the interviewee and more details regarding the threats are gathered for assessment.

7.2.1 Controls' Evaluation Criteria

After assessing the research problem, the first step in the assessment is to evaluate the eight controls identified to address the research problem:

1. **Control #1:** A consistent information layers structure should be provided throughout the collaboration that reflects PC care.
2. **Control #2:** A PCAC model should be deployed to govern information in the collaboration, where access decisions are based on the patient's condition and treatment stage.
3. **Control #3:** The information should be organised in chronological order (timeline) with a stamp that includes: date and time of care point, and who saw the patient.
4. **Control #4:** The information should be gathered and filtered from the different LIS at each point of care based on the PCAC access decisions.
5. **Control #5:** Referrals should be automated to a CT member's role and picked up by the recipient with all information they need.

6. **Control #6:** If speedy access to information is needed in an emergency, trusted CT members in the circle-of-trust should be able have access to all information they need and justify it, and this should automatically alert everyone involved, when it happens.

7. **Control #7:** Information may only be edited after sharing by the originator and such editing shall be notified to all who have access to the information.

8. **Control #8:** The sensitivity level of patient-identifiable information should be labelled and communicated to all healthcare professionals as a technique to raise their information security awareness.

7.2.2 SHarE's Evaluation Criteria

After evaluating the controls, their implementation in SHarE is assessed based on three general evaluation criteria. The criteria selected for an interview are based on the interviewee's role but cover: SHarE usefulness and acceptance, setup and integration, and information governance.

1. **Usefulness and acceptance.** This focuses on evaluating the usefulness and acceptance of the SHarE prototype system by a user of the current cancer care support systems. Particularly, it aims to assess the usefulness of the controls that SHarE aims to add to the LIS, any value these controls can add to current LIS, the potential of them to address the information sharing issue and the use and adoption of SHarE in everyday practice, to highlight any challenges to its adoption, and suggest any improvements to SHarE.

2. **Setup and integration.** This focuses on evaluating the SHarE system from the technical specialist's point of view, mainly from an IT and systems developer perspective. This is achieved by discussing the potential adoption and integration of SHarE with current systems from a more technical view point, the challenges this integration may face, and any suggested improvements.

3. **Information governance.** This focuses on the evaluation of the SHarE system from an information governance perspective by discussing the potential of SHarE to address the information security balance in healthcare collaborative environments, if the information security requirements comply with the Caldicott Guardian's principles, and if there is a potential for adoption, use, and integration of SHarE with current systems, the challenges this adoption may face, and how it can be improved.

7.3 Evaluation Method

The research evaluation stage aims to assess the outcomes of the SCE approach at each level of the information security design. This necessitates a qualitative approach that can confirm the research problem, the presence of the information security threats identified from the interview with the Caldicott Guardian, and the controls implemented in SHarE as a solution to eliminate the impact of these threats. This assessment investigates the perspectives of healthcare professionals for the achievement of the research aim, and thus, qualitative methods were chosen over quantitative ones [72]. Therefore, an evaluation method is required where a set of questions can be asked regarding the problem and threats, then a full demonstration of SHarE along with its main eight controls can be given before another set of questions reflecting the evaluation criteria and the interviewee's role can be asked to evaluate whether the controls work. Therefore, face-to-face semistructured interviews with carefully picked interviewees were chosen as the evaluation method of SHarE based on the evaluation criteria, mentioned in Section 7.2.2 with a distinct separation between the stages of evaluation.

7.3.1 Semi-Structured Interviews

Interviewees Sample

Five different interview sessions were conducted to evaluate SHarE and they are presented in chronological order. Four of the sessions were conducted with a single interviewee, while one was conducted with two interviewees and the lead research supervisor. The evaluation was based on three criteria: usefulness, integration and setup, and information governance. The sample of interviewees includes six personnel having the roles in Table 7.1. Each role is given a code for easy reference which will be used to refer to the assigned role.

Both the interviewees' roles and their total number in the chosen sample is believed to be representative for the following reasons. Initially, it is important to be selective when it comes to the roles to cover the three evaluation criteria: usefulness, integration and setup, and information governance. The sample choice of interviewees' roles was made for the following reasons. Firstly, the breast cancer scenario is the type of cancer addressed in the prototype system implementation, and thus, the usefulness of SHarE is best assessed by those already familiar with the scenario and the information needs in this scenario. Therefore, three different healthcare professionals following the breast cancer treatment scenario were interviewed: a Breast Cancer Oncologist, a Breast Cancer Nurse Specialist, and the Normal Breast Cancer MDT Coordinator. To assess the generality of the proposed system, an oncologist specialising in another type of cancer that has been studied but not implemented in SHarE was also interviewed. Secondly,

Table 7.1: Evaluation interviews.

Evaluation Category	Name	Role(s)	Code
Usefulness and acceptance	Ms. Mital Patel	The Normal Breast Cancer MDT Co-ordinator	R1
	Ms. Helen McGarrigle	A Breast Cancer Nurse Specialist	R2
	Dr. Annabel Borley	A Breast Cancer Oncologist	R3
	Dr. Tom Crosby	An UGI Oncologist	R4
Setup and integration	Dr. Dave Morrey	The former Head of the developers' team in the cancer centre's CIU at Velindre Hospital	R5
Information governance	Dr. Tom Crosby	The Caldicott Guardian at Velindre NHS Hospital	R6
	Ms. Ann Marie Stockdale	An IT lead at Velindre Hospital	R7

the systems developer team at the CIU who developed CaNISC which is the leading legacy system used today in cancer care across Wales to determine if SHarE can be integrated with it. Therefore, the head of this team was interviewed to assess the possibility of adopting SHarE and integrating it with CaNISC and other LIS, also an IT lead at the Velindre, who is aware of the informatics needs in cancer care and the systems used to support it. Finally, information governance can only be assessed by a Caldicott Guardian who understands fully the information governance needs in cancer care and the fine line between information availability and confidentiality in a healthcare collaborative environment, and is the person who identified the threats in the first instance.

Furthermore, the total number of interviewees selected for each category is also considered representative, since most of these key roles for the evaluation of the research are undertaken by one person and only the selected interviewee can fully understand the job description in order to assess SHarE from the perspective of that role. First, there is only one Caldicott Guardian for each hospital, although there are other Caldicott Guardians at the district level supervising them. The Caldicott Guardian appointed in Velindre Hospital, Dr. Tom Crosby, was interviewed and when an attempt to be introduced to his superior Caldicott Guardian failed, Dr. Crosby highlighted the fact that his superior Caldicott Guardian has a very busy schedule and the local Caldicott Guardians find it very hard to get hold of him. This made it almost impossible to meet him for the purpose of this research. This left the sample with one Caldicott Guardian. Second, there is only one Normal Breast Cancer MDT Coordinator, Mital, although some other cancer MDT coordinators may cover for her, when she has sick leave for example. Mital was the perfect interviewee to provide a full picture of that role as the breast cancer scenario was selected for this research. Third, the head of developers is also a solo position, and since the

interviewee was interviewed before at the early stages of research when the research problem was under investigation and Dr. Morrey was working full-time in this position, he was included in the evaluation sample, although at this stage he had recently retired. Fourth, there are only two oncologists in the breast cancer centre, and one of them was in our sample. However, an UGI cancer oncologist who also has the role of the Caldicott Guardian was also interviewed to evaluate information needs and to assess generalisation of SHarE to other cancer areas. The order of interviews was based on the availability of the selected sample.

Interview Variations

The interview sessions varied in terms of their aim, question list, and duration. The aim of each session reflected the evaluation category of the interviewee. Each of the evaluation criteria varied in its aim. The first category focused on evaluating the usefulness and user acceptance of the SHarE prototype system, while the second category focused on evaluating the SharE system from both a developer and IT perspectives by discussing its potential adoption and integration with current systems from a more technical point of view, the challenges this integration may face, and any suggested improvements. Finally, the last category focused on the evaluation of the SHarE system from an information governance perspective by discussing the potential of SHarE to address the information security balance problem and if the information security requirements comply with the Caldicott Guardian's principles. The question list used related to the interviewee's role in the research scenario and/ or in the healthcare organisation. With regard to the duration, interviews varied in terms of the time allowed to conduct it. This was mainly influenced by the busy schedule of the interviewees. The shortest interview took 35 minutes while the longest took 120 minutes the average was 71.8 minutes. The longest interview was with the former head of the CIU at Velindre Hospital who had that role in the initial stages of the research, when the research problem was investigated with him, but was recently retired at the time the evaluation stage was reached. Therefore, he managed to give as much time as was needed. On the other hand, the shortest interview was conducted with the Normal Breast Cancer MDT Coordinator. Since the Normal Breast Cancer MDT review is only conducted every Thursday between 8.30 am-10.30 am, she is not available in the hospital on any other day during the week. Therefore, she has a extremely busy day. This made it difficult to meet her for more than 35 minutes in total.

7.3.2 Interview Design

The evaluation process of this research has three parts: one for research problem assessment (including the goal and threats), and two others for research proposal assessment: one for the

controls and the other for SHarE. Therefore, each of these evaluations requires an interview design that reflect their aim. The opening questions and intermediate are more general to all interviewees, while the ending questions are more tailored to the interviewee's role and the criteria in which they fit. Therefore, flexible qualitative interviewing is chosen as it is more theory driven and flexible with open-ended questions [76]. This form supports an interview design that meets the evaluation aim and criteria that is driven by the formed research questions and the study.

1. **Research problem interview questions:** First, the research problem is assessed by asking each of the interviewees the following question: *"do you agree on the fact that patient information is sometimes not available at the point of care?"* This question is asked regardless of the interviewee's role as it helps gather as much information as possible about the role's perspective to the main reason behind this problem if he/ she agrees to it, or the reason why the Caldicott Guardian thinks so if he/ she disagrees.

2. **Research proposal (controls) interview question list:** Second, evaluating each of the eight controls identified in SHarE is carried out by asking each interviewee the following questions:

   (a) Do current systems provide it?;

   (b) Is it an important control?;

   (c) How it can be improved?; and

   (d) Are there any potential challenges to its implementation?

3. **Research proposal (SHarE) interview question list:** Finally, this last part of the evaluation process aims to assess SHarE usefulness and acceptance, setup and integration, and information governance. Therefore, the question list used related to the interviewee's role in the research scenario and/ or in the healthcare organisation. In addition, some comments from the interviewees shed light on other concerns or raised further questions. Therefore, some additional questions were asked at some interviews but not in others. For example, the first two interviews had contradictory responses to the same question, and hence, both opinions were presented in the following interviews to gain a better understanding of the reason behind such a conflict and get a reasonable justification for it happening. For full details on the questions asked at each of the five interviews, see Appendixes B, C, D, E and F.

Finally, the researcher had to conduct the three parts in the same interview session. This is because the early research stages of the research methodology (see Fig 3.1) along with the interview with the Caldicott Guardian collected most of the information needed to design the high-level of the SCE and the analysis of the very same interview helped derive most of the threats and controls. Therefore, an almost complete version of SHarE was developed in a couple of months to demonstrate the outcomes. Furthermore, the evaluation process is most effective if the same sample assesses them, and there was a risk of not achieving that due to the limited time allowed for the interview and tight schedule of interviewees making availability limited. Therefore, as much information as possible is collected from the interviewees. However, it was determined that if the interviewee was to disagree with the research problem in the first part of the evaluation session, then the interview session is to end at that stage for reflection on the interviewee's view and justification for the disagreement. Then the remaining parts would be assessed at a later session. Nevertheless, none of the interviewees actually disagreed with the identified research problem, but each provided a different justification for what they believe is actually causing it from their role's perspective. This collected data helped enrich the design and implementation with finer details, mostly of how the controls should be implemented to help the interviewees undertake their roles.

7.4 Interviews Analysis

The interviews collected a large amount of data and information based on narratives that had to be analysed for results and findings. There are a number of different interview analysis strategies, but according to Gubrium and Holistein [76] grounded theory methods could be used to shape qualitative interviewing by guiding the analysis of interview collected data. Grounded theory has different variations, one of its key strategies is inductive construction of abstract categories that explain and synthesise these processes [76]. Based on that, first and foremost, the interviews were audio recorded and fully transcribed. Second, the opening, intermediate, and ending questions categorise the transcript of each interview into three chunks one for each part of the assessment. Each of the first two parts had general questions used with all interviewees and these were analysed for each person as the first stage of the analysis. While the third part is analysed separately for each interviewee as it was more specific to the interviewee's role. Manual synthesis of key words and grouping similar responses was used in this second stage.

1. **Research problem- interviews analysis:** All transcripts relating to the research problem were gathered together and analysed by first checking if the interviewee agreed with the research problem, disagreed with it, or was somewhere in the middle. Then the justification of the reason behind it was collected from all interviews and interpreted.

2. **Research proposal (controls)- interviews analysis:** each interviewee was asked a set of questions about each of the eight controls. All transcripts relating to each control were grouped together before being analysed. A table (shown later in 7.2) aggregating all responses was created to paint the full picture of each of these controls. However, some interviewees did not respond to the question, or agreed/ disagreed to some extent. Therefore, a table key is developed to reflect all types of responses. A "Y" is used when the interviewee agrees, an "N" when he/ she disagrees, and "N/E" when he/ she disagrees with the interviewer to some extent, a "Y/E" when he/ she agrees with the interviewer to some extent, an "N/A" when the interviewer did not discuss it with the interviewee, and an "N/M" when it was discussed but the interviewee does not mention it or make a comment. From the responses it was clear that the responses from the interviewees were very positive when they expressed an opinion.

3. **Research proposal (SHarE)- interviews analysis:** The third part of the assessment is analysed separately for each interviewee. This is because the list of questions differed to reflect the interviewee's role and the category in which the assessment of SHarE fell. Then those responses falling into the same evaluation criteria (usefulness, integration and setup, and information governance sessions) were grouped together and further analysed to group similar responses and produce them in a table (shown later in 7.3) that paints a bigger picture of the interviewees assessment of SHarE. Again, a table key is developed to reflect all types of responses. A "Y" is used when the interviewee agrees, an "N" when he/ she disagrees, an "N/A" when the interviewer did not discuss it with the interviewee, and an "N/M" when it was discussed but the interviewee does not mention it or make a comment. Again the responses by the interviewees expressing an opinion were positive.

7.5 Findings and Outcomes

This section presents the key findings from the five interviews, which fall into three categories. In the context of the breast cancer treatment scenario, in each discussion the interviewee expressed the information they process as part of their role in that scenario or cancer care in general, and the information systems they use. This identified the specific information needs of the role. Second, there was the reflection of interviewees on each of the eight controls identified to achieve an SCE in cancer care. Finally, there is the reflection of interviewees on SHarE from the perspective of the evaluation criteria if appropriate to their role: the usefulness and acceptance of the proposed system, the possibility of integration with LIS to achieve the research objectives, and the significance of the information security requirements identified and implemented.

7.5.1 CT Roles in Breast Cancer Treatment

In order to understand the problems CT members and support personnel face when implementing PC care in cancer care, a detailed role description for each of the six interviewees is presented in the following section to give an idea of the specific information needs of each role:

- **Normal Breast Cancer MDT Coordinator:** Miss Mital Patel [78] plays the role of an MDT coordinator in Llandough Hospital. There are two breast cancer MDT reviews: Normal Breast Cancer MDT, and Metastatic Breast Cancer MDT. The former has an average of 35-40 patients per session reaching 50 patients in some weeks. This MDT is represented in the *"Happy Pathway"* selected as the main treatment scenario in this research. The second MDT review has fewer patients, normally under 30 patients in total per review, and is not included in the research scenario. Mital is the coordinator for the Normal Breast Cancer MDT review but she also covers for other cancer MDTs in hospitals. Mital's job is to make sure the right information is available at the MDT review, and hence her job includes gathering all the information from the patients' clinical appointments so that they can be discussed in the MDT review. This information normally includes results from the triple assessment involving: referrals, consultants' patient case notes including history and examination, pathology results, and radiology results. Once all this information is available for the review, the patient case is discussed with the aim of deciding on a treatment plan and indicating the next step in the treatment which the coordinator records in CaNISC.

- **Clinical Nurse Specialist in Breast Care:** Helen McGarrigle [8] is a Breast Care Nurse and a Key Worker in breast cancer care for patients in Llandough, Cardiff and Vale Breast Centre. Her job is to look after patients throughout their breast cancer treatment journey and interpret the results for them. She is normally immediately involved at an early stages of the patient's treatment pathway, once they are referred from primary care to a surgeon in secondary care. This means her first involvement is when the surgeon sees the referred patient and then at all stages of their treatment pathway including: radiology imaging, pathology results, before, during, and after their surgery, and the MDT review. According to Helen, she is the closest to the patient and considered a key CT member with a major input at the beginning of the pathway. Especially, she works closely with the surgeons and not for them. Helen explains the nature of her job as: *"the surgeon says to the patient: 'you have got breast cancer. This is what we are going to do, and these are the choices you have to make,' and a lot of our job is interpreting what that actually means in the real world."* In addition, the oncologist may delegate her role to Helen when the patient is scheduled for chemotherapy and the oncologist is on leave. She says: *"sometimes*

they will see an oncologist, sometimes they will see a nurse instead of an oncologist." Eventually, Helen summarises her role in patient care in one sentence as: *"we are patient advocates, the patient is our priority."* It is no wonder the information Helen collects and processes as part of her job includes, *"everything, everything,"* as she claims. She explained:

> *"well, we want to know breast history, general medical history, surgical, have they had surgery before, family details, social history, that type of thing, what medications they are on. We would want to know about their specific situation, everything like the size, the presentation, the side, everything!"* [8]

This information is recorded and collected at different points of care following the patient's treatment pathway, and has different formats; some are paper-based and others are in an electronic format. According to Helen, most of the information she gains is from MDT reviews where she takes hand-written notes of the discussions. Thereafter information *"comes piecemeal,"* Helen claims, *"so you do not get it all straight away."* She continued, *"so we often organise the system to get the rest"* [8]. However, currently this information is not stored in one system, but in different isolated systems each serving a healthcare professional using it to store and manage his information silo. Helen accesses mainly three other information systems as part of her daily job to access the rest of information she needs to care for the patient. These systems are:

- Patient Management System which is a medical system for outpatients who are admitted to the hospital, medical details can be accessed and certain information checked in this system,
- Clinical Portal to access test results and doctors' letters, and
- CaNISC when the patient is transferred to the oncologist.

- **Breast Cancer Oncologist:** Dr. Annabel Borley [86] works for Velindre Hospital, which is a tertiary oncology service. Her job is to look after the non-surgical treatment of breast cancer. The information Dr. Borley needs as a breast cancer oncologist, also includes *"everything,"* according to her. She elaborated:

> *"I need to know their demographics, their basic address, age. I need to know what has happened to them so far, so all the details about their examination, their presentation, their imaging, their pathology, and the MDT discussion, but I also need to know their personal medical history"* [86].

- **Former Head of Clinical Information Unit (CIU):** Dr. Dave Morrey [107] is the former Head of CIU at Velindre NHS Hospital. The CIU mainly focuses on the following three elements: helping clinicians and patients, clinical outcomes, and clinical trials and research. From Dr. Morrey's past experience as the head of this unit, he explained its role:

  > *"there are three main aims at the CIU. First, to use technology to help clinicians as they care for the patient in order to directly benefit both patients and those clinicians,"* which means *"there was an element of developing systems for cancer care." "Second, to measure the quality of care given in the Cancer Care Centre at Velindre Hospital and be able to benchmark that against other centres,"* by *"using the clinical information to provide the management information for Velindre Hospital, as a trust. Because there were certain figures that needed to be derived for performance of the hospital in terms of number of patients, whether the referrals to the hospital were changing with time."* Finally, *"the CIU got involved in helping medical research, helping the clinicians with their research and also in audit. Checking the outcomes for patients and the quality of care"* [107].

  Furthermore, according to Dr. Morrey there have been 20 years of fruitful collaboration between CIU and the School of Computer Science & Informatics at Cardiff University. He explained:

  > *"the research contributed mainly to the development of CaNISC in a number of ways. The research and collaboration helped look at new areas identified by ideas coming from clinicians, developers, university students and the university. Bringing information from the literature and testing things out in particular areas. Some of these were highly successful and we were able to adopt them straight away, others had to wait for the technology to catch up to implement the ideas, and others went the wrong way which is pretty much the nature of research"* [107].

- **Information Technology Lead:** Ann Marie Stockdale [85] is an IT Lead at Velindre Hospital, she also sits on the CaNISC Service Management Board and the Change Advisory Board and heads the IM&T Department at Velindre Cancer Centre.

- **Caldicott Guardian:** Dr. Tom Crosby [84] is a Medical Director of the South Wales Cancer Network who plays a number of roles (see Table 3.2). These include: Chair of the Cancer Service Management Board, Clinical Director of Velindre Cancer Centre, Cancer Centre Caldicott Guardian, UGI cancer consultant clinical oncologist. However, the evaluation aimed to assess SHarE from the perspective of two of his roles - Caldicott Guardian for the Cancer Centre, and UGI cancer consultant clinical oncologist - to understand

the fine line between information availability and confidentiality as he is an oncologist who has to access patient information for patient care continuity, and at the same time, Caldicott Guardian who is concerned about patient privacy and information governance. These contradicting roles make Dr. Crosby the perfect person to set and understand the right balance between information availability and confidentiality in the context of healthcare.

7.5.2 One Problem with Many Causes

All of the interviewees regardless of their role or the evaluation criteria they were in, were asked whether they agreed that patient information is sometimes not available at the point of care because current systems may block the flow of this information with the patient. They all agreed to this research problem and confirmed that this is an existing issue they face on a day-to-day basis, however, their responses varied as to what is causing this issue. This variation is due to the different perspective of each role when considering this problem.

1. **Large number of patients.** Initially, the Normal Breast Cancer MDT Coordinator agreed with this problem to some extent at one extreme, she agreed to the fact that sometimes it is a problem to make the treatment plan and results available in a timely manner after a Normal Breast Cancer MDT review in CaNISC. This is due to the average number of patients in Normal Breast Cancer MDT reviews being fairly high, which makes it hard for Mital to record this information live into CaNISC during the review. Therefore, she takes hand-written notes during the review then records this information along with the treatment plan after the MDT review into CaNISC. In addition, benign patients are not recorded into CaNISC as it is time-consuming with the large number of patients. Also, since most patients in the Normal Breast Cancer MDT review are diagnosed with cancer for the first time, these patients did not exist in CaNISC before this point in time. Mital says:

   > *"the breast cancer MDT works a bit differently to the other MDTs it would be a bit harder if you diagnosed a patient today and then went straight onto our database because the patient won't be there."* Mital justifies the reason why this is happening in her MDT: *"because there is such a big quantity of patients you just do not have the time to do that. Also to reduce workload, benign patients are not recorded. The thing is if you notice today a quarter of them are benign and are not going to be on the system anyway so you would be basically reversing what we are trying to get rid of in the first place so*

> *there would just be no point. They leave a lot of it to me to put the patients onto MDT."* Whereas, *"other MDTs type in the MDT live so their information is available within half an hour,"* Mital added, *"their patient would already be on the database regardless of whether they are malignant or benign. Like with sarcoma cancer patients they will put them on regardless and then say they came to clinic they would have the information in front of them"* [78].

Mital records this information in Llandough Hospital's partition in CaNISC in a new MDT module. Whether a surgery or chemo treatment option was chosen in an MDT review held in Llandough Hospital, Velindre Hospital will need to have access to the patient information Mital recorded in the Llandough Hospital's partition. This is critical as it informs the CT members working at Velindre Hospital about the treatment plan and recent results, as some of the treatments are carried out by CT members at Velindre. Although CaNISC is also used in Velindre to record and access cancer-related patient information, CT members in Velindre do not have access to information recorded in another hospital's partition of CaNISC unless they were granted access by the other hospital. Therefore, in order for Mital to share an MDT treatment plan and results with CT members caring for the patient in Velindre, their referral needs to be added to the patient's case note. Once this is done, Velindre healthcare professionals will have access to that partition and will be able to see Mital's notes from the MDT as well as her referral back to them for treatment purposes. This time-consuming process results in the system not being updated as regularly as it should be, especially if the patients discussed in the MDT have appointments with the consultants on the same day. In such cases Mital would not have enough time to make this information available for the consultant to discuss the treatment plan with the patient.

2. **Finding and locating information is time-consuming.** Mital believes that information should be available among CT members once they are granted access to the other hospital's partition on CaNISC. She explains that if any CT members claims that the information is not available, this is most probably because either they do not have the time to find it and would like someone to do this task for them, or because they are not experienced in finding their way into the system to find what they are looking for. She says:

   > *"the problem with information access is that you will have two tabs in current system at the top and consultants do not understand where the other page has gone"*. For example, after I update the CaNISC system at my endpoint in Llandough Hospital, CT members in *"Velindre still say that we do not understand what happened to this patient. The patient is on the system, why are you not looking?"* she thinks *"it is not so much that the information is not*

> *there I think people are not willing to look for that information."* However, according to Mital, *"although there are different places where you look for information, people want the information to be handed to them whereas you have not got the time for that. Our system is generated for all hospitals, every hospital uses it like the Gwent, the Royal Glamorgan. So the information does flow it is just not available because people think it is not available, I think! or they assume it is not there. So I think the information is there if people used it but people are not willing to use that information."* She said: *"people know that they have got the system and they have got the information available but I think a lot of people do not have time to look for that information"*. She justified this: *"if they find an easier way to find information they might even use it"* [78].

The nurse agreed with Mital and also added that the information is sometimes hard to locate not only between different systems sharing the information, but sometimes even within the same system. However, in such cases Helen normally has to communicate with the person by e-mail to get access to information in another system, which is immensely time consuming. This explains the complaint made by Mital about what CT members choose to do whenever they do not find information. Moreover, Helen elaborated through an example:

> *"if there's somebody who's been seen at Velindre by the oncologist, at the moment we should be able to access in CaNISC, because they do go right in CaNISC like real time. So they are very good at that, but because I as yet am not kind of up to speed with that [CaNISC usage], I would probably email the oncologist and say, what happened with this one? How did this go? or its that type of thing"* [8].

Nonetheless, Helen has some difficulties using existing systems to find relevant information she needs for patient care in a timely-manner. She said:

> *"CaNISC is very slow, even when you know what you are doing, it is quite slow, and when you do not know what you are doing, it is really slow. At the moment, I do not have time for really slow, and the rest of my team, because they have got a little bit more time, perhaps they have been practising and using it more often"* [8].

These two opinions show that Mital uses CaNISC on a daily basis but Helen does not, which is due to the nature of their jobs. That explains why Mital claims that the information is actually there, and why Helen does not have the time or the skill to try to find what

she needs but wants the information ready for her, regardless. Dr. Morrey supported both opinions and tried to explain the reason behind it from a technical point of view:

> *"well, I think probably both are right in that you got to understand the clinician for a lot of the MDT's round Wales won't know how to use the radiology system, or the pathology system. Now the MDT, do they really want to get involved in all the intricacy that others have."* Ideally in such a case the availability of the right information, not all the information is the aim. So he continued: *"if you just access the raw radiology system you're going to see everything, all the details a radiologist needs to know. Well you don't want to see, the clinician who is trying to treat the patient doesn't want to see that. They just want to see the filtered information as you've got it. So that's absolutely right, so both of them are right and the MDT coordinator has had to overcome those problems and knows just where to go, to individual systems to get it out. But it really is asking a bit much for the clinicians to actually do that, and most of them may know about CaNISC or their bits, or they may know about their local system or they may not. A lot of them don't use clinical systems on a day-to-day basis. So to ask them to suddenly flip between a pathology system or a radiology system or CaNISC, it's a bit much. So they're both right to a certain extent."* Furthermore, he elaborated: *"also they may well not have security credentials in all those systems. You tend to find that radiology systems are only made available to radiologists and not the other people, because they say well this system isn't really designed to be made available for everyone else, because you could just have clinicians going in and messing up systems. It's not protected, as a clinician you go in there, radiologists expected to make changes. Well we don't have a separate module for clinicians to log the information so it is, it becomes a real security risk to the local systems, to have lots of these people who don't know, not trained in the system, who don't think in the way those systems work, to access them"* [18].

3. **User-hostile systems.** This is the key reason hindering Helen's usage of CaNISC and the Clinical Portal. First and foremost, Helen describes CaNISC as a slow user-hostile system that requires intensive training to be properly used to locate relevant information. CaNISC makes it very difficult to find information, *"it's hard work,"* Helen complained, *"CaNISC is not easy!"* she added. Although Helen had training on using the system twice so far, she still finds it hard to find her way around the system to locate information she needs in a timely-manner. She clarified:

> *"I've actually been trained in CaNISC about a year ago, and I haven't used it yet. I've been retrained about a month ago, but I will use it now. Because if you don't practice it, you won't, use it or lose it"*. Helen added, *"one of our consultants uses CaNISC a lot and he's very good, and he's very computer literate, but watching him go through to get the information he wants on CaNISC when we're sitting in the clinic here, it's just like, and that's somebody who really knows what they're doing with it. He's very used to it"* [8].

Despite these factors, Helen finds no-way out of this situation without practicing and using CaNISC more often, because she stated that before CaNISC everything was paper-based and admitted: *"I think we're moving towards CaNISC,"* and thus, *"we are beginning to use CaNISC a bit now"*. Helen concluded by demanding a system that should be an easy one to use, she justified that: *"it has to be for us, because we are not very kind of IT literate as a rule. We can do things, but the easier it is for us, the better. CaNISC is not easy!"*. The Clinical Portal, although it does not have the same issues as CaNISC has more of an organisation-based access control system making Helen's access more of an issue. She commented about the Clinical Portal, *"Portal is OK. Portal is quite quick"*, in contrast with CaNISC. Nonetheless, *"the biggest problem [with] Clinical Portal is getting into it in the first place"*. According to Helen, this is mainly *"because if you don't have the hospital number, it doesn't like letting you in just with a name. It will sometimes, and you have to find out the right address"* [8].

4. **Access inequity based on organisational division.** CaNISC was fully developed in-house for cancer care, and Velindre is the home of its development. Although it is intended for Wales-wide usage, Helen and fellow nurses working outside Velindre suffer from access inequity with fellow nurses working within Velindre NHS, lack of communication with the development team, and even a clear neglect in the development process which all hinder their usage of CaNISC. Initially, Helen claims not to have the same access rights as other fellow breast cancer nurses working in Velindre, which she personally finds unfair. She explained: *"certainly all the nurses in Velindre, work directly onto CaNISC, whereas we do not"* [8]. She explained: *"I think it is just because we have never been involved in CaNISC really. They have been quite precious about who gets access to it, at the moment we have access to it, but we cannot put anything on it. We are not actually able to change anything"* [8]. Consequently, Helen is prevented from using CaNISC to record her information, obviously, and no wonder Helen claimed: *"CaNISC has not got our information on it"* [8]. This is mainly because Helen and her fellow breast cancer nurses working outside Velindre seem to lack communication with the development team, and she complains that she is being neglected and excluded from using CaNISC as much as she wanted since she works outside Velindre. This was evidenced from the

interview as Helen did not know that treatment plans decided in the MDT reviews and other MDT information are recorded into CaNISC by the MDT Coordinator. Therefore, she takes hand-written notes herself to record information from the discussions at the meeting. Whereas, according to the UGI MDT Coordinator, at one of the observed MDT reviews held in Velindre Hospital, all other hospitals can access patients registered on CaNISC after the UGI MDT review meeting to see a treatment plan [105].

5. **Systems are not connected.** The nurse also stated that she needs to share information with other healthcare professionals across systems, but *"now, most of these systems are not connected,"* [8]. She did not question the fact that the systems are isolated, and this sometimes blocks information flow with a patient. The breast cancer oncologist agreed with Helen by saying: *"yes, it's frustrating that there are so many systems, which in isolation are quite good, but they don't talk to each other"* [86]. Dr. Borley also confirmed that she finds it hard to find information about the patient sometimes. Her biggest irritation was:

   > *"the biggest problem we have is that some of the patients who get diagnosed through screening service have their initial biopsies in a different place than the breast centre. They get sent, the biopsies get sent to a different pathology department in Newport, and they don't release the results, they don't put the receptor tests, which are the things that we really need, back onto the patients Clinical Portal. They keep it in their system, and they won't release it, so that's my biggest irritation"* [86].

   Although Dr. Borley claimed that this delay does not normally cause any delays to the treatment, she said: *"but it causes a lot of hassle trying to find it out"* [86], because in such cases she would normally: *"telephone them, and then they fax it over with the names blanked out on it"* [86].

   Dr. Morrey agreed with both the nurse and oncologist, and justifies it from a technical point-of-view: *"yes, and I've also seen the difficulty from a national level of trying to get CaNISC to get information from other systems. And it's just beyond our resources to try and solve really."* According to Dr. Morrey, CaNISC started about 1991 at a time when collaboration was not a major thing and *"it was really 1997 that the idea of collaboration came in,"* and agreed that there is more pressure on healthcare systems to share information between hospitals: *"I think that is true, with this multidisciplinary care that we are talking about here"*. As a result of that pressure, *"it was at that stage that CaNISC was completely redesigned to deal with that. And it had to be a pragmatic way of dealing with it, which leads you to certain problems and the rest of it."* Dr. Morrey

explained, *"it's always tricky with the LIS actually getting into them and gaining access to the information."* He was asked which of the currently used systems are actually linked to CaNISC, Dr. Morrey responded: *"it depends where about in Wales you are talking about,"* before he continued:

> *"certainly within Velindre, the radiology system at Velindre was linked in, as was chemotherapy and radiotherapy. So those were linked in, and so, were relatively easy to get hold of. As you moved to other hospitals the situation was much more patchy. In that probably radiologists and pathologies weren't linked in because of security aspects and volume of information and all the rest of it. So the further away you got from Velindre, the less links to some of the stuff in University Hospital Wales in Cardiff, certain results were there because we depended on the cancer centre being some small unit on it's own"* [18].

On top on this, Dr. Tom Crosby and Ann Marie agree with the fact that there is more pressure on current systems used, Ann Marie commented *"it's certainly an increased requirement to share the information or to have access to the information related to a patient,"* [85] and Dr. Crosby supported her by saying: *"yes, yes I agree and that it is a really important issue and it's become more so since I think we do record this information electronically now in lots of different systems, so that has raised the level of frustration that we cannot see it all and it's not joined up around the patient"* [84]. He also added the patients' perspectives of this pressure: *"one of the things that the patients have frequently complained at is that they go to different providers and have to repeat their story and to see - providers who don't know the information about them as an individual. So I think that would just add weight to it. You know, sort of coming from patients that they find it frustrating"* [84]. Also Dr. Crosby justified: *"Yeah. The design of CaNISC is not intuitive; it's on a provider level and not a patient level. So you have to find your way around it and then - so if Cardiff and Vale, the Surgeon put in information, even if they put it into CaNISC, they'd put it under their provider episode. And you have to have a fairly good knowledge to navigate around the case note to find that if you were say a Velindre person"* [84]. He also added *"Sometimes yes, the information is not there at all; it's just on their PAS system or Merlin or somewhere else, so I suspect it's true"* [84].

6. **Security concerns.** At the time when CaNISC was redesigned to meet the collaboration needs, Dr. Morrey said: *"there were security concerns and the clinicians would be worried there is too much information being brought across that did not belong in the cancer domain if you like"*. So they wanted to restrict other access to their information, and so Dr. Morrey commented

> *"yes, the data protection people, and their system started putting up shutters [i.e. partitions], because they said why do you want to know all of that. But there was also data volume concerns as well. Because some of these databases were huge, the patients had been seen for years, before they maybe got their referral for cancer, or whatever. So when do you bring things across"* [18].

This explains the information layers structure of CaNISC and the partitions between providers. Moreover, Dr. Morrey explained how current systems are coping with both pressures of sharing and security by saying *"with difficulty, the clinicians are switching between systems and screens and the projector has to flip between systems to do it,"* and according to him the information is not flowing because of that. He elaborated:

> *"in the MDT's the clunky way it works at the moment, in that you might have the MDT coordinator with one screen with CaNISC up, which is the shared information, might be with it's limitations at the moment. But on another screen, another system, the radiologist is logged into their local radiology system, bringing up information on the screen about that patient in order to read it out to the meeting, which then has to be transcribed across there because there's not a direct linkage across it. Either because of security because of data protection but also difficulty of integration of systems on a technical level. And then the pathologist might be on another system bringing up their pathology reports which may just be a text report"*. Dr. Morrey then said: *"yes, and you can see why the frustration of the clinicians in that it's clunky, it doesn't flow between systems on a system level, and the security, the clinicians are told it stands in their way of sharing. So it's at both levels yes"* [18].

7. **Short in resources and difficulty of integration of systems.** Dr. Morrey said that the block of information is also a result from the shortage in resources. He explained:

> *"it is simply the resources and the will to do it. Also because they are trying desperately to catch up. If you like CaNISC and what we have done, and what you are able to do within this prototype here and way beyond what's available on the ground in most cases of the hospitals. And what the national people are trying to do is to get those people on the ground up to a common level before moving on and that's proving very difficult on that"*. He added: *"yes and also as clinical director, when the other consultants are getting problems, they will go to Tom and bend his ear'.'* As a result, *"we [CIU] just used to say well we think you ought to do it like this, and we'd have the meeting*

and decide to just go and do it, and it would be done, prototype fashion fairly quickly so the prototype you're describing, the next stage would be a prototype implementation in CaNISC and it would happen, and then you'd start seeing what the practical problems are, and evolve your prototype into the real system. It's not quite the same". Dr. Morrey mentioned later in the interview that *"NHS Wales Informatics Services (NWIS) are withdrawn, most developers have gone on to try the first stage of the Welsh Clinical Portal. So CaNISC no longer has the development for sources devoted to it, that they used to have. It's almost legacy tick over to carry on. So that's the only proviso on that"* [18].

8. **Multiple patient identifiers.** There are different hospital numbers in hospitals for the same patient which are used as patient identifiers. This makes, from a technical perspective, a problem in current systems as there is no unique unified identifier across the systems. The main reason for this is that they were different systems, Dr. Morrey explained:

   "when they started out those LIS, there didn't use to be a universal identifier so you just issued a number for the patient identifier for that system. And you kept on using that, it's only at a later date that the idea of a more universal identifier the NHS number. It's an emerging scenario to try and over come that". This makes it *"tricky with the LIS actually getting into them and gaining access to the information"*, and continued: *"it's always tricky the integration, because that's part of the reason why we've had problems now. And the Welsh Clinical Portal and the other portals that have been round hospitals they have the same issues basically. Because they need to grab information and you put one identifier in and hope you can get across"*. Dr. Morrey added: *"it could be the different hospital numbers, or the patient name and what number is there, because a very simple example is that, the surgery might have been done in Gwent and they will have maybe used a local patient number there. But you're in Brotaff or Velindre and you've got a different number for that patient. So you've got to link the two in some way. The way CANIS does it, it will grab, it will store any number of hospital patient numbers against the patients name and address"*. As a result the patient has different numbers on different systems and *"basically you can use any of those numbers to search on those"*. Dr. Morrey commented, then he justified *"because again at a low level implementation you'd have to know I'm going to that local system, what sort of identifier do I need to use for that patient to*

> *actually gain access to that. A lot of the local systems now do store the NHS number. You know it's been mandated, it's not completely unique, but it's much better than what we used to have before with all of the local systems. So it's usually a lot of systems do have that number there"* [18].

9. **Misinterpretation of security.** Dr. Crosby stressed in the evaluation interview the fact that the main problem he is facing as a Caldicott Guardian is the mis-interpretation of security: *"I think it's sometimes the interpretation of the security rules are not in harmony as opposed to the actual security rules"* [84]. He elaborated: *"I mean it's local interpretation of standard advice as it were and leads to barriers"* [84], and he seemed to agree on the technical explanation for that misinterpretation in that the different systems employ different security controls, that make the systems not in harmony and this brings the concept of misinterpretation of security as well, so different security context and different interpretations. Moreover, he commented about the research problem about the information not flowing sometimes and not available at the point of care: *"frustratingly slowly, but there always a lot of that work going on"* [84], and Ann Marie continued: *"there are dependencies, especially for CaNISC, so it's not as straightforward"* [85]. This makes it not as simple as it sounds.

7.5.3 Reflection on the Controls

- ***Control One and Three:*** **Consistent PC information layers structure and Chronological organisation of information as stamped treatment timeline:** Helen thought about how important these controls are: *"I would have thought so, very important yes"* for easy to read and access information. Helen added, *"in current systems, you have to go and find the information,"* this is mainly because the system does not show it in an obvious way to help pick up things easily. Although current systems do not provide it, Helen said: *"because I'm used to using it, so I don't have a major problem with it, but it's not the easiest way of doing things."* Furthermore, Helen found the chronological order of treatment points with the details of the CT member's name seeing the patient is helpful because other CT members can look at it and say: *"alright, so she was seen last Tuesday, so I know she'll have this done, so we can sort that out or we can look for these results"* [8]. Also Dr. Borley agreed with Helen that this functionality is important, and mentioned that only the Clinical Portal provides it as a functionality when she said: *"well the Clinical Portal results and letters are all in chronicle order,"* and that she would want that to be the case for all the other systems, which is not the case today. She also mentioned that this scenario shows a straightforward pathway, whereas most cases are more complicated than that. She said: *"I think what you'll find is that some cases are like that, but quite*

a lot are a bit more difficult, like they may go round this loop a few times, diagnostic MDT biopsies, it's quite common for patients to have more than one biopsy." However, SHarE already implemented the loop as an option because these loops are already in the guidelines and the whole treatment pathway is mapped in the system with the option of repeating a treatment point. Besides, SHarE shows the treatment pathway as a time-line, so even if a treatment is replicated (which should be an existing option in the guidelines) still it will be time stamped and all information will be provided. Furthermore, Dr. Borley appreciated that in SHarE not all the information is shown to the CT member in the timeline, but if he/ she needs it, all they have to do is to hover over the treatment point and more information will show. She commented about that: *"I think it's quite good to have the date hidden, I don't need to know what date they saw it,"* [86] but agreed that if she needs to see it, it's available to her. Finally, regarding how the functionality can be improved, Helen asked for bigger writing, *"just make it nice and easy to pick up things, and when somebody, when they've done break-glass [for example] you want something that kind of be quite obvious, or when the new information comes out, so you want something you can pick at easily"* [8].

Dr. Morrey also commented: *"yes I think that is important yes"* [18]. He then explained how information is presented in CaNISC:

> *"it's not the primary way of presenting the information you can get a summary in CaNISC. There is a summary that brings up all the things that have happened, similar to this but not in the logical treatment pathway that you've done it, ok? But it does show you the different organisations the patient has been to see and whose put stuff in there, but it is a bit clunky because it doesn't follow the pathway as yours, yours is a more logical pathway way of presenting it. And also that summary page is not the default one you get when you go into CaNISC, I log in as Velindre clinician or a UHW clinician, so it's not the default one"* [18].

In addition, Dr. Morrey mentioned that the Welsh Clinical Portal, in its first stage, is implemented as a linkage between the mini local Clinical Portals. This means, although this system will address the cross-referencing and gathering most of the information about the patient from the different hospital to help with the comorbidity, it still won't change the way it is organised. In other words, it will still organise the information the same way these local portals do, namely categorising it based on its type. Although these controls were approved by Dr. Crosby and Ann Marie, some concerns were expressed. Initially, Ann Marie commented about the importance of this functionality: *"I think it's very useful"* [85]. However, although Dr. Crosby agreed he highlighted a concern: *"yes,*

but potentially there should be the ability to re-order it for different needs. So that you may just want a list of all the radiology investigations on their own, so you should be able to have different views" [84]. Ann Marie justified: *"because it could become very, very, very busy"* [85] and Dr. Crosby agreed with her. They both wanted the ability to select sub-sets that would still be in chronological order within the sub-set, Dr. Crosby said:

> *"absolutely, yes and obviously should be able to do that [sub-set order] with various categorisation. I mean there is that we are at a level where we still would prefer to be overburdened with information. I yet have to be, you know, because there is the risk of it. But I'd still prefer to look through and have to trawl through and find the relevant parts than what we have at the moment where it's not available. But it definitely is a risk as more and more healthcare professionals add into the record"* [84].

Furthermore, SHarE did not fully implement two-treatment scenarios in SHarE to illustrate comorbidity to show how information can come from different treatment pathways. This was left for future work. However, since Dr. Crosby and Ann Marie expressed concerns about how the information is presented, they were asked about their opinion on how the information should be presented in comorbidities. For example, is it important to consider all conditions in one page or have different pages for different conditions? Dr. Crosby thought:

> *"I think again it's probably you need both, because I think increasingly cancer is becoming a disease of old age, well it always has been, but where patients have other comorbidities and it's important to see those. And I don't think we've begun to really address the issues of comorbidity, they're complicated. And so if you're coming down the cancer pathway you're going to need to look into their diabetic history or their other things"* [84].

That's when Ann Marie interrupted: *"and we do need that information"* [85]. Then Dr. Crosby continued: *"yes, so again it's an ability to be able to order it in a cancer only but then have views of others as well"* [84].

- ***Control Two:*** **PCAC model with access decision reflecting the patient's condition and treatment stage:** All interviewees apart from Mital (who did not mention it) agreed that this is an important control. Helen agreed that changing the way of information access to be beyond a disease or an organisation towards being more PC is very important, and Dr. Crosby and Ann Marie commented about this control by saying that it is *"very important"* [84]. However, they all did not seem to be on the same page as some thought current systems actually provide this to some extent and others thought the opposite.

At one extreme, Helen and Dr. Morrey both thought that current systems are trying to provide it in that way, to a certain degree. For example, according to Helen the way the information is organised in the clinical portal is based on the type of information, she explained: *"there is a list of results, list of referral letters, and so on"* [8]. She said that any one accessing a patient's record can see all test results done for that patient even if it is not cancer related. She said: *"I can go in the Clinical Portal here, and have all the results now. It's not just the breast ones, by any means, it's everything that she's had done"* [8]. Although this might not be good from a privacy perspective, Helen explained how useful she found this model because it helps show comorbidity easily by listing all tests, which can be checked to spot any other problems the patient has been having. She said:

> *"you are trying to find something and you might think, well there's quite a few bone profiles here. Why are we looking at these bones? Why are we doing this? Why are we worried about this woman's bones so much?"* Helen added: *"you know what to look for, but you also sometimes find out about some tests that you did not know they had done,"* which *"you could then link and think, well actually, I did not know about that, but that is actually quite relevant to what we are doing here, because somebody else has not made that jump of, or maybe the breast care bit has come afterwards, but because I have got past results as well, that you think, well, she's been complaining of bone pain. Has she got bone secondaries. So you go looking at things like that"* [8].

However, this PC view is limited to the tests done for that patient in the hospital being checked. So, in order to see all tests and get a real holistic view, Helen would have to log into the other hospital's and check any other test results for that patient, separately. Therefore, it partially meets this requirement, and would need to be improved to extend the view across organisations by the use of SHarE. According to Helen, Clinical Portal makes it easier to find relevant information about the patient since once you access to it, you can see everybody's results. This is much easier than CaNISC. This accidentally represents PC care which is not planned but shows the need for systems to be more holistic.

Dr. Morrey also agrees with Helen that current LIS provide it *"to a limited extent"* [18]. He continued saying:

> *"because even as you've seen, to a very limited extent only CaNISC really understands the multi-organisational, crosses the boundaries and even then there's criticisms of CaNISC."* He also explained, *"well because you log in*

> *as a particular organisation and you see information presented about that organisation. Now you can click down the bottom to see information that has been entered somewhere else. You can see a summary of it and click into that information, so you can actually see it, but it's not all presented at the same time. So some of the clinicians especially those that are not used to using CaNISC on a regular basis say well I want to see it complete centric, I don't want to see this organisation, I want it to be organisation transparent as far as I'm concerned, so that's the criticism that they would make."* He added: *"it's partition based, that's right the partitions are visible to the user. If you know the system very well then you can easily overcome it. So Tom Crosby says well it isn't really a problem, but Ian Moneypenny who doesn't use the system on a regular basis says, wow I just want to see it. Whereas SHarE would show it all there, he would say yes that's much better for me, because you hide some of the barriers and partitions"* [18].

At the other extent, Dr. Borley, Dr. Crosby, and Ann Marie all agreed that current systems do not provide it *"yet"* [84] which indicates the fact that this research is foreseeing the future need in the current developments, which are moving towards the route this research is taking. Finally, Dr. Borely appreciated that in SHarE each patient would have their own page, and thought it useful.

- ***Control Four:*** **Gathering and filtering information from discrete systems:** Dr. Borley agreed that this functionality is important as *"I think as long as you know where to go if you want more, then I think filtering is fine to make it simple."* Then confirmed that current systems do not filter the information: *"no, I think you've got to wade through all the information yourself"* and then have to read through it, so it is time consuming. She added, *"if you're seeing a new patient what you really need to know is the MDT summary, and what the MDT said the treatment plan should be, then I'd usually go back and check. Ok right that's fine, let me just check the pathology results,"* [86] and based on the category she will choose, and thus, she finds filtering the information helpful. Dr. Morrey agrees with her that current systems do not provide such a functionality when he said: "no, I don't think there is an automatic way of doing that," he emphasised its importance: *"Yes I think that would be very helpful, yes."* On the other hand, Ann Marie and Dr. Crosby had a different thought. They mentioned that in current systems, clinicians can actually select what information they want to access.

  Nevertheless, Helen and Dr. Crosby were both concerned with this control initially, as they both emphasised that all breast CT members should have access to everything! They prefer everything even if it is overwhelming rather than filtered information which may

miss out things that they may be interested in, while Dr. Crosby commented that in the current situation, there isn't enough information. Helen commented: *"any kind of clinician looking after that patient, should have access to everything that is not ultra-sensitive, but does not necessarily have to plough through it all to get what they need."* So they were asked about the best way of organising filtered information if they had enough information flowing to make it more organised for them, Helen thought and said: *"it depends on what you want to know,"* and favoured the order by the treatment pathway *"because you kind of know what's likely to happen each time."* This would help as they know what information to expect at each point based on the treatment pathway against that particular point. Then she commented:

> *"yes, it's just knowing, it is getting the filter right, I suppose. I think it should be like a basic filter but with access to the whole lot."* She explained the reason behind it: *"so you can get the information if you want it, and, because some people, there might be something that is actually quite obscure, some kind of quite obscure connection between one disease and another, that your filter's not going to come through with, or your average person is not going, the average consultant might not make the connection, but you've got somebody who says, well actually in very rare cases, such and such is"* [8].

This highlights two possible conclusions, either this need reflects Helen's lack of trust in any system that it would provide her with the information that she actually needs, or that simply she does not know what she wants or needs until she accesses the whole information resource.

While Dr. Crosby commented that in the current situation, there isn't enough information but he would prefer sub-set organisation that would perform a filtration of some sort as well which involves the organisation of the information mentioned in control two. He commented: *"well I think this will evolve under the system and I think at first I'd love to be in a system where I have too much information, and then after a bit, they go hang on a sec, it would be helpful if we only had this information; at the moment we don't have enough!"* [84]. Ann Marie then provided her opinion: *"I think what would be useful is where information is copied and pasted into one section so the Oncologist has all the information in one place as opposed to having to look,"* [85] which Dr. Crosby agreed with, before she added: *"and if there was some functionality that could do that, that could be bring information into a summary page for the Oncologist, I think that would be really useful"* [85]. They both need a sort of filter that can coalesce things or amalgamate them in some way? Dr. Crosby answered immediately, *"yes, yes, yes!"* [84] at the same time Ann Marie added: *"absolutely, because in clinic it's busy, they don't have time to go*

clicking through records and other systems and if there was a mechanism to summarise information into one place" [85].

- ***Control Five:*** **Automated referrals between healthcare providers:** Helen, Dr. Crosby, and Ann Marie all agreed that referrals in current practice are not automated, Ann Marie explained: *"from the referral perspective only, we have it in paper format anyway. So by the time it reaches us you've got that time delay by the time you process"* [85], and three of them agreed that it saves time to automate referrals. Although Helen thought as long as the information is there, it is not important to automate it, but she believed that if *"it's through the system, that will be easier and a lot quicker"* [8], while Ann Marie commented: *"so if it's electronic it will save time and we can audit it, we can manage it electronically. Whereas if you lose a bit of paper"* [85]. Dr. Crosby agreed, then added:

  > *"yes, yes. Well we sit in a meeting and if we decide that it needs to be referred, then frequently that'll mean going back, the Surgeon remembering to dictate a letter; dictate a letter; the Secretary types it; sent; so our post was received in our mailbox, gets to us. And realistically that's always going to be a week and that could've been instant, or nearly instant, yes, yes"* [84].

  Additionally, as Dr. Crosby explained the future agenda for systems' development to help cope with the increasing pressure for cross-organisational information sharing, he mentioned that: *"the cancer community is trying to design the referral pro formas"* [84]. This indicated a need for automated referrals, so the interviewer pressed: *"so there is a need for electronic referrals in the system?"* and Dr. Crosby's answered *"yes"* [84].

  Furthermore, Dr. Borley thought that automating the referrals would help improve the communication, especially in cases when she has a patient referred that is still waiting for a letter to be sent or to be faxed over in the post, and in lengthy treatments to help get everyone to know what is happening. She explained: *"because my treatment goes on for a long time,"* she continued *"it can be up to a year."* Therefore, she demands this functionality to be flexible enough to go back and forth between her and other CT members involved, namely the surgeon. She said: *"but it should carry on then, I should write my piece, what I propose and then I send a letter back. I could just enter it onto the system couldn't I"* so the system automatically *"tells the surgeon what I'm going to do, and then there is an ongoing updates."* She added: *"but then, one the radiologist is going to be a follow up mammogram, so if they could be prompted in that, one that these people need mammograms"* to get everyone to know what is happening. Moreover, Dr. Borely was happy to realise that SHarE replaces her case notes when she said: *"so it's really just, instead of looking in the case notes to see what I need to know and do, I'll find that on here"* [86].

However, both Mital and Dr. Borley had contradicting comments about this control and its effect on information accuracy. Although Mital believed that an automated referral will help solve the information availability issue we talked about, she was concerned about it affecting the accuracy of information in a negative way. She said: *"the only thing is you have also got to realise it is the accuracy as well because you are passing this information on to five/ six different people. So the first person that inputs this information should be accurate. You cannot afford to have any mistakes"* [78]. While Dr. Borley believed that this control could actually improve the accuracy of information included in referrals, she commented:

> *"I think automatic referrals, not depending on secretaries and letters is good,"* she explained: *"because there's lots of nuances, that the surgeon might say, they don't do it very often actually, but they might say, please see this lady for chemotherapy but she's not very fit, and not very keen. So I get the referral, but that information might be lost if it's not put on there,"* she explained: *"but they're still going to have to, some secretaries are still going to have to put those into this aren't they? Or are they not?"* because *"I don't send out my appointments, I haven't got time to send out appointments, so that referral, push referral has got to go to an administrator here to organise it for me"* [86].

Dr. Morrey commented on this control: *"I think that is important,"* [18], and he confirmed that none of the current systems automate referrals although Dr. Crosby thought the opposite. Dr. Morrey said: *"no, it's no, you've got to go and dig it out from that, there's nothing. That's one of the limitations of CaNISC, in that it doesn't have anything active about it, you're always going to do things yourself"* [18]. While Dr. Crosby had another opinion:

> *"I think we've had that sort of functionality that's never been switched on in CaNISC and I think we've had it in part of the MDTs or something I'm sure. With sort of - I think it might exist, but I don't think it's ever been switched on. You can email letters, but anyway it doesn't work anyway; we don't use it so in effect it's not there."* However, he added regarding how important he thinks this functionality is: *"yes, it would be really good. With qualifications"*, he explained: *"when you do a referral you add in other information around that patient in context and things. So it's about having the right information."* This is because today, they rely heavily on letters to communicate missing relevant information after a patient is referred. Dr. Crosby explained: *"at the moment for that, because there's not enough information. We still get more*

> *in the letters. So at the moment some do accept the referral because it's just better to get the patient in quickly. Other people sort of say: 'yes, we accept the referral but send us a letter as well while the patient is getting' So people are using it in different ways"* [84].

Dr. Crosby and Ann Marie agree that this functionality is sort of shifting a burden across because it allows the person, who the information is referred to, to have access to all of the information that are for example in the MDT, GP, and even the extra letters. Dr. Crosby commented: *"if we had access to all the other information, you know the GP's, that would give you more information."* So the CT member can then extract what might be relevant. Whereas in current practice they're doing a relevant thing but *"taking an information from one form and purpose"* [84] and copying it into the referral letter. So SHarE is balancing this thing all the time at any referral.

- ***Control Six:*** **Break-glass enabler for emergencies using the Circle-of-Trust:** It was clear from the interviews that there is a struggle in some cases to access patient-relevant information using current systems, and this control was chosen to address the block of information flow to legitimate CT members, regardless of the reason behind it. So this would allow the healthcare provider to have speedy access to information already collected and recorded but not shared and available when needed at a point of care. This research is based on some level of trust as a foundation, and so it only allows legitimate CT members whom the patients' trust with their lives, to break-glass to information they need to care for the patient, and so this control has an element of trust. This is also the expectation of the CT members themselves, as highlighted by Helen and Dr. Borley. Helen said: *"you have to trust your health professionals"* [8] when she talked about access to patient information, also Dr. Borley added: *"we're all responsible for keeping data confidential, that's part of our role as, information governance and the Caldicott Guardian, it's his responsibility to make sure we all do it properly"* [86].

  All interviewees with no exception strongly believe that CT members should access everything. Mital thought the break-glass functionality would be useful, and reflected on it by justifying, *"you need to know all the information. You also need to know if the patient has any problems previously which you can only really say is whether it is sensitive or not sensitive"* [78], while Helen said that anyone in the breast CT should access all information automatically without the need to break or justify access into information. Therefore, she did not find it useful as she strongly believed that no information should be hidden from the CT in the first place. She agreed it could be useful if the CT member was not provided with the information in cases when there is something wrong with the system not providing information, believing the break-glass is going to be in very extreme

cases. Although Dr. Borley agree with Helen: *"from what you've shown me [SHarE], everything is there anyway, so what more is there going to be? But if everything is done properly as it goes along, then it shouldn't really be needed should it?"* [86], she thought this is an important control. Especially in unorganised MDT review cases when the patient list that the MDT coordinator, surgeon, and pathologist had were all totally different [86]. *"So, if this would prompt the pathologist, help the MDT coordinator and the pathologist get the right results to the right MDT that would be very helpful"* [86]. Dr. Morrey also thought that this control is important, he commented: *"break glass is a great concept because it's easy to explain to patients and everything"* [18]. Furthermore, this control has an immediate effect on the the balance of information availability and confidentiality to trusted CT members, Dr. Crosby explained how he would expect this control to be used in the context of cancer care:

> *"the principle should be I think that the information follows the patient at their point of need. And the expectation I think from patients would be that the clinician of course should be able to see the information around that event. There could be things like psychiatric histories, genetics histories; there may be things that require a break-glass. I'd just set that threshold a bit higher to be that more security, more confidential information that requires a break-glass to look at it"* [84].

This means he would expect this control to be used more outside the treatment, the CT is part of. This means this could be one of the key controls in comorbidities.

Dr. Morrey explained how CaNISC deals with access needs outside the norm, he said: *"if a medical secretary worked for Dr. Tom Crosby, but was asked to cover for Peter Barrett Lee, then justifiably she's looking at Peter Barrett Lee's patients, information about those patients or reading it"* [18]. Dr. Morrey added: *"she always logs in with her name, the CaNISC security model is quite wide. Anybody within Velindre can see the patients that have been referred to Velindre."* He thought that it may be better to tighten the security model to block the secretary from having access at all time, and only use the break-glass in such cases. He justified:

> *"that might be legitimate use of break-the-glass, because that medical secretary doesn't normally provide any cover for Peter Barrett Lee, because he's up the end of the corridor and there's a different team providing cover. But under those circumstances she may need to break-the-glass simply because nobody is available to authorise her on the system and she's got to provide some care, under those circumstances"* [18].

Dr. Borley stated that current systems do not provide this functionality at all, and as a result of that, *"if it's not there you can't get it"* [86]. However, Helen, Dr. Crosby and Ann Marie all think otherwise. Helen claimed: *"Clinical Portal deals with very sensitive information by hiding it behind a glass"* [8]. This glass feature is implemented in the Clinical Portal by having a red exclamation mark in the results list, that when clicked should reveal very sensitive results that are normally not related to cancer. So, Helen never thought she would need to access that information. She explained: *"there is a little, the red exclamation mark, and you know you do not go into that, that is where its things like HIV testing. It is very, very sensitive testings, stuff that you are not allowed to know, unless you have got a good reason, and I would have no reason to know that information"* [8]. When she was asked whether knowing what is already behind the glass about HIV or any other infectious disease is crucial to her, she responded that their rule is that they should treat everybody as if they have got HIV, or any other infectious disease. *"Just because they have not had a test, does not mean to say they have not got it"* [8]. Therefore, this information won't change the way they look after the patient, although only *"whoever is looking after somebody at that particular time"* [8] can see this information, Helen stated, *"it is where they have sent off for that result at the time"* [8]. Dr. Crosby and Ann Marie agree with Helen, *"it does exist and we do have break-glass in national systems, the portal being one of them,"* [85] Ann Marie responded, before she explained how current systems do it: *"the highly sensitive information you have to select and you have to put your password in again and notification is sent to appropriate colleagues so they know that that has been activated, to make sure that it is right and proper"* [85], which means current systems do not justify it apart from confirming it through a second password check.

However, in the evaluation sessions interviewees had different interpretations representing different needs for this functionality that can be categorised into the following two main categories.

1. *Information-focused Breaking-glass:* this category aims to limit access to extremely sensitive information by putting this information behind the box. Hiding information that is labelled as *"very sensitive"* is kept in the box which should not affect the treatment, and only a handful of trusted CT members should have access to it if they need it. The only current system that implements break-glass control is the Clinical Portal, and it falls into this category. Among all interviewees only the Caldicott Guardian and IT lead preferred it. Ann Marie justified: *"that's the common approach that's been adopted, because we do have break glass functionality and it's fully audited"* [85].

2. *CT Member's Role-focused Breaking-glass:* Although SHarE is a PC system providing a holistic view of the patient's condition, some interviewees favoured that access allowed in the break-glass control, should be role-based. In this category, the CT member is the main focus and it is thought of in three cases: bad referral, urgent treatment point, and emergency outside-treatment case. The first case is when not all the information needed was shared in a referral. The second case fits within the regular predefined treatment pathway the patient follows, some patient cases are marked as urgent when any delays to the treatment highly affects the patients' health. The final case, however, is normally outside a regular treatment point and could be when the patient needs immediate care in an *"out of hours"* and thus, all information about the patient should be revealed to the healthcare professional seeing the patient. Note that this user is neither a member of the CT, nor in the circle-of-trust dedicated for the treatment scenario. Maybe in such cases a justification is required along with a report about what happened to the patient and how he/ she was treated. Regardless of the case, this category allows information to be accessed based on the user's need in his or her role. All remaining interviewees (Helen, Mital, Dr, Borley, and Dr. Morrey) favour this category. Mital thought: *"you do not want to overwhelm them with information, so only the basics"* [78], and Helen thought it is very important *"that everybody who's in that CT should have access to everything."* She also commented about what information CT should be allowed to break into: *"only what she wants really, then she should only click on that,"* and then justified: *"because otherwise they just spend ages working, wading through all the stuff to see what they actually need."* Helen found this category more important than protecting sensitive information as she described the first category a political thing [8]. Dr. Borley said: *"it is better to break into only the information at the selected treatment point instead of all information recorded up until that particular point"* [86] to meet the CT member's information need. While Dr. Morrey preferred giving the CT member the ability to be selective about information he would need to break into: *"you can see it's a simple situation and you don't really need the break-the-glass for that one. But the break-the-glass is for something down here,"* to allow access to *"the system at a raw level really basically"* [18].

With regard to the need for justification for break-glass incidents, all interviewees also seem to agree on the fact that justifying access to information as part of this control could be meaningless, time-consuming, and a burden. Initially, Mital said: *"if you will need to justify at each point you break a glass, then the system users will not want to use the system."* She added: *"justification may actually put off the users,"* Mital said that *"I can see that they are not going to want to use it are they because they are going to have to*

justify everything. So I suggested that justification happens at the end of the session of break-glass incidents to make it easier, and she thought it would be easier" [78]. Helen agreed with Mital believing the break glass action and its justification is actually a waste of time to some roles who should have access to everything as part of their role like oncologists. She explained:

> *"if you have got an oncologist who should have access to all the information, rather than them having to break glass because somebody has not given them a good referral. Could not there be certain people who are just given an automatic break glass, without having to justify it, because it is going to be time consuming to break the glass and even justify it? well there's certain people who should just be allowed access to all the information relevant to that patient. Well, they should not have to justify why they do it, just the fact of their role maybe should allow them to have access. They should not have to go in and say, well I want to know the mammogram, because I want to know, you know, I want to see the side of it or something like that."* She continued: *"because if I kind of thought, oh I want to see this woman's mammogram results, because she's coming to clinic tomorrow, and I'd like to be prepared, because I know I have got certain things to put, to find out, it is going to be bad news. The same with the pathologist. There are certain things I need to do, that I would not have to do, and if I am going to have to make a justification every time, it is going to be, I'm going to have a set sentence eventually, after, where I'm just going to be spewing out. So it is not actually practical. It's going to be meaningless."* She added, *"if the system already tells you who broke the glass, then why bother those people to justify it?"* [8].

Dr. Borley agrees with Mital and Helen that it is time consuming for CT members to justify it, however, she thought it might be a good idea if the justification and break-glass is used by anyone who is not in the treatment CT. For example out-of-hours, when according to Dr. Borley it makes more sense. She justified that there must be an element of trust: *"yes because we're all responsible for keeping data confidential, that's part of our role as, information governance and the Caldicott Guardian, it's his responsibility to make sure we all do it properly"* [86]. While Dr. Crosby commented about the need for justification in SHarE: *"it depends at what level it's set. If it is really, truly break-glass (i.e. for exceptional reasons), yes you'd want to sort of provide it"* [84], whereas Ann Marie responded: *"I'm not sure it [CaNISC] asks for justification; just asks you to re-enter your password so that it's a deliberate act and I think there's a clear definition of what is held behind break glass"* [85]. This led to the conclusion that CT member

do not need to justify access to information they need as the audit trails are there, and in case of an abuse incident, then these logs can be used afterwards as a post-justification if it's needed and say, Oy! you did this, why? Dr. Crosby said: *"yes, if needed then yes"* [84]. The main reason the justification is not used in CaNISC as understood from both interviewees is because that's getting in the road of the immediate access as Ann Marie confirmed: *"I think so, yes"* [85]. Hence Dr. Crosby was more concerned about how often the justification should happen than the justification itself:

> *"so, I would still say that issue is around how often you need to do it and as soon as you start needing to do it frequently asking people to justify it is silly, they don't do it and they'll write whatever, write rubbish in. So if it's exceptional then it's OK to justify it, but as you say I think probably then it's done on an audit basis rather than an all time justification"* [84].

Eventually, everyone agreed that it should not be too big the amount of information that's being put in this super-sensitive section and that it has got to be done very carefully. Finally, the discussion led to the use of alerts in this functionality after a break-glass incident. So the interviewer explained the concept in SHarE and compared it with how current systems do it: *"and this is where I have alerting everyone after the incident of break-glass. So, maybe in the case of current use it's only alerting through the audit."* Dr. Crosby commented: *"I would say it doesn't need to be brought, yes!"* [84], whereas Ann Marie thought *"I don't think it - yes, it doesn't need to alert everybody"* [85]. Dr. Crosby supported her, adding: *"well for everybody getting an email ten times a day that somebody's glass has been broken is a big issue,"* [84] then continued, *"so it would be things like a Primary Care Manager or whoever their governance people are,"* [84] Ann Marie interrupted saying: *"it normally goes to the Medical Records Manager"* [85] who can then take action if there's a breach of trust and both interviewees agreed.

- ***Control Seven:*** **Remote amendment of owned information:** Initially Mital was concerned with information accuracy and she agreed this control would help to maintain it. Additionally, Helen thought this functionality is very useful: *"yes, I think that would be very useful."* Moreover, she was not aware of whether current systems can amend information after it was shared, *"I don't think there is anything like that, where you could like put a little kind of red flag up everybody can see,"* she commented on the way SHarE deals with such situations by alerting everyone in such incidents. Finally, Helen agreed on the fact that the amendments should only be done by the original person to check whether this information is actually correct or wrong, when she explained through an example: I think they should really go back to the original person, because he might say: *"oh no! I have checked my notes, and I'm absolutely sure. There might be something else on the*

left side [of the breast], but it was definitely the right side I was worried about." Because it is the right side that was worrying, in such a case they can check the left side as well as a precaution as they may find an incidental left side, but if the surgeon finds nothing then he/ she may say: *"left side was fine, but incidentally right finding on mammogram of a small tumour, yes"* [8]. Moreover, Dr. Borley agreed on the usefulness of such a functionality:

> *"yes if it's wrong, because then there's, if you don't correct it there's a chance for ongoing errors isn't there when anyone goes back to look at it."* However, she said: *"but for instance, me, I would perhaps say this is what I want to give, this chemotherapy, but I have to do a test on your heart to see if it's safe to give it to you. If it's not safe to give it to you, then I might have to revisit that decision and give them different chemotherapy. So I wouldn't want to change originally what I said, because that would still be the original plan, but it changed on the basis of subsequent information"* [86].

The interviewer explained to her that this feature covers both cases, once the information is being amended or another piece of information is added to it. Nevertheless, she cared to ask about the alert by asking:

> *"how are they alerted?"* She added: *"do you have to go into every patient to look at that, to see if you get an alert? so if something has changed, a patient had a new problem or something, and everybody gets alerted, is there a sort of summary page that says: 'look up Susan, something has happened to her'? Because I've got about eight hundred patients, I can't open every case"* [86].

So the interviewer explained that technically the system does not deal with amendments and adding additional information any differently. It will give the chance to either simply change the text or add to it. Finally, Dr. Borley gave an example when this functionality would be of help: *"yes so pathologists often issue supplementary reports, if something new. So they say this is breast cancer, but then a bit later, they come back and say, we've done extra tests and it's a special kind of breast cancer"* [86]. She then predicted that lots of challenges may be faced to adopt these functionalities without elaborating.

Regarding this functionality, Dr. Morrey said: *"I think it's certainly important to do that."* He also added: *"then you've got to make sure it's cascaded through. Yes it is important to know about those, because there could be some important changes."* However, current systems *"deal with it, poorly,"* Dr. Morrey commented, then elaborated:

> *"it has to be manual. You know they used to, currently the way they do it, because they're used to generating reports by paper to go through, they'd have to generate another report and send it through. Sending it through electronically to another system, they do it poorly at the moment but it would have to be done. That's something that is a challenge for your low level integration engine, what are you going to do about that"* [18].

Furthermore, the interviewer elaborated and asked whether the amendment should be done by anyone in the CT or only the person who reported it, and Dr. Morrey's response was:

> *"no, it's, in our experience on CaNISC, it has the be the person who recorded it, because they might have a different opinion of it, and for, should we say a nurse, or lets take the worse case scenario, medical secretary of Dr. Tom Crosby thinks oh that's wrong, and goes and changes something from a consultant on another system in another organisation I think that's wrong, because they haven't got the knowledge to do it. I think you do need, I think it is a functionality that you need in your security system to recognise that someone is going to see, with this sharing you improve information accuracy and therefore the information security system or the workflow system needs some way of trying to make that as smooth as possible. Alerting the other people, the other end, hey there's an issue here, can you please attend to it, then they need to cascade through."* Then he concludes: *"and you can see the security system finding a way of bringing things together within the one context, you have got a better way to improve the accuracy of the system because it's easier to review. And also if you then use your workflow to implement you've got maybe a way of better alerting people at the other end that there's an issue, and also hopefully then cascading that result through. So again it works much better"* [18].

Finally, *"I think a mechanism to alert is quite useful and then it's up to the individuals if they want to go and look at that information,"* [85] Ann Marie thought about this functionality. However, Dr. Crosby thought differently about this functionality and he expressed it: *"I wouldn't routinely let everybody know that information has been amended, but you just need to be able to see the trail if you want to look for it, who it was amended by and when. And we do that with ERMA forms quite a bit, don't we. You can, I never look at it, but you can find that trail"* [84]. The interviewer questioned whether this is because he does not want the alert or because he wants the amendment to happen but does not

want alerts too much? He responded: *"well, alerts are always helpful if they're there somewhere and they're functioned to Warning or sort of, yes"* [84]. Then Ann Marie added: *"I don't know if it's alert in it's true fashion, I just think some visual,"* [85] and the interviewer suggested using icons like the one used in SHarE's classification scheme, and they both agreed that it is something that they want, they will need it, but they don't want it most of the time, and Dr. Crosby agreed: *"absolutely, yes"* [84]. Ann Marie justified that need: *"because if you send alerts constantly we'll lose what the true alert is,"* [85] and Dr. Crosby added: *"yes, you lose the value of them anyway"* [84].

- ***Control Eight:*** **Icon-based labelling for information security awareness:** some interviewees commented about how sensitive they believe the information they process is. Mital said *"it is very sensitive information because you are playing with people's lives"* [78]. She also suggested that the sensitivity icons label patients with problems to make it easier to spot them when she commented: *"need to know if the patient has any problems previously which you can only really say in whether it is sensitive or not sensitive"* [78]. Helen had expressed what she thinks about the sensitivity level of information stored in these systems: *"it's a difficult one, because to us it is our day-in day-out stuff, but it is whether somebody is got cancer or not, so that is fairly sensitive I would have thought, to the patients it is highly sensitive"* [8]. She added, *"to us, to a certain extent, we are dealing with it on a daily basis, so it is still very sensitive, but it is routinely highly sensitive"* [8]. Therefore, on a scale of 10, she would choose eight to reflect how sensitive the information she processes would be. Helen highlighted that for CT members information sensitivity is not an issue, for the rule is that if they need it they should access it regardless of how sensitive it is. However, she stated that information especially if it is sensitive should be hidden behind a glass to those who do not need to access it for their role but for other reasons like with the Clinical Portal, although she is not sure who decides what is sensitive and what's not. Moreover, although she favoured using the break-glass to access any information needed, Helen thought the break-glass feature is mostly useful with very very sensitive information.

  Dr. Borley stated: *"well it's personal medical records, so they should always be confidential, but I don't really know how to do that, because it's widely available to all healthcare professionals"* [86]. However, she agreed with the interviewer that this information needs to be looked after, it merits being confidential and at the same time available to those who need it. Furthermore, Dr. Borley asked the interviewer what she meant by raising awareness when it comes to sensitive information? and she also wondered what sensitive is normal? so when I explained to her what the nurse told me about the Clinical Portal having a button there saying break the glass, she actually didn't know about it, this confirms that different CT members don't know all the systems very well, they are only famil-

iar with the systems they use on an every day basis. However, when I asked her if she thought labelling sensitive information is essential in this context, she said: *"would it be flagged up to make it obvious there is sensitive information?"* [86] when the interviewer explained with an example illustrating its usage at a break-glass incident, and added that the labels can also be used to show the sensitivity level at the different steps, for example when there is a referral to actually see how sensitive that information is. Dr. Borley's response made it clear that the way she perceives the word *"sensitive"* as a clinician is totally different from how this research defines it. In this research, we define a piece of information as sensitive if it contains information that would physically or emotionally harm the patient if it is disclosed and falls into the wrong person's hand, whereas Dr. Borley would label information as sensitive if the patient has a test result that shows he/ she is a high risk one and his samples for example need extra care when processed to protect CT members' from catching a contagious disease from these samples. She explained:

> *"I'm not sure we'd ever use it that much to be honest, I think everything is, I don't know what, I can't imagine, what would not be relevant to be part of the core information. For instance this week, they were referred a patient from the GP for an ultrasound of an arm pit lump, and so they saw the patient, did an ultrasound. They didn't really know what was wrong with the patient, the patient didn't tell them, but it turns out she had active TB on treatment and HIV, so an extremely high risk patient. There was no label, they'd already done the biopsy, they sent the tissue to pathology, without any of these extra labels, because they didn't know it was sensitive. But I was wondering if there was a danger you make it so sensitive that's not obvious, that should be the first thing. I know it's, because you're talking about the protection of the people doing their jobs really. They would have taken extra care, they would have labelled the samples properly and none of that happened. That's a downside of separating it out into different people."* She added: *"I mean you still have to do it, but you would perhaps be more careful with your gloving and stuff like that"* [86].

Consequently, the interviewer asked Dr. Borley whether she suggested that labelling should include certain information. For example it would give you the option as a CT to put information with a label, or is it just super sensitive and only the four classifications. She said:

> *"well is it, are you envisaging that the pathologist, no because this is replacing your forms isn't it? So it's got to go on there that this woman is high risk? There ought*

> *to be a flag saying high risk, because of something. I don't know if that should be sensitive because that would put people off looking at it. It needs to be really obvious doesn't it, that it is sensitive obviously, but it's also important, it needs to be not hidden"* [86].

So Dr. Borley wanted to differentiate between something that is sensitive in the sense that it is important to look at, and labelling information as sensitive in a sense that stops clinicians from accessing it to preserve patient's privacy. She actually suggested using it to label high risk patients at each stage of the treatment pathway when she explained:

> *"at every stage, the GP needs to say this patient is high risk and then the surgeon when he refers her on says this patient is high risk, then the pathologist that is going to handle the specimen needs to know that. The only people who don't need to know are the MDT coordinators and stuff, because they never see the patient,"* which happens in *"very rare cases,"* according to Dr. Borley [86].

The interviewer wanted to know whether Dr. Borley approved the selected classification scheme to be used for the same suggested purpose. She suggested that CT members use the 'Highly Sensitive' label to flag a high-risk patient reflecting the need for more caution, and Dr. Borley agreed *"you need to flag, you need to flag to say there is a problem, a sensitive problem, and it needs to be obvious"* [86]. Dr. Morrey, on the other hand from a technical point of view, thought this functionality should have a default and agreed with the interviewer that *"Care Team"* should be the default. He commented:

> *"the reason I ask about the default is that by establishing a default which is 'Care Team,' which is a logical choice, it means that putting the information in, doesn't involve lots of extra work, because you've got a default there, you haven't actually got to keep pressing that button"* [18].

Initially, the interviewer explained the concept behind this functionality through examples of usage. First a mechanism to label the sensitivity of information which may be useful to a Caldicott Guardian from a managerial point of view, or second to mark high risk patients as a mechanism that the person recording information, can flag those patients using a label. She asked the interviewees how important it is, and Dr. Crosby commented: *"yes, set up at the right level of sensitivity"* [84] and the interviewer suggested putting labelled super-sensitive information behind the glass and then when there's a referral from the GP you can see the label, only a label and then in a break-glass incident for example this label is shown. Do you think that it is important to raise awareness, does

the current systems do it? Ann Marie: *"I think it's restricted who the information goes to initially, so by definition it's managed as sensitive. It's not available to all"* [85]. However, Ann Marie thought *"I'm not quite sure what that's going to add to you as as an Oncologist that there's sensitive data in there"* [85]. Then another question was raised if the consultant or the people who are possibly going to break-glass need to know that information might be available behind? Because there's no point in break-glass if it's not going to be there. Ann Marie responded: *"well you just break it just to see what it is and it might- yes"* [85]. However, when the interviewer explained that when she spoke to the nurse, she said: 'I never broke the glass. It's there but I never dared clicking on it, because I don't think there's anything that I need extra that is not available on the system.' So the interviewer asked how can you let them know what's inside the box to make the decision as to whether they need to break it or not? and Dr. Crosby responded: *"no, but there will be a time, there's the genetic staff and things and..."* [84], Ann Marie added added: *"and mental health also comes under that category,"* [85]. Dr. Crosby continued: *"we're doing psychology, which I think they're wanting to keep separate to some degree, which I'm not sure that they should. But there will be information that some people will have given in confidence"* [84], Ann Marie also said: *"it's under the Act isn't it, the mental health, paediatrics and gynaecology is all treated differently"* [84]. Eventually Dr. Crosby said:

> *"I think the default should be to all care providers and then have - and I think what you're talking about a little bit with the break-glass is bordering onto alerts as well, you know, around HIV risk or something else that is routinely available and that you just want somebody to know it and factor that in as opposed to having to break-glass to find out the information. I think they're slightly different things"* [84].

However, Prof. Gray asked do they need to know the sort of area the supersensitive data is in? In other words, super-sensitive data can probably be classified into different areas; should there be something that says there is super-sensitive data of this type or will that encourage people to look at it? Dr. Crosby answered: *"yes, I don't know,"* but Prof. Gray laughed and commented that this is your danger isn't it? Curiosity? Dr. Crosby agreed: *"yes, it is. I think you'd have to say there is super-sensitive information but probably not start describing what it's about. I think that'll probably lose the value"* [84]. Eventually, agreed just to say there is super-sensitive data but not say any more than that.

Table 7.2 summarises the controls evaluation. A Y is used when the interviewee agrees, an N when he/ she disagrees, an N/E when he/ she disagrees with the interviewer to some extent, a Y/E when he/ she agrees with the interviewer to some extent, an N/A when the interviewer did not discuss it with the interviewee, and an N/M when it was discussed but the interviewee does

Table 7.2: Summary of controls' evaluation criteria.

Detailed Evaluation Criteria	R1	R2	R3	R4	R5	R6	R7
Control One and Three							
Provided by current systems	N/M	N	N/E	N/M	N/M	N/M	N/M
Important	N/M	Y	Y	N/M	N/M	N/M	N/M
Useful	N/M	Y	N/M	Y/E	N/M	Y/E	Y
Helpful	N/M	Y	Y	N/M	N/M	N/M	N/M
Logical presentation	N/M	N/M	N/M	N/M	Y	N/M	N/M
Control Two							
Provided by current systems	N/M	N/E	N	N	N/E	N	N
Important	N/M	Y	Y	Y	Y	Y	Y
Control Four							
Provided by current systems	N/M	N/M	N	Y	N	Y	Y
Important	N/M	Y/E	Y	N/M	Y	N/M	N/M
Helpful	N/M	N/M	Y	N/M	Y	N/M	N/M
Useful	N/M	N/M	N/M	Y/E	N/M	Y/E	Y/E
Control Five							
Provided by current systems	N/M	N	N	N/E	N	N/E	N
Important	Y/E	N	Y/E	Y	Y	Y	Y
Saves time	N/M	Y	N/M	Y	N/M	Y	Y
Improves communication	N/M	N/M	Y	N/M	N/M	N/M	N/M
Improves information accuracy	N/M	N/M	Y	N/M	N/M	N/M	N/M
Control Six							
Provided by current systems	N/M	Y	N	Y	N/E	Y	Y
Important	Y	Y/E	Y	N/M	Y	N/M	N/M
Useful	Y	Y/E	N/M	N/M	Y	N/M	N/M
Need for justification	N	N	N	N/M	N/M	N/M	N/M
Control Seven							
Provided by current systems	N/M	N	N/M	N/E	N/E	N/E	N/M
Important	N/M	N/M	N/M	N/M	Y	N/M	N/M
Helpful	Y	N/M	N/M	N/M	N/M	N/M	N/M
Useful	N/M	Y	Y	N/M	N/M	Y/E	Y
Control Eight							
Provided by current systems	N/M	N/M	N	N	N/M	N	N/M
Important	Y	Y	Y/E	Y	N/M	Y	N

[Y] = Agree, [N] = Disagree, [N/E] = Disagree to some Extent, [Y/E] = Agree to some Extent.
[N/A] = Not Applicable, [N/M] = Not Mentioned.

not mention it or make a comment. From the responses it is clear that the responses from the interviewees were very positive when they expressed an opinion.

7.5.4 Reflection on SHarE

- **Usefulness and acceptance** All interviewees were asked questions about the usefulness of SHarE and they all agreed that SHarE has the potential to be adopted in cancer care practice. Initially, the MDT Coordinator said: *"it looks for me quite easy to use,"* [78] she continued, *"if you came to our office and you said this is the new system say you were selling it to us I think half of my office would literally turn around and say I would use it, because we are all quite fast at just using different systems so I do not think anyone would have a problem"* [78]. Helen also found SHarE a useful system. *"I think anything that makes sharing information between the relevant people easier, has got to be a great idea,"* Helen commented about the system's usefulness, and continued:

  > *"I suppose there is the opportunity for the allied professionals like physio and people like that, to input to that, because really it is like case notes, isn't it? And you just want them, all the information in one place or accessible so that you can get all that information"* [8].

  Moreover, she believes that SHarE is an easy system to understand, easier to use and more useful than current systems especially with regard to locating patients' information, by saying: *"it looks quite user friendly."* Furthermore, Helen believes that SHarE is going to help with making the information available and has the potential to address the problem as she commented: *"I thought it would save me time,"* and continued:

  > *"we want something very simple, because as you can see, we are very simple people. You know, we're nurses and we're doctors, and we're not, none of us is stupid, but that's not our priority. This is supposed to be a tool for us. Need to be able to just help us do our job, not learn somebody else's job and we don't have much time to learn how to make it work"* [8].

  Helen strongly agrees that healthcare systems should really adapt to her practice, and it should not be the other way around where Helen should learn how to use the system and adapt her practice to fit the system, she commented: *"Absolutely, absolutely. That's the whole point, is that we, and that's why, as nurses, it's taken us a while to get round"* [8], because the current systems are user-hostile and they were not involved in their development. Finally, there is a potential for nurses to use that system to access the information to care for the patient.

  Dr. Annabel Borely appreciates that SHarE is trying to address the cross-organisational information sharing issue when she commented about the system in general: *"I think it is got to happen, we've got to have joined up systems, and it's very frustrating that we*

don't. It's really important." Moreover, the interviewer asked if she believes that there is potential for clinicians to adopt SHarE in the future, and she responded: *"yeah I do,"* then added *"for a simple, straightforward healthy breast care patient, that's fine. But they're not all like that."* Therefore, she explained that there is a high degree of complexity in breast cancer care:

> *"a lot of patients aren't treated in isolation, there's a lot of other things feeding in as well, so with comorbidities or they come in a different route to the breast CT, or perhaps the surgeon would see somebody and think oh actually they're not that fit for an anaesthetic, they go for cardiology and anaesthetic opinions"* [86].

This means that SHarE will have to consider the level of complexity in this domain and meet these needs. Furthermore, Dr. Borley agreed that, first, SHarE is a user-friendly system by commenting: *"yes it looks easy yes."* Second, it could help in terms of information availability at the point of care *"yes as long as everything is entered yes,"* she commented, and this would help address the problem. Third, it enhances communication at the collaboration level, because Dr. Borley thought that SHarE *"would help us be more joined up, certainly."* Finally, she thought that she would have to adapt to SHarE instead of it adapting to her practice, and the only difference in behaviour would be when it comes to automatic referrals. She commented: *"the information getting, I can do anyway on the Clinical Portal quite easily. The difference in this, is in the organisation, it's in the automatic referral I think"* [86].

Dr. Morrey commented about SHarE in general: *"yes I can see the logical model following on that, and I like the way it builds on what we done before with the work flow and I think that will be helpful to demonstrate to the other clinicians on that. So I think yep, as you said there it does have the potential to address the issues, yes it does."* In addition, Dr. Morrey saw a potential for healthcare professionals to adopt and use SHarE when he said: *"I think there is"* he commented: *"I think that's good, I like that model because it's logical and follows a natural model at the moment,"* he added: *"I think in terms of logical things, I think all the clinicians would sign up that, and understand that"* [18]. While Dr. Crosby commented on SHarE: *"well I think it's great, if it's set at - there were sort of tweaks to how we'd want it to look and run as we've sort of talked about, I think is just what we're trying to achieve,"* [84] and he also agreed on the fact that it has a potential to address the identified problem. Ann Marie also added: *"it looked like it had an element of workflow in it, which is something that would be useful for us. Well, that you can move things around the system, that you can then see"* [85].

Dr. Crosby elaborated by appreciating how SHarE is doing things differently:

> *"yes and we haven't really talked around that, the way you build on an information source rather than we start again every time. So I don't to a certain degree, because when it's allowed to people cut and paste and put information into my referral and I just put, 'further to above', you know she has a sort of fit on everything about cutting and pasting which is bad practice, but because the system doesn't work in another way, it's electronic, somewhere we can put it where we want it. And so for a new patient I just have to say, 'further to above,' put my oncology additional information in and it takes me about two minutes to type myself. Whereas other people are writing, 'this patient has present...' rehearsing all the information that's been given to them in paper format, starting again; our Secretaries have to type it de novo and it leads to risks of errors. You forget something because you've got four attempts to take somebody's history as it were"* [84].

Ann Marie added *"I think what we don't have is a common grounding do we in terms of how we capture information and where in fact it is captured in CaNISC"* [85] and Dr. Crosby totally agreed with her statement. However, some of the interviewees highlighted some challenges when it comes to the adoption of SHarE in cancer care. Initially, the MDT Coordinator said:

> *"but you have got to understand that the consultants are all in their fifties. So even your system is making things easier, I think possibly the same because these consultants some of them are quite happy to use anything on the computer and then you have got others that have been trained and do not touch it. So your system seems fine but your system might not be the problem."* She continued: *"but you are trying to get this information for everyone to use it on the computer so that no one has to go on paper or no one can see a patient without the information."* She also added: *"some of the older consultants might find it problematic not because they are older it is just they are so used to their system that change is not something they want."* Then she explained: *"the amount of times I have trained them they have not appreciated it once but I have done it because I have decided I am not doing it the other way, I do not want to do it the other way,"* she concluded: *"I think if they had a firm, if their Director of Management turned up and said you have to use the system they would not have a choice really. And eventually they will have to"* [78].

- **Setup and integration:** Dr. Morrey generally commented about the research idea: *"I can see the logical consistency you are doing from that over arching framework there, I know it links in with the pathways we've done, so that's nice and logical."* He also appreciated

the fact that SHarE aims to build the common security complex to meet the sharing needs on top of the systems and maintain the security concept of local systems. So CaNISC, for example, and all other systems functions like normal with no interruptions while SHarE is built on top of it to create a new common security context for the collaboration. So, it has it's own security concepts to help with sharing between them. He commented: *"so it can help with the fact that the local systems or the existing systems do not know about multiple organisations or you have got issues with what you can share and what you cannot share because their systems rely on different data."* He also added: *"well, it's always tricky with the LIS actually getting into them and gaining access to the information, it's always you've got integration engines to try and do these things. And I suppose that's the way you'd have to do it. You'd program some integration engine to link the systems."* Dr. Morrey concluded: *"I like the concept you are proposing, it's logical and it builds on what work we've done before and builds on Hessah's workflow [11] and you can see how it's coming along and links to those things. But the practice of actually getting information out and effectively being somebody to gain access to that information"* is the tricky bit. However, Dr. Morrey agreed that SHarE will help with the integration regardless of the issues, he predicts: *"yes I guess the answer is it's just at the moment integrating systems, wouldn't have to use integration engines, and it's a bit dirty how they actually link and get information across. You'd still have those issues, just the same as they are now, and you'd probably use an integration engine with it's rules and things. It then sits behind the security framework on that."* Furthermore, Dr. Morrey explained:

> *"from a Wales point of view you can see the patient goes around there, so what you need to do is link those systems in some way, in that local region of Wales. Or it could be the local region of London, or whatever, and you know that in there, as you've identified on your slides there, you've got linking the GP's with the local hospital systems and etc. etc. and I would expect for something similar to how they foresee it working in Wales which is some sort of Welsh Clinical Portal where all clinicians use this portal. And the Welsh Clinical Portal implements some sort of security model, just the same as yours. And some sort of local integration engine behind there and it provides a common portal for implementing information and then they envisage, do not know whether it will happen, but they envisage that clinical portal will link to CaNISC so that whether you say it's a cancer patient, suddenly you bring in CaNISC into the picture to gain information. And actually the information will be stored in CaNISC so that it will avoid needing to go into the local radiology system. Because the Welsh Clinical Portal, no matter where it is in Wales, will link in with the local radiology system. Or the local pathology system or the local patient and administration system. So there must be some sort of security model, and security*

> *system as you've indicated in order to cope with that. Don't know what it will be, I don't think they know themselves at the moment, it's quite a complex situation"* [18].

With regard to a possibility for SHarE to be integrated with CaNISC with previous mentioned concerns in mind, Dr. Morrey promisingly stated:

> *"yes I think maybe with provisos of the integration engines etc, then it's a much better model to try these things out than others. Because in a sense CaNISC is trying to do something similar, but it's a much more less sophisticated level. So yes I think there is the real potential to try it out, the practical things are that NWIS are withdrawn, most developers have gone on to try the first stage of the Welsh Clinical Portal. So CaNISC no longer has the development resources devoted to it, that they used to have. It's almost legacy tick over to carry on. So that's the only proviso on that, but yes, SHarE is a much closer model to, because at least it understands that there is more than one organisation"* [18].

Furthermore, *"yes I think it will"* was Dr. Morrey's response to a question about SHarE adding any value to CaNISC if it is to be integrated with it. He then added, *"yes I think it can add that extra functionality because it makes the sharing security model a bit more explicit and anything that helps with getting the information out, would be a help in that one."* At the end Dr. Morrey commented:

> *"I don't think you've missed anything. I like what you've done, I would love to be in post, and have sources within CaNISC to actually be in a good position to use it, because it's, the issue we've run into a few, over recent years, in that the research has run ahead of our ability to implement it in there. Because we've been slowed down by the national people in their view of things"* [18].

Finally, Dr. Crosby and Ann Marie were also asked if they believe there is a potential for integration with CaNISC and other systems, before answering Ann Marie questioned: *"so it's just viewing?"* [85] and the interviewer explained that it is a viewing system and you can still record on it, but it will go to the database that is shared between the LIS and this. So there is no replication done, so it's the same recorded information stored directly in the local systems' databases, it's just where you view it either through SHarE or the local systems. Then Dr. Crosby said: *"so that is more like a Clinical Portal then, that hopes to be the sort of Google of all information about that individual that you look up and orders it and structures it"* [84], and Ann Marie added: *"so you go to a single point as opposed to multiple"* [85]. They both approved it and stated that SHarE could add value to LIS with its functionalities.

- **Information governance:** The interviewer asked Dr. Morrey if the controls and functionalities identified in this research in general can assist in building the Welsh Clinical Portal's security model? *"yes, I think it's certainly ideas, I think that could be,"*Dr. Morrey responded. He also added:

  > *"I don't know what security model, because in a sense it may well be there's somebody behind the scenes is sketching this even out now, and I don't know who that is, or how far advanced it is. You'd need to contact someone within the Wales NHS informatics services, not quite sure how far advanced that is. I used to know someone who was doing that. I'm pretty certain that's still the state of play at the present time"* [18].

  Furthermore, Dr. Crosby responded to a question about the degree to which they agree that there is a need to carefully balance between information availability for clinical decisions and confidentiality to avoid the information falling into the wrong hands: *"Yeah, I think that is obviously important."* He was also asked whether SHarE and its controls comply with the six Principles of the Caldicott Guardian, and he responded: *"I think they're fine and they are in principle. So, the tone is all restrictive isn't it? Rather than ensure that everybody in the system who's going to manage an individual patient has access to it, that should be one of the principles shouldn't it, really?"* [84] Ann Marie added *"it's in the patient's best interests then as long as you can evidence that,"* [85] which Dr. Crosby agrees with and then commented: *"yes and nine times out of ten it is, or you can audit it and have to justify it if called to. So, with electronic systems it's much easier to have audit trails than with paper records"* [84].

Finally, Dr. Morrey concluded that healthcare is an extremely complex domain, and he commented about the fact that any solution that works in healthcare can work any where else: *"I wouldn't be at all surprised, you're talking about very long longitudinal records in terms of time history and complex organisations and different systems, it is probably one of the most complex systems, and the integration engines are one of the most complex. And the security aspects of them are the most complex yes"* [18].

Table 7.3 summarises SHarE's evaluation criteria and the responses. A Y is used when the interviewee agrees, an N when he/ she disagrees, an N/A when the interviewer did not discuss it with the interviewee, and an N/M when it was discussed but the interviewee does not mention it or make a comment. Again the responses by the interviewees expressing an opinion were positive.

Table 7.3: Summary of SHarE's evaluation criteria.

Detailed Evaluation Criteria	R1	R2	R3	R4	R5	R6	R7
1. Usefulness and acceptance evaluation criteria							
Potential adoption	Y	Y	Y	Y	Y	Y	Y
Easy to use	Y	Y	Y	N/M	Y	N/M	N/M
Useful	N/M	Y	Y	N/M	N/M	Y	Y
Important	N/M	N/M	Y	N/M	N/M	N/M	N/M
Helps locate information	N/M	Y	N/M	N/M	Y	Y	Y
2. Setup and integration evaluation criteria							
Adds value to current LIS	N/M	N/M	N/M	N/M	Y	Y	Y
Possibility of integration	N/A	N/A	N/A	N/A	Y	N/A	N/A
3. Information governance evaluation criteria							
Enhances communication	N/M	N/M	Y	N/M	N/M	N/M	N/M
Address the research problem	Y	Y	Y	Y	Y	Y	Y
Complete solution to the problem	N/M	N/M	N/M	N/M	Y	Y	Y
Comply with Caldicott Guardian's Principles	N/A	N/A	N/A	N/A	N/A	N/A	Y

[Y] = Agree, [N] = Disagree, [N/A] = Not Applicable, [N/M] = Not Mentioned.

7.6 Beneath the Surface

This chapter aimed to present the findings from the evaluation of the proposed prototype system by CT members and senior personnel in cancer care. The variety of roles shows that although the information needs are different among the CT members, they all need to share information to care for any patient. Therefore, all interviewees agreed on the research problem, regardless of the cause. They all agreed that the information is sometimes hard to locate and the process is time-consuming, including the Caldicott Guardian who said in the second interview when SHarE is evaluated: *"it's great. I mean you've sort of caught the essence of a lot of the problems that we have"* [84]. The main advantage of SHarE is that it does not require CT members to log into many systems and find their way round the difficult ones to find the information they need. Everything that is needed is available in a single page. However, although it addresses the research problem, that does not mean it won't face a number of challenges to bring it to life, and does not have its own limitations.

7.6.1 Potential Challenges

- ***Integration engines and multi-identifiers:*** One of the crystal clear challenges in the integration of SHarE with LIS, is the fact that patients have different identifiers for the various hospital. Although there is a unified NHS number, current systems have local

identifiers, and it would be challenging how to map these identifiers to link the patient to the different records in the different systems to view it on SHarE. Dr. Morrey said:

> *"well, it's always tricky with the LIS actually getting into them and gaining access to the information, it's always you've got integration engines to try and do these things."* He added: *"well it's a case of putting identifiers into the information engine and passing that information the identifier and saying I want to gain access to that record."* Dr. Morrey said: *"it's always tricky the integration, because that's part of the reason why we've had problems now. And the Welsh Clinical Portal and the other portals that have been round hospitals they have the same issues basically. Because they need to grab information and you put one identifier in and hope you can get across."* He added: *"it could be the different hospital numbers, or the patient name and what number is there, because very simple example is that, the surgery might have been done in Gwent and they will have maybe used a local patient number there. But you're in Brotaff or Velindre and you've got a different number for that patient. So you've got to link the two in some way. The way CaNISC does it, it will grab, it will store any number of hospital patient numbers against the patients name and address,"* and according to Dr. Morrey, *"basically you can use any of those numbers to search on those."* He added: *"because again at a low level implementation you'd have to know I'm going to that local system, what sort of identifier do I need to use for that patient to actually gain access to that. A lot of the local systems now do store the NHS number. You know it's been mandated, it's not completely unique, but it's much better than what we used to have before with all of the local systems. So it's usually a lot of systems do have that number there,"* especially, according to Dr. Morrey, when the patient moves *"from organisation to organisation, which is something concerned with security, because the last thing you want to do is bring up information for the wrong patient, from a different system."* He continued, *"once you get into Welsh names you've got all sorts of problems, and I'm sure there's lots of scare stories. You can have all sorts of scenarios where you've got, you can even have silly systems where parents may have named two twins a similar name, the first name is similar or same first letter, or even the initials are the same. And there they are, got the same date of birth, born in the same place, same parents. And they've got the same initials. It is tricky. So all these are security issues. And they're not unique to your system, but they are cases that can happen. And obviously these integration engines can help do that."* Eventually, Dr. Morrey suggested the possible

unique identifier that can be used in SHarE, he said: *"well I do think NHS number is very useful, it's probably the best that we've got, yes! But just be aware that just like CaNISC, you might need a database behind it, that says well yes the NHS has got that number, but there are other local numbers for local systems"* [18].

- ***Becoming a Burden:*** System acceptance is a key factor in SHarE's success, and there are three main challenges that might hinder its adoption. First, SHarE is designed to assist CT members locate relevant information in LIS, and so it should be used alongside LIS. However, the potential for healthcare professionals to use SHarE with the current LIS may add more pressure and become an additional burden. Dr. Morrey from a developer point-of-view was concerned that SHarE may actually become a burden as it will be another extra system that will need to be used along with a number of other systems, while Dr. Crosby as a CT member disagrees with Dr. Morrey. Dr. Crosby said: *"we're always having to learn new systems and it's really irritating and hard but we accept it. And I think on both sides it depends on what side of the bed you got up on."* So he was asked if he thinks it is going to be an extra burden? he said:

  "I think the prize is pretty good and so I think people would be undergoing some training, make it as intuitive as possible and not additional burden as much as possible. And yes, they'll always be prepared to learn a different system. Well yes, well they will - we're either going - we're not going to stay using paper; we're not going to stay with lots of different systems in Wales; we will have to move and merge and see things in different views and yes, I wouldn't say it's a huge problem" [84].

Another issue that may hinder SHarE's adoption is how the information is going to be recorded with having two systems used at the same time: SHarE and the currently used legacy system. This raised a number of questions with Helen and at the same time it showed that she felt strongly that the information should not be recorded twice into each system separately because this would be ineffective and an extremely time-wasting process. Therefore, one of the suggestions is to use SHarE at the treatment point and record information at that time for that purpose, this should automatically store that information in the current systems' database for synchronisation. Then this information can be viewed on the current system when logged in to catch up with the treatment. Moreover, she suggested considering the usage of a dictation system with SHarE, as it is used today to dictate referrals letters. Also, Helen requested a change in the order of treatment points mapped into SHarE to reflect current practice: *"the surgeon would send them [the patient] for an ultrasound and mammogram, and under ultrasound, they would have a biopsy"* [8]. The prototype picked up the treatment in the wrong sequence by having the patient's

biopsy done before the scan, which is not the case. This comment suggests the need for more involvement of healthcare professionals to double check all the mapped treatments into SHarE to make sure it follows the guidelines. Although this is time-consuming, it would pay-off in the long-run by producing a system the healthcare professionals believed met their needs.

Finally, although Dr. Morrey promised a potential for healthcare professionals to adopt and use SHarE, he predicted a possible barrier when it comes to changing the practice to fit the new system by saying:

> *"the barriers as you say, and as we discussed a little are the integration with those other systems. The clinicians will immediately say as a GP, do I have to enter information separately into my SHarE system as well as into my GP system, what I'd really like to do is implement it in my GP system then SHarE to automatically extract it via my interface to present it within SHarE"* [18].

Therefore, the clinicians would prefer to keep the day-to-day practice using SHarE without extra training. So the information is entered through SHarE, which collects that information and presents it in a screen, and then a button is pressed for referral. Dave said:

> *"that's right yes, and similarly if someone is regular user of CaNISC like Dr. Tom Crosby, the information that he puts into CaNISC he would expect to be made available to others just as he'd expect to have the information from the radiology system or the pathology system to just be available to him. He's got to enter it into, two separate systems, then you're running up against the flow."* He concluded: *"and it may well be that that's where it puts additional pressure on your integration engine and how your low level stuff gets in to the system. Is it just one way extracting information for presentation only or not"* [18].

- ***Sign-up across organisations:*** Dr. Crosby expressed that getting sign-up across organisations and across services could be a key challenge for SHarE. He explained: *"so, you wouldn't do all of this for cancer without other people having it, for rheumatology or other sort of situations; trying to integrate in with existing developments in Wales. I think those would be the big ones"* [84]. He also mentioned that although we are *"really sure about how to use emails and information, I know there's various guidance that comes out of the things"* [84] an overarching governance, however, with all of those organisations may be a challenge. He elaborated and explained: *"NWIS have really struggled to be that central governance body that says, right this is perfectly safe to everybody if you do it this*

way" [84]. Ann Marie added: *"yes, what it kind of says is tells you what you can't do but doesn't give you an alternative solution"* [85]. Then Dr. Crosby elaborated:

> *"yes and if you're going to do this, you'd better do it this way than any other. Rather than be very clear, it's absolutely fine to do that. And then as soon as you get that ambiguity, different organisations, different Caldicott Guardians, some very relaxed like me, other people interpret that they feel that patient safety is in their hands and they're holding it and they mustn't let it go to anybody else in case there's an error. I come to it from a tertiary point of view where we are constantly challenged by not having information available at the point of need to manage the patient that's in front of you. And the reports that we'll hear are where information went to the wrong person, which is very rare, very rarely leads to any harm, unless it's population information, large quantities of it, and it seems to influence more the governance agenda of some"* [84].

However, the Caldicott Guardian definitely agreed that there's more harm done to the patient if the information is not available than it falling into the wrong hands.

- ***Patient Consent:*** Dr. Morrey expressed a concern about patient's consent in SHarE in general, and in a break-glass incident in particular. He gave an example regarding taking the patient consent in current systems to break into their information when he said:

> *"one of the things that NWIS have done with the out of hours system, because what they've got is access to the GP systems, the scenario in Wales, is that the GP practices is that they don't have the GP's on the out of hours service, so you've got somebody who doesn't know anything about that patient. And they've got the patient in front of them and they need information on that patient in order to treat them, because the patient is there and needs treating. And what they actually do which has worked in unlocking the GP's system, is that they actually have the patient in front of them and say do you, give me permission to access your system in order to treat you, and of course, that's a completely different question to asking the general public, do you think you should share that information or not, and under that circumstance people are very sensitive. But if you ask the patient, the poorly patient, whether you can access their information, well of course I'm feeling ill, I need that access"*[18].

Then he was asked about what happens if the patient is not conscious? and he responded:

> *"well that's then maybe when you need the break-the-glass, but ordinarily with the out of hours one, and probably with this cancer system here you may well be going*

> *to discuss the patient in the MDT, discussing that patient, you need that information, you may well come along with something which helps you break-the-glass, because the patient has given their implicit consent. Because a lot of this is implied consent between there. You may have something which you need to put complicit consent in order to get over this issue. I don't know, it's not something that's been done in the cancer field, because they don't feel that, they've seen so many patients in the cancer field, to have to go to each one and say do you agree to share that information with the patient, by and large, thinks of course I need to share this information, how the hell, I've just been to see the surgeon down there, why on earth don't you know what's happened to me there, I don't want to providing that information. But that might be another scenario into the break-glass. I know that complicates things for you a little. It is a case of balancing, I would have thought"* [18].

The interviewer interrupted and made a comment: *"in that case, maybe the person is not normally supposed to see that information. He's taking this information because this is an emerging case, it's not the regular treatment, so now that this is happening,"* and Dr. Morrey responded: *"yes because I suppose most of time we're presuming compliant consent"* [18].

7.6.2 Limitations of the Approach and Outcomes

A qualitative study approach has some key limitations which affect the results and outcomes. First, the data collected using interviews for the definition of the balance between information security goals comes from a fairly small-scale qualitative study that is limited to a small number of system users, that makes it hard to generalise the findings. Moreover, the interview method heavily relies on users' perspective on the system and they may forget essential requirements or change their minds over time. This makes it hard to determine whether there are any other requirements, threats, and or controls missing until a complete version of the implementation reaches a testing phase so an iterative process of receiving users feedback can be used to improve the system. This small community had key senior roles and are involved in the decision making process in relation to information security in healthcare information systems used in cancer care, and although there are more people using the system, most of these users are not involved in the information security of the system and so are not suitable as interviewees.

Second, conducting both the assessment of this research problem along with the proposal in the same interview session could introduce a limitation in the interview design and analysis results. Although the evaluation of the research problem as a first step helps identify a number of reasons from various perspectives as to why this problem exists. However, some responses

from the interviewees conflicted regarding the reason behind the block of information flow, and other comments shed light on other concerns or raised further questions. For example, the first two interviews had contradictory responses to the same question, and hence, both opinions were presented in the following interviews to gain a better understanding of the reason behind such a conflict and get a reasonable justification for it happening. Analysing each part individually would have made the results more accurate and richer as this would have added more questions raised by those interviews. In this study, the researcher managed to raise only the concerns she could recall from previous interviews and not those resulting from a full analysis. Therefore, separating the sessions with each interviewee into two sessions, one for the problem and the other for the solution, would have given a chance for reflection on the analysis of the results of the first session into the second.

Furthermore, although none of the interviewees actually disagreed with the identified research problem in the first part of the interview, they sometimes disagreed on the implementation of the controls. For example the use of the breaking-glass feature and justification for it. Some believed justification should happen before access, others thought it is better to justify afterwards, and some believed there is no need to justify the action. Results would be more effective if each of the parts were assessed individually so that details of the implementation can be collected from all of the interviewees not only from the Caldicott Guardian and the interpretations done by the researcher. This would help reach a common ground before the implementation and avoid situations like this. However, having a temporal gap between the parts may also have an implication on the results if not all interviewees were able to participate in them as a shift in their thinking may occur, and thus, a trade-off had to be made. However, the evaluation process is most effective if the same sample assesses both, and there was a risk of not achieving that due to the limited time allowed for the interview and tight schedule of interviewees. Therefore, as much information as possible was collected from the interviewees in the single session. Nevertheless, if the interviewee had disagreed with the research problem, then the interview would have terminated to allow reflection on the interviewee's view and justification.

7.6.3 Limitations of SHarE

Finally the design of SHarE has a limitation due to the small number of users within cancer care in Wales who were interviewed for its design requirements. The main role contributing to the design was the Caldicott Guardian, this is because his role is responsible for taking decisions regarding information security for the whole cancer care community and ensuring they are in line with national norms. This could affect the reliability of the outcome if it is generalised. Therefore, the evaluation of this research does not cover the performance, scalability, complexity and completeness of the technical implementation. This is left for future work when a robust

system is developed. Furthermore, SHarE is mainly a proof-of-concept prototype that validates the SCE idea as an implementation of the adopted information security design primarily to show that it can be achieved, and it is not a full implementation of the lower level. Also the evaluation of SHarE is limited by the small number of users within the cancer care in Wales who were interviewed to evaluate it. However, those users were asked whether the security design identified by the Caldicott Guardian actually helps/ hinders them from carrying out their jobs as cancer carers. This affects the reliability of the outcome to generalisation. But it shows how others can learn from this research for the implementation of SCEs in collaborative environments in other domains in the future.

Finally, SHarE has the following technical limitations:

- ***Delegation:*** SHarE does not consider delegation in the current implementation. For example if the oncologist goes on leave, she/ he can delegate the treatment point to a nurse, so the person who should log into the system to pick up the patient's outstanding referred case is the nurse and not the oncologist. This is one of the limitations in SHarE. However, Velindre Cancer Centre is a small community and SHarE needs to meet that need in a more flexible manner to fit a cancer care community of any scale. Delegation means that each person has different views for their jobs and they cannot perform other tasks without delegation. So, systems in the context of cancer care collaboration should give the option of delegation, which SHarE does not have at the moment.

- ***Beyond treatment points:*** SHarE is designed to help the information flow with the patient between the different healthcare providers in cancer care. In an information-intensive collaborative environment like cancer care, WfT and Business Process were used to manage this collaboration using the organisation-transparent treatment pathways to organise the treatment points and control them by making access decisions at each point based on the PCAC model. This is the focus of this prototype system, and thus, this does not make it fit for other purposes beyond the treatment points. For example, Helen highlighted the need for a system that could actually flag important things to CT members without logging into the system, simply as a method to catch their attention so they can log into the system and read more about it. Helen explained:

  > *"I suppose it's like, if you're not spending all your time on the computer, because that's the thing, you're sat at the desk, it's OK, but if you're actually out doing clinics and things like that, and doing, moving around and physically not in front of your computer all the time, then actually to know at some point that there's something that you have to do"* [8].

What SHarE can do in the future is to link a CT member's Intray to a mobile device where they can check outstanding cases. This is alerts related to the status of treatment points, and it is not something that SHarE is designed to do at the moment.

- ***Single-condition treatment:*** There is very little said and little done in the real world to support comorbidities in the context of information sharing, and this is important as we live in an ageing population with increasing comorbidities. SHarE targets this area and proposes a solution to help healthcare professionals access more information on the patient so that they can provide holistic care. However, the current implementation does not fully show this capability as only one treatment pathway was tested. Although SHarE's evaluation highlights the potential to successfully address this problem, SHarE's effectiveness is in multiple pathways. For example, all interviewees without exception did not understand why CT members should break-the-glass to access information they expect to be there, the reason for this is that in the evaluation, only one treatment pathway is illustrated. This control is expected by the Caldicott Guardian to be mostly needed outside the treatment the CT is part of, making this one of the key controls in comorbidities, and more likely to be used in such complex environments.

- ***Single-system usage:*** SHarE can be used in any type of collaborative environment that has a common predefined business process, whether internal or external to an organisation, as long as there is more than one system involved. Therefore, it is not perfectly suited to present information available in a single system outside treatment points as it is not considered an electronic healthcare record by itself, but a tool to help enhance LIS to implement care in a PC manner.

7.7 Conclusion

The main research problem, which is a real-world problem in one of the bigger healthcare communities in the UK, is concerned with information availability. This chapter outlined the assessment of this problem and the proposed system, SHarE, to address it through five semi-structured interviews with six different healthcare providers and senior personnel in Welsh secondary and tertiary healthcare trusts in cancer care. In order to perform this assessment, three general evaluation criteria were selected based on the interviewee sample: SHarE's usefulness and acceptance, setup and integration, and information governance. The main findings of this evaluation process covered three areas: the different information needs meeting the various CT member's roles, causes of the research problem from the various perspectives of these roles, their reflection on each of the identified controls, and on SHarE as a system in general. Results

show that all Interviewees agree on the research problem identified and the nine reasons for the block of information flow with the patient between the different treatment points. This is due to the large number of patients, the time it takes to find relevant information using current systems, the user-hostile systems used today, access inequity based on organisational division, disconnected systems, security concerns, shortage in resources and difficulty of integration of systems, existence of multiple patient identifiers across the different systems, and finally the mis-interpretation of security rules. Results from Table 7.3 also show that all interviewees without exception agree that SHarE has the potential to be adopted by CT members in cancer care, and that SHarE addresses the research problem in hand by improving the information flow with the patient between healthcare providers following a treatment journey. Furthermore, four interviewees out of seven agreed that it is an easy to use system, useful, and helps locate information. The remaining three interviewees just did not mention it. Moreover, results from Table 7.3 also show that there is a strong possibility for SHarE to be integrated with CaNISC as it is a much simpler system, although the multiple patient identifier is predicted to be at the top of the integration challenges if this is done. Results also show that SHarE and its controls comply with the six Principles of the Caldicott Guardian and attain the right balance of information security defined by the Caldicott Guardian. Finally, the assessment of the proposal highlighted a number of challenges and limitations in SHarE that may hinder its adoption and integration if not carefully considered in the future.

Chapter 8

Conclusions and Future Work

Overview

This chapter highlights the key aspects of the work, assesses the achievements against the aims, draws conclusions from this research, and concludes with an appraisal of the overall research experience and outcomes. Finally, suggestions are made for future work which could be carried out based on this research and areas identified by this research which will be worth further investigation.

8.1 Key Aspects and Drawn Conclusions

8.1.1 The New SCE Approach

This research highlighted the increasing threats to information assets nowadays, and the need for it to be protected using a comprehensive approach. It also discussed the key difference between information security in discrete information systems, with a single point-of-control, and collaboration, with multiple points-of-control. This presents four challenges that collaborative environments face to comprehensively secure their information assets across organisations. First, such collaborative environments lack collaboration-driven information security policies that best meet the protection needs in the collaboration sharing and security contexts. Second, they deploy incompatible AC models that are not perimeter-transparent, and thus, unable to stretch across the discrete information systems to cover the whole collaborative environment. Third, these environments do not deploy a single obvious point-of-control with authority for policy enforcement. Finally, they bring in heterogeneous LIS that are not compatible with each other. This research studied in its early chapters the limitations in existing proposals in the literature to meet these challenges. On this basis, the thesis introduced the notion of an SCE that has a sound approach towards securing collaborative environments with inconsistent information security policies to bridge the gap in the literature and facilitate cross-organisational information sharing. This approach is adapted from widely used information security designs which govern information security in discrete information systems with a single point-of-control. It has three conceptual levels: the upper level aims to define the information security goal, while the middle level identifies what is needed to achieve it, and the lowest level identifies how to achieve this goal. The application of this approach with its conceptual levels is adapted to suit collaborative environments with multiple points-of-control for the achievement of an SCE design.

8.1.2 The Achievement of an SCE in Modern Healthcare

The key aim of this research is the achievement of an SCE in modern healthcare in order to address the research questions, and assess the achievements of the new approach in challenging collaborative environments against the research aims and objectives. Healthcare collaborative environments were selected as one of the more complex environments where the four challenges are clearly present. The drive was to study, implement, test, and evaluate a proposed approach towards an SCE. The aim of achieving an SCE in modern healthcare collaborative environments that targets all levels of information security design and supports secure sharing of information from LIS was met, since this project has:

- First, used domain analysis, conceptual modelling, and observations to study healthcare collaborative environments closely, and identify the evolutionary movement in healthcare delivery from a traditional disease-centred treatment approach towards an integrated PC one using LIS.

- Second, using interviews, studied both the information sharing and security contexts in PC care in the cancer domain. This identified the main research issue of healthcare professionals being blocked sometimes from accessing relevant information in diverse LIS when following a treatment plan for a patient which requires information to flow between healthcare providers. The interviews also helped collect data to identify the PC-driven balance of information security in cancer care that if attained addresses the research problem identified. This meets the upper-level of the information security design which sets the information security goal that supports PC care when a patient's treatment pathway crosses organisation boundaries.

- Third, using data analysis and synthesis, met the middle-level challenge by, first identifying the threats in LIS currently used in cancer care that can breach the defined balance, along with eight security controls for the PCAC model needed in these systems to attain that balance and achieve an SCE supporting PC healthcare.

- Fourth, using WfT, created a wrapper-based prototype system, SHarE, implementing these security controls to achieve an SCE in PC care which was studied, developed, and evaluated. Using WffICP WFMS, SHarE constructed an independent layer that lies on top of the interfaces of the currently used LIS to formalise and manage a unique treatment journey, while the PCAC model enforces access rules as the patient progresses through their treatment journey. This layer is loosely-coupled with these LIS to be capable of embracing the local organisation-driven access controls without interruption to sustain their balance of information security while making information available to all members of the CT at a treatment point. This flexible architecture allows many LIS to join the collaboration to meet the dynamism of modern collaborative environments, at the lower levels. However, these LIS must adhere to the high-level information security goals, and conform to the information security controls. This guarantees that all LIS are in harmony with each other and creates an SCE that assists the collaboration to achieve the ultimate goal. The PCAC with customised security rules achieved by SHarE achieves the SCE by meeting all the challenges in adopting to adopt PC care and so attains the security balance at all levels necessary to support PC care systems using discrete LIS.

- Finally, used interviews to evaluate the outcomes of the SCE approach at each level of its design.

8.1.3 Assessment of the Approach and Outcomes

This section assess the research achievements against the research aims and objectives, and highlights the generalisation and limitations of the approach and outcomes.

– **Meeting research aims and objectives, and bridging the gap.** The information security design created for the attainment of an SCE is the fundamental achievement of this research in that it addressed the research questions, met its key aim and objectives, and bridged the gap in the literature. The SCE roadmap is a comprehensive and holistic approach that addressed information security in PC collaboration at all of the conceptual levels of the information security design to meet all SCE challenges. This approach bridges a gap in the literature as none of the available solutions (categorised in section 2.5) is comprehensive enough to address all the challenges at the same time.

  The upper levels of the conceptual model address the first research question by defining the right collaboration-driven balance of information security goals (availability, confidentiality, and integrity) required to establish a PC treatment approach, where information is held in one or more LIS. Moreover, it addresses the second research question by identifying threats in using LIS that can breach the balance. Sticky Policies [23] and the policy integration and conflict reconciliation solutions [30] also address information security at this upper level of the information security design. However, these solutions lack a common collaboration-driven policy, and thus, they are highly dependent on the interpretation of received high-level policies at lower-levels of their information security design to enforce this policy at the machine level. This interpretation makes the solutions vulnerable to misinterpretation of information security policies. While the lower levels of the proposed information security design address the last research question by implementing an PCAC model to achieve that balance of information security, which also addresses the threats. This addresses the three research questions and meets its objectives. DRM [65], Welsh Clinical Portal [66], CaNISC [68], and Usage Control [26] are all solutions that target information security at this lower level of the information security design. Although they address the misinterpretation of policies problem by moving part(s) of the originator's AC elements along with the information for remote enforcement, they lack a common collaboration-driven policy which is needed to meet the holistic information security needs in the collaborative context. More holistic approaches targeting all levels of the information security design are proposed by SPIDER [32] and the Information Labelling Palette [7]. These solutions aim to meet the holistic information security needs in the collaboration by proposing

different information classification schemes, they are inconsistent with LIS as a dedicated application is required to make then work. Finally, none of the solutions available today in the literature fully meets all the challenges in securing collaborative environments incorporating LIS identified in section 2.4.2 to achieve an SCE. This makes the approaches not applicable in collaborative environments with multiple inconsistent points-of-control, and thus, not sufficient and flexible enough for the achievement of an SCE.

The proposed information security design approach is comprehensive and holistic and so is able to address security in as collaboration with multiple points-of-control and thus bridge the gap identified in the literature by meeting the SCE challenges which current solutions do not address. This research defined a common collaboration-driven information security policy that meets the needs of information sharing and security contexts in PC care. The SHarE prototype addresses the lower-level enforcement of this policy that meets the SCE challenges. This is achieved by enforcing a policy for the collaboration in a single point-of-control using the PCAC model in a neutral information layer, that stretches across all LIS needed in a patient's treatment, and most importantly SHarE is designed as a loose-coupled system which retains the local information security of its LIS without interruption. The SHarE approach contributes to improving information security in collaborative environments and allows LIS to be incorporated in such environments without being discarded thereby allowing an evolutionary approach to the migration of healthcare systems to PC.

– **Assessing the research problem and proposed system.** This project assessed the research problem and the proposed system, SHarE, through five semistructured interviews with six different healthcare providers and senior personnel in Welsh secondary and tertiary healthcare trusts involved in cancer care. In order to perform this assessment, three general evaluation criteria were selected based on the interviewee sample: SHarE's usefulness and acceptance, setup and integration, and information governance. The main findings of this evaluation process cover three areas: the different information needs meeting the various CT member's roles, the causes of the research problem from the various perspectives of these roles, their reflection on each of the identified the controls, and on SHarE as a system in general. The evaluation results show that all the interviewees agree on the research problem and expressed nine cases where there was a block on the information flow with the patient between different treatment points. These were due to the large number of patients, the time it takes to find relevant information using current systems, the user-hostile systems used today, access inequity based on organisational

division, disconnected systems, security concerns, shortage of resources and difficulty of integration of systems, existence of multiple patient identifiers across the different systems, and finally misinterpretation of security rules applied particularly at the lower levels. The results also show that all the interviewees without exception agree that SHarE has the potential to be adopted by CT members in cancer care, as well as, that SHarE addresses the research problem and so helps the information flow with the patient between healthcare providers following a treatment journey. Furthermore, four interviewees out of the seven agreed that it is an easy to use system, useful, and helps locate information. The remaining three interviewees just did not mention this aspect. The results also show that there is an opportunity for SHarE to be integrated with CaNISC as it is a much simpler system, although the multiple patient identifier is predicted to be top of the integration challenges. The results also show that SHarE and its controls comply with the six Principles of the Caldicott Guardian and attain the right balance of information security defined by the Caldicott Guardian. Finally, the assessment of the proposal highlighted a number of challenges and limitations in SHarE and its development that may hinder its adoption and integration if not carefully considered in the future.

– **Limitations of the qualitative study methods and proposed security approach and outcomes.** Both the qualitative study methods and the adopted security approach, have limitations that need to be considered before the approach is applied. First, the balance between information security goals was defined using open-ended interview questions to collect data for the definition of this collaboration-driven goal and the threats that can breach that balance. These interviews were conducted in a small community which may result in limitations on the study outcomes as it reflects the views of a very small sample. Although this study was conducted on one of the most complex collaborative environments which is healthcare, and one of the most complex treatment pathways in that domain, namely breast cancer, it is a fairly small-scale qualitative study that is limited to a small number of system users. This makes it hard to generalise the findings. Moreover, the interview method relies heavily on the user's perspective and they may forget essential requirements or change their minds over time. This makes it hard to determine whether there are any other requirements, threats, and or controls missing until a complete version of the implementation reaches a testing phase where an iterative process of receiving user feedback to improve the system can be used. Nevertheless, this small community had key senior roles who are involved in the decision making process in relation to information security in healthcare information systems used in cancer care, and although there are more people using the system, most of these users are

not involved in deciding on the information security of the system and so are not suitable as interviewees.

– **Generalisation of the proposed approach and outcomes.** The approach is designed to bridge the gap identified in the literature. This renders it suitable to address information security in any collaborative environment with a similar set of four information security challenges identified from the literature. This limits the generalisability of the approach to these types of collaborative environments. However, the outcome of the study and the results in the evaluation are limited in their generalisation. This is because the main results and outcomes from the study- including, but not limited to, the PC-driven information security goal, threats, information security controls, and their implementation in SHarE- are designed to address the information security problem in PC care. Therefore, they are not necessarily applicable to other collaborative environments with a different information security problem. The aim behind the need for a comprehensive approach towards information security in collaboration is to cover as many potential threats to information assets as possible. This makes the information security controls, identified and implemented at the lower levels of the information security design, targeted on these threats to the information sharing and security contexts and most effective within the scope of this context. This means they may not be able to mitigate threats outside this scope. However, the rule for generalisation of the SCE outcome is that the more commonalities there are between the outcomes of the upper levels of the information security design, the more likely the outcome is to be applicable at the lower levels, provided careful considerations is given to the differences in technologies used at the machines level. For example, if the outcome from the cancer care case is to be applied on diabetes care in the UK, there is a chance it is applicable. This is mainly because they are both PC collaborative care environments in the same country under the umbrella of the NHS information security plan and guidelines. On the other hand, if the outcomes from this study are to be applied in e-business collaborative environments, most probably they will not work. This is mainly due to the differences in the business models in the two types of collaborative environments, which are reflected in the high-level information security goal each aims to achieve. This indicates that the research aim is not adequately tested for generalisation. Thus, leaves the study of the approach in collaborative environments with the four challenges present, but with a different information security problem needs to be done in a future project.

8.2 Future Work

8.2.1 Patients reflection on SHarE

This research was conducted and completed, with one firm decision at the start that the patient is out of the scope of this research. Although the aim of PC care is to improve the quality of care by making more patient shared-decisions about the best treatment. However, regardless of the decisions taken, the patient and only the patient will live with the consequences of that decision which in most cases will affect the quality of their lives. The decision to exclude the patient in this research was made from day one for a number of key reasons (see Section 1.3). This means important future work would be to see how fit SHarE is for patient's involvement. Although Helen, the breast cancer nurse, stood strongly against the involvement of patients in the use of systems supporting their care, she also highlighted the fact that the *"younger generation wants to be heavily involved in this, and then they are going to not like being kept out, and they hack into it and get into it anyway"* [8]. She also warned us of the potential privacy invasion this movement would cause, when she said: *"I think then you have got to be very careful about people accessing other people's information"* [8]. However, maybe there is no choice but to involve the patient, the sooner this is done the better so that there is enough time to improve this area before it is out of control. To be optimistic, maybe the user's successful experience with social networking websites can be compared with the patient's potential experience with healthcare systems. In social media, users are given tools to use and they are given a lot of control over them. Such a user-driven environment with control by the user of their own uploaded digital contents and tools to flag abusive material posted by others, that demand an immediate action to help maintain a health and safe environment, is probably the best way forward. This conclusion is made on the grounds that it is the same young generation who will be our future healthcare professionals, future systems' designers and developers, and even patients. Although these are all predictions with no experiments to validate these forecasts, it is very likely there will be a revolution in healthcare in the near future. The loose coupling of SHarE in its wrapper architecture should make it possible to add a patient focus to it in the future and allow it to meet the changing needs.

8.2.2 Information access needs in comorbidity

In this research, we tested information access needs and issues in healthcare collaborative environments by studying three cancer treatment pathways. In the evaluation, the thesis discussed how the solution can be generalised to fit any possible treatment pathway for any health condition as long as the treatment points can be predicted. The scope of this

research included collaboration between different healthcare organisations when a patient is following a treatment pathway, where the information is related to a main disease. However, it excluded situations when information is related to more than one disease for patients following more than one treatment pathway, and this occurs when there is comorbidity. According to the interview with the breast cancer nurse, comorbidity is common in older patients with breast cancer and, as part of her job, she needs to look at information about the patient that is not necessarily breast cancer generated. This is part of the aim of PC care provision. Therefore, in the future it would be interesting to test how different information access needs are in such cases, when from a technical point of view, it comes to bringing the treatment processes together, but the decisions will be far more complicated than in a single treatment process as no one knows at which point the interaction will happen.

8.2.3 Generalisation of the outcomes beyond cancer care

The study was limited to a small number of systems users in cancer care who defined the goals and assessment of the SCE approach and its outcomes. Initially, the design of SHarE has a limitation due to the small number of users within cancer care in Wales who were interviewed for its design requirements. The main role contributing to the design was the Caldicott Guardian, this is because his role has the responsibility to take decisions regarding information security for the whole cancer care community. This reliance on one person could affect the reliability of the outcome if it is generalised. The evaluation of this research does not cover the performance, scalability, complexity and completeness of the technical implementation as it was a proof of concept system used to gain feedback from users on the approach. Moreover, the selected sample for SCE assessment at the three levels of its design was limited. This can be addressed in future by including a bigger sample of users in collaborative healthcare within and beyond cancer care. This would assess the generalisation as well as the limitations of the outcome in different collaborative environments in healthcare implementing PC care.

8.2.4 Generalisation of the approach beyond healthcare collaboration

It is crystal clear that healthcare collaborative environments introduce complex challenges when it comes to patient information sharing. This research drew boundaries around healthcare collaborative environments as it is believed to be one of the more complex environments if not the most. This is due to the fact that it involves a large number of

users coming from geographically distributed environments where the fine line between information availability and confidentiality can easily get blurred. However, the study is limited to assessment of the SCE approach in cancer care. Therefore, it is essential in future work to achieve SCE in collaborative environments with the four challenges present, but with different information security problem. This problem is mainly reflected in the balance between the information security goals that suit the application domain. There are other applicable domains for these approaches with less complications, future research can study and test how general this prototype is and whether it is applicable to other domains. It is also important to consider more system users. The experiments conducted in this research suggests a number of characteristics that can predict the applicability of SHarE: large geographical area, large number of users with different roles, heterogeneous information systems with inconsistent information security contexts and AC models, and a common collaborative goal. Collaborative environments sharing these characteristics are more likely to suit SHarE's approach, and appreciation in these domains would help adequately test the approach, and reassess its limitations and achievements against the aims and objectives.

8.2.5 Security patterns

The SCE achievement roadmap, PCAC model, and break-glass with circle-of-trust are key research achievements which address the research problem. They are the basis of developing the underpinning for these patterns in the future, so they can be adopted, improved, and tested as solutions in other domains with similar attributes.

8.2.6 Where to start to evolve SHarE?

Information classification scheme. Information classification schemes are one way to represent protection requirements, and because they can be standardised among different parties, it is a suitable way to communicate these requirements in collaborative environments. This research used a Traffic Light information classification scheme, and results from this project lay the foundation for the development of an PC information classification scheme suitable to represent protection needs in PC care.

Mobile Intray. It would be useful as expressed by one of the interviewees to help alert CT members when they are moving around beds and physically not in front of their computers. Therefore, SHarE could be improved in the future by linking each CT member's Intray to a mobile device where they can check outstanding cases or any alerts that occur.

Developing a mobile SHarE application for smart phones that develops a lighter version of the complete system would be a good example.

Dictation system add-on. One of challenges brought up during an evaluation interview session is the use of a dictation system alongside SHarE. Currently, consultants dictate notes to a recording device with a handset which the secretaries uses to make sure the notes are correct. Although it causes problems according to Helen, the breast cancer nurse, as the system does not always recognise the words correctly especially medical terminologies. However, in dictation systems, if the recognised word is not correct, the system matches the nearest word in its dictionary. Therefore, the text needs to be revised manually by a human after the recognition task is over. Some systems allow users to teach the system new mis-recognised words, mainly names and field-specific terms, and thus, this reduces the mistake rate and improves the recognition. There are a large number of speech dictation systems available in the market for different types of usage and even in different languages. These are speech-enabled dialling systems, and others for filling specific forms. Although the latter system has to have a form-specifically implemented to be able to move the mouse effectively within the form, this is widely used in routine administrative duties. When it comes to systems or reports with free-text, mostly used in health records, there are many different types of dictation systems available: live and recorded dictation systems. Although the former type has a higher error rate it is less time-consuming as the system recognises the pronounced words as the user dictates it, while in the latter type the user records the full text and then the system transcribes it. In both types, if the dictation system is developed as a stand alone system, then the text will be typed within the system and the user will have to copy and paste it into the health record. Otherwise, if it is developed as an add-on to another hosting healthcare system (SHarE for example), which would be more practical, then it types in the transcript wherever the mouse is located. Dragon [114], is one of the leading standalone dictation systems, once installed and the user has gone through the one-off voice training then it can be used with any computer application installed into the same computer system. However, a number of challenges may arise. Firstly, the dictation system must have a dictionary that is medical-field focused for a low error rate. Secondly, it has to be regularly updated with new terms. Thirdly, new users need to train the system to their voices before using it which is quite time-consuming. Therefore, it is better to have the same users using it as the error rate decreases over time. this is because the system learns the unrecognised words. Eventually, although it requires a level of expertise in natural language processing and speech recognition, it would be interesting as much as it is challenging, to develop a dictation system as an add-on to SHarE with collaboration with experts in that field. It is believed that if properly implemented, the provision of a dictation system to SHarE would

make it more effective.

8.3 Conclusion

There is a global effort to modernise healthcare delivery by shifting towards PC care in pursuit of better-quality care. The earlier chapters in this thesis aimed to test the possibility of improving LIS to cope with the emerging needs of this movement. To achieve this goal a number of key decisions had to be made early on to draw concrete boundaries around the scope of this research. This mainly excluded patients' input and limited the study to the healthcare domain. Therefore, this thesis suggests key areas for future work which can be carried out to address limitations of the study approach and outcomes, and so extend this research. In addition, it introduces other scholarly research areas which are worth further investigation hoping it will help fellow researchers build on it and take it further towards the main goal, to improve the quality of care we all receive as patients for a better health, better nation, and a better tomorrow.

Appendix A

Requirements Identification Semi-Stuctured Interview with Caldicott Guardian (Dr. Tom Crosby)

A.1 Interviewee's Role

Dr. Crosby plays two main roles: a Consultant Oncologist treating UGI cancer, and Caldicott Guardian for the Cancer Centre. This is in addition to several other leading roles including: Clinical Director of the Velindre Cancer Centre, and Chair of the Cancer Service Management Board. Being an oncologist who takes care to access to patient information for patient care continuity, and at the same time, a Caldicott Guardian who is concerned about patient privacy and information governance, these contradicting roles enable Dr. Crosby to set the right balance between information availability and confidentiality in the context of healthcare.

A.2 Interview Aim

The initial interview with Caldicott Guardian aims to understand the balance between information security and information sharing needs through a breast cancer treatment scenario, and identify information security issues in legacy information systems used in PC care and requirements needed to address these issues.

A.3 Questions List

The questions are categorised into a number of main categories as shown in Table A.1.

Table A.1: Interview questions with Caldicott Guardian for research problem identification.

Category	Questions list
Role in healthcare organisation	What are the role(s) you play in the healthcare organisation(s)?
Security perspective	What do you think the role of security is/ should be in healthcare?
	Why is the Caldicott Guardian role is important?
	From your role(s), how do you see information security in general?
Treatment scenario	The breast cancer treatment scenario (below in page2) describes a simple treatment pathway, any comments about it? Any changes suggested?
	How does it relate to a scenario in UGI cancer?
Information sharing	The sequence diagram (shown in page3) illustrates the information shared between different healthcare organisations to treat patients following the breast cancer treatment scenario (mentioned in page 2), any comments about it? Any changes suggested?
	Based on this sequence diagram, I'd like to discuss various aspects of this sharing of information such as: ownership, its level of sensitivity, protection needs, methods of sharing, and any sharing problems?
	What if information is needed in an emergency case and it's not available? Can you give us an example? And why it is not available? Is it to do with security constraints?
Information security in current systems	Do you know all collaborating hospitals' policies?
	How do you protect local information? In other words, what do you put in place to safeguard the information stored in your system?
	What about when it is shared outside or exported; is it protected at the same level (or as good as it is locally in your system)?
Welsh Clinical Portal	Have heard of the Welsh Clinical Portal?
	What are your views on that as a method of information sharing?
Further connections	Do you recommend anyone who we can speak to about the areas we mentioned above? (e.g. those dealing with Information Governance)

A.4 Interview supporting material: Breast Cancer Treatment Scenario

The treatment pathway starts with the patient visiting the GP in a GP surgery after noticing any of the breast cancer symptoms. The GP then examines the patient and collects some information about the abnormality observed, patient's clinical history, and clinical

examination details. This information is stored in the GP's system. Then the patient is referred to a local hospital (name it Hospital 1) in order for a breast cancer specialist to make further tests. A letter with a summary of the information collected is passed to Hospital 1. In Hospital 1, an oncologist/breast cancer clinical nurse requests more tests to determine whether the patient has breast cancer or not. These tests include: blood test (by a Haematologist), imaging-mammography, ultrasound and MRI (by a Radiologist), and biopsy (by a Pathologist). The results of these tests (assuming they were carried out in the same hospital) will feed into the oncologist's system to determine the type of cancer, the stage and grade of the cancer if the patient was diagnosed with breast cancer. The oncologist should then discuss this thoroughly with the patient and inform the GP. In order to plan treatment for the patient, her case is then referred to a Multi-Disciplinary Team (MDT) review for discussion. Hospital 2 hosts the MDT meetings and must ensure that information necessary for effective team functioning and clinical decision-making is available at each meeting. Therefore, Hospital 2 requests the patient's information from Hospital 1. The MDT recommends a treatment plan (let us say in this case scenario, surgery was planned for the patient). Then Hospital 2 should inform Hospital 1 about the treatment plan and recommendations and pass on any relevant documents. If Hospital 1, the local hospital, does not have sufficient facilities to perform the surgery, then it refers the patient to a better-equipped hospital, Hospital 3, to perform the necessary surgery. This will require that Hospital 1 shares all relevant information on the patient with Hospital 3. In Hospital 3, following surgery, more information will be collected and recorded in the surgeon's system, and a surgery summary will be provided to Hospital 1. Following the surgery, the patient's case is discussed in another MDT review, meaning that Hospital 2 (hosting the meetings) will request all the patient's case notes and reports from both Hospital 1 and Hospital 3, compare them with the previous MDT meeting notes kept at Hospital 2 in order to come up with an updated treatment plan and recommendations following surgery. If the team suggests no further treatment, then the patient will be discharged and this should be followed up with the Breast Screening Programme for regular checks for any recurrence.

A.5 Full Interview Transcript with Dr. Tom Crosby

Key:
Shada = Lead interviewer, PhD Student
Alex: = second interviewer, Prof. Alex Gray, research supervisor
Tom = Interviewee, Dr. Tom Crosby

Shada: Ok thank you first of all. Now the aim of this meeting is for me to understand things better from different perspectives depending on your role in the healthcare organisation. So I'll start off by asking you about your roles.

Tom: OK, sure.

Alex: Well I think the thing that we are really wanting to look at is security privacy that's the area.

Tom: I'll scan through that.

Shada: Well that's a whole list of questions I would really appreciate it if we can go through it.

Tom: Yes.

Shada: The bold ones are the really important ones

Tom: Yes so my role I am a clinical director of the Velindre Cancer Centre. I have led and have a sort of leading role in Upper Gastrointestinal (UGI) cancer in this hospital, the network, the Wales and things and I am medical director of the South Wales Cancer Network and I do lots of things unfortunately, I chair the CaNISC Service Management Board but all of those things may come out in this at some stage of the interview. They are all relevant I'm not just trying to show off. I'm Caldicott Guardian for the Cancer Centre and there are other Caldicott Guardians within the Trust.

Alex: That's within the Velindre.

Tom: Yes that's within the wider Velindre Trust so the Cancer Centre I have a Caldicott Guardian role. I also have a sort of a Caldicott, that is a bit ish, for CaNISC because it's a little bit less clear the role because CaNISC is an all Wales national IT system but obviously is our local power system as well, so there is an overarching clinical governance IT lead in NWIS. NWIS are really now technically or strictly or really, own and manage CaNISC as a National System and there is an information Governance lead, Darren Lloyd who works in NWIS for that. Martin Murphy is the clinical lead is overarching Caldicott Guardian but he has delegated certain responsibilities to me. But if I'm asked for information release on a more Wales approach or crossing healthcare organisations I would always run it past Martin and Darren in NWIS as a process.

Alex: So that was Martin Murphy and Darren

Tom: Darren Lloyd who is the true information governance lead in NWIS.

Alex: So is he a computing ICT guy?

Tom: He's from a background of information governance.

Alex: right I'm just seeing how they fit it because one of the things we are picking up is the slight confusion that comes because of an IT approach being very different to how the consultants medical staff see it and it's one of those things we are hoping we might be able to address for you because I think there are differences of opinion in there.

Tom: Yes.

Shada: Yes these are the roles they are plenty. So the questions here may, you may answer from different perspectives because we've got all these you know views on things from being a Caldicott Guardian and a Clinical Director. So the first question I would ask after is just you know what do you think the role of the security in healthcare, may be as a medical director from both sides, in general?

Tom: In very broad terms there is a balance between information security particularly around clinical information and patient identifiable information being seen by only those people that need to see it and that's on an individual case record basis and also on a more population wider group basis which is obviously a wider consensus and I think that's always going to be balanced around access to clinical information needed to support decision making. So there is two roles, my role as clinical director, certainly of the Cancer Centre is to ensure that when my clinicians and staff see patients they have the right amount of clinical information available as a Caldicott guardian they just need to ensure that as much security is put in place that is reasonable and practical to ensure that that is done safely.

Shada: That's exactly what I want to know and understand from this meeting, reasonable security that can help them you know gain access to the right information at the right time to treat the patient.

Tom: I mean I think if you just want to start on a very high level I think there is, because of varying interpretation of guidance around information security, clinicians are often blocked from having the right information to treat a patient and I don't think enough weight is put on that i.e. patients' rights of access to the best healthcare available because of variation in the interpretation of security rules.

Alex: And is this variation coming from the fact that you take CaNISC, its going across all Wales, you've got different Trusts?

Tom: CaNISC is only one part of that problem, it may be radiology information, it may be other clinical information from other systems as well, but yes it's individual health organisations interpreting what must be standard guidance around sharing clinical information by e-mail, by transfer, by access to portals etc and firewalls, there's various interpretation, you know varying interpretations of that certainly.

Alex: So you're covering exactly what we wanted to hear.

Tom: But I just wanted to emphasise I am more on the side on an individual patient basis, that access to clinical information has been too restrictive on the basis of theoretical risks of information getting into the wrong persons hands and that when we are devising new clinical IT electronic systems, we seem to set a different standard which is way higher than access to paper records, which is pretty loose and the ability for anybody to really walk around the hospital and open a set of notes and read through it, and notes left around, etc etc. Or paper records being sent to the wrong addresses and all of the things I know you're aware of it is hugely higher than the standard we seem to be putting into electronic records. I guess for me having thought about it a lot, the big caveat I would say around that and seeing some of the problems that there have been, is there needs to be a completely different level of security around access to population of people's records so...

Shada: So what do you mean?

Tom: So if ...

Alex: Is that if you were doing a clinical audit...

Tom: or a trial so you know, so you are able, as well as, I think the risk of somebody opening an individual record and then being able to abuse that privilege is much lower than the ability, the risk is much higher for somebody to do an audit search, have access to all of health records, be able to obviously take virtually the whole of CaNISC on one memory stick and leave it, you know leave it lying around or leave it, so the risk of that is much higher than any potential abuse on an individual patient record which is just like you know, say paper records whereas the risk is not high, the actual sort of quantifying that risk is much lower when it's you know insurance companies or something else, you've got your hands on one set of notes, it's very unlikely to be helpful to them but if they don't have the memory stick with lots of clinical identifiable information you know its very, very worrying. So that is where there is a difference I think in terms of us moving electronically you know the amount of information that can be accessed.

Alex: This is exactly where we are wanting to get and understand because we have been struggling at the outset and it's clear from the talks we have had with Dave that there is majorance Some people say oh the NHS is great, it's all covered. Well at that very high level it is, but when we get down to the individual hospitals and this is, and even within, is there a problem in say the Velindre that there's different levels, in other words you've mentioned radiology, we've got CaNISC, we've got presumably other systems say for yourself in the upper tract, are there all these different systems and do they have different ones or is there a firewall here that protects things...

Tom: No for use of it within Velindre we only have two or three different systems that we all have access to, mainly we really just have CaNISC and then through CaNISC we

have web links to radiology systems, there is a chemotherapy prescribing system called Chemocare where we are able to put clinical information in, the problem we have as we are in transition from paper based records to electronic based records, we have three places where we can put clinical information now, so we have both a paper record, a case note that walks around, we have CaNISC, electronic record and we have Chemocare. So if a patient's, if a nurse or a doctor has to access clinical information it is not necessarily clear where that information will be stored, so pharmacy will tend to have good access to Chemocare, they will look for Chemocare for a record but it's not there and it may be in the paper record which may sitting anywhere in the hospital. So there's a drive towards CaNISC being the ultimate clinical recorder and if it's not on CaNISC it doesn't exist sort of mentality that I'm trying to encourage.

Shada: Ok. How different is the Chemocare and CaNISC?

Tom: Well Chemocare is obviously just for chemotherapy prescribing so it's a chemotherapy electronic prescribing system but information related to patient's treatment, chemotherapy treatment, can be put in that system so patient unwell therefore it needs dose reduction or needs something. That is something that Chemocare has had the ability to do and some people put that information on Chemocare for Pharmacy. The problem is if a nurse needed to see that or a doctor or at home you are not necessarily going to look into Chemocare for that piece of information, but I would say the sort of rules around that could be more explicit, you know they get nagged from me to always put it on CaNISC but we probably need sort of great so I would sort of say rigidity or sort of structured rules around where clinical information is stored. But in terms of a problem of access no by and large sort of all those three systems are available as Icons on our opening webpage, we can just open them.

Alex: As long as you're within the Velindre?

Tom: Yes in Velindre yes.

Shada: Ok. So just a conclusion from this, that you see security it should be help but not a hindrance?

Tom: Yes I think well, as I say go back to the point, my point is more harm certainly much more harm is done to patients through lack of access for clinicians making clinical decisions than the risk of the wrong person seeing information for which there is an.

Alex: Well what you're actually saying there is I think that you want clinical staff, all clinical staff, nurses etc to have that type of access because they need it.

Tom: And I want to give them the responsibility, I would give them the training, obviously the necessary passwords for audit trails for any access that's made that we will be

monitoring you potentially or at least could do, and it's much more rights of responsibility but give clinicians, nurses etc access.

Alex: At the moment the Information Governance people seem to be seeing it in a different light.

Tom: Well that's our internal system which has grown I think if they were devising our system they wouldn't have passed this system, I think it is but just as an example we are now bringing in a new chemotherapy prescribing system to replace our role on Chemocare something called Mosaic and at the moment as their standard health record at the top it will have even the Hospital number. Now apparently that's an absolute bond or fail because that's not enough information to correctly identify the patient whereas I think well you know, that's what we have in CaNISC you know at the top we just have the name and I don't know any patient who for that reason has been misidentified and subsequently mismanaged. Much bigger problem is on clinic lists you know the David/Davis two David/Davis' apply and you just read that quickly. So at the moment they are saying that they would not accept that governance standard that system which is an off the shelf system whereas in fact we have that basis of that level of ID on all of our patients. So CaNISC has evolved, it has now been adopted by NWIS as a national system and they are finally I think, giving it full credit for what it can do but at the same time, they are adding in rigid rules for rigidity and I would say, putting in unnecessary barriers to the development of the service around the so called information governance. But it's a grey area and it's where you draw the line.

Alex: This was one of the reasons why they saw it as a useful area first to investigate.

Tom: Absolutely.

Alex: As you know, we are not trying to do what NWIS want, we are just trying to investigate it as a serious problem and then anything that feeds back to you and helps you is useful and Char has struggled with it because I'll be saying things to her like I know that this is tension and also I think there is going to be tensions as it goes nationwide CaNISC.

Tom: Yes very much so.

Alex: Because you'll find as you're saying already differences and there's these different Caldicott governors.

Tom: The main area of concern in the sort of clinical pathway, there are sort of three examples, is that we here are a tertiary organisation so Pathway suggests, you know client's are diagnosed elsewhere and they come here for certain parts of their treatment, go for other parts of their treatment or for follow up elsewhere and clinical information

that's available in other systems or in the start of the journey doesn't always flow with the patient as here. So that's a particular problem here.

Shada: Why do you think that's happened?

Tom: Well because you're taking clinical information from one organisation, from one system across a health care boundary, across the statutory.....

Shada: How is that sharing, I mean why think you know, the result is that sometimes information doesn't flow with a patient is it because the way the method of sharing is not really appropriate? It's not suitable or?

Tom: so there's two examples, if CaNISC is being used as the national system and that information is being put on CaNISC at source, the CaNISC is devised so that it's based on a provider level basis level, so within CaNISC each provider has a set of notes, so if you were devising CaNISC how do you divide a patient's care up, you could either have it as a disease episode and all providers come in and provide for that disease...

Shada: When you say providers what do you mean?

Tom: Healthcare providers so Cardiff and Vale...

Alex: The Trusts.

Tom: Or Health Boards is the statutory organisation...

Shada: Who are dealing with the same patient?

Tom: Dealing with the same patient, so if they have put it in CaNISC apart from the sort of clumsiness of knowing your way around CaNISC the information is there and as soon as they are put on there's a referrer, rather they are referred to me and I am put down as a provider of care I can have access to their information.

Alex: But I think the point you're making to us is if I was a patient in, I was going to say Heath, but that's not, Swansea let's say.. I was referred to you there could be a problem at the start until you were given as one of the carers is that as I see it.

Tom: Certainly I couldn't just look at that patient if somebody phoned up about a Swansea patient who was on CaNISC and had I hadn't been put down as a referrer or as an MDT member I couldn't open that case record.

Shada: Oh ok.

Alex: and that's because there's different firewalls going on.

Tom: Within CaNISC there's more, it's provider led and unless you are put down as a provider or a referrer into that system or as an MDT member it's just privileged access you can't see it.

Shada: Oh ok. So the access mean base role. We can say that?

Tom: Yes. But anyway that's normally ok because they are used on the same system and I think it's reasonable the difficulty is you know, if you want just a clinic... I have been stopped from looking at clinical information that would have been very helpful to the care of the patient, I don't know may be 5 or 10 times a year, it's frustrating but it doesn't happen often.

Alex: Was it for a long period or?

Tom: Well permanently you know really for that patient I just couldn't access the clinical information so I would have to go to other sources.

Alex: So there's no way of sort of someone making an override for you?

Tom: Not here. You know it would have to be a sort of, I would have to be put down as a referrer for that patient which would have to have the permission of the organisation.

Alex: So it would have to go back to the other organisation and then be them approve you.

Tom: There's someone in Velindre who could register the patient here, the bottom line, so as I say, that's not too bad, I think there is a right, If I'm not down as looking after the patient or a member of the MD team that's managing that patient you know I shouldn't have direct access to the record but most of the time that is fine because it's on CaNISC, they refer the patient to me, my secretary registers the patient at Velindre and I have access to all the information that's put on on that patient from other organisations. The problem is when it's not on and it will be on either one of their clinical portals their Path systems or patients referred to me from Swansea, but they've had scans and I need to see those scans but I haven't got access to those images which sit on a different system in their own health organisation system and because we're a tertiary centre different healthcare organisations will put up different barriers to me accessing that information so...

Shada: Can you give me an example?

Tom: So we have, we run the South Wales service for Hepatic surgery, so patients how have secondary cancers in the liver, the surgical service is based in Cardiff and the Oncology is largely based here but we take patients from all of Wales so patients referred from West Wales to the surgeon who considers managing them, they send their films or x-rays electronically or by disk to Cardiff but they are discussed here in MDT that you came to or a similar one to the one you sort of came to. But Cardiff won't give us direct access to those images because they say they are only holding on to them as the statutory owner of the information is the patient and the original healthcare organisation. Now you know, Darren Lloyd who is the Head of Information Governance has said basically

that's a wrong interpretation of the rules clinical information should be allowed to follow a patient and that is perfectly reasonable.

Shada: So the MDT is held in a different place but still the people...

Tom: Clinical care will happen in a number of places.

Shada: Yes yes.

Alex: This is exactly what we thought the problem was but we were told by some people it didn't exist.

Tom: Yes, no it does, sharing information, particularly I would say about radiology more than anything else.

Alex: We were seeing it, we actually wrote a paper on this, a number of pages paper where I took it apart, a student who is in to, well he's now a member of staff, he's in security and he said there were no problems, he had this thing he had got from talking to somebody up at the Heath. I took one look at it and said no it doesn't work like that. It was exactly the problem you were saying, we were saying if somebody comes here or one of the hospitals they are referred after an MDT they are referred for surgery somewhere else and who owns that information, it's the big questioned and they want changes...

Tom: Absolutely.

Alex: You've got a sort of scenario that he then worked on in the paper where we were assuming the person went to an MDT were referred for surgery, there might be additional notes added by the surgeon and then you're in to all the questions of who owns it. If it has to go back to the MDT you've got all sorts of questions as to whether everything can be available, who has the honorary rights on it, do they only own the... It's interesting that's what I thought was happening.

Tom: Yes, so it is a very real problem. Why don't we come into my office, my new office furnished you can be the first people.

Alex: I'll just hold the door for her.

Tom: There we are how about that.

Alex: This is the new chairs.

Tom: So a very real the advantage of that is around the ownership of that where clinical information has been put on and when the patient follows through the journey we find that information to be incorrect.

Shada: Incorrect?

Tom: Yes. So I am referred a patient with breast cancer and the code you know a very low level is banded out at as breast cancer instead of a lung cancer, they just coded it wrong. I see it's incorrect what do you do about it. Who owns that information to change.

Shada: That's a very important question.

Tom: Yes and the only, the statutory organisations in Wales have to be the health Boards. Ultimately the health boards, somebody in the health board has to own that information.

Shada: Somebody in the Health Board

Tom: So you know if it's come from Swansea and they've got it wrong technically we will have to go back to Swansea to correct that information.

Shada: So they delete it and then they provide the right one or do they add to it?

Tom: There needs to be a system in place to correct that and that's unclear at the moment.

Shada: Ok, so just to comment on that, do you still see that what was wrong there was an error in there, or is it just deleted and then re written, I mean...?

Tom: I don't know.

Shada: You don't know ok.

Tom: It's just deleted and re written but there will be within the system a pathway that you can be looked at.

Shada: So the information sharing problems or may be mainly arise from during the treatment where the patient is flowing from one place to another with the information or is it to do with outside treatment scenarios, I mean?

Tom: Sorry can you explain the difference of those?

Shada: I mean clinical information may be being used, may be outsiders from people who directly contact.

Tom: I mean audit and other people?

Shada: Yes. Where it's not really important you know it's the treatment that is the main thing.

Tom: The main thing obviously from my point of view is that whoever is directly looking after the clinical care of the patient has the clinical information they need to manage that patient. In terms of access for national audits for other information for outcomes clearly what we need then is to be able to limit the amount of information that's available to those people that are undertaking that role to the absolute minimum. It nearly always is not to have patient identity....

Shada: But you don't have that view when it comes to treating the patient as long as the information is important for treating the patient ok.

Alex: And if so such a barrier, we understood that there could be, somebody mentioned the braking glass didn't they.....Let's get that where you've got a patient that's come in here you urgently need the information, do you have any bypass that let's you get to it.

Tom: No so I think in CaNISC there's sort of strength, the potential weakness for the system is that we don't have break glass sort of scenarios as far as I know. So if you have access to CaNISC you have access to all records by and large. That can be limited but broadly that has been a little bit of an issue.

Alex: So I know that the new national systems have certainly have a break glass system within it.

Shada: You mean with the national system, what do you mean by the national system?

Tom: Well so with the Welsh with other NWIS systems Welsh clinical, well that one principally.

Shada: So how do you know about it.

Tom: So that if you had a patient you know with HIV or some genetic sort of history that you would have a system, I haven't used it where you have to go through some procedure to say I am looking at this, I know I don't normally have access to it and I know somebody will be told or be aware and be able to monitor the fact that I have decided I need it on this case, I don't routinely need it but I need it for this case, and I don't think that exists in CaNISC, genetics, medical genetics used to use CaNISC as a record but as far as I know I certainly haven't been told how to break any glass to get information so I assume that that system doesn't exist.

Shada: How would you think about it in the future I mean ideally?

Tom: I think that's great.

Alex: You want a break glass?

Tom: I would say that would be fine.

Shada: So you think it would be fine the glass and then you think of the probability of breaking it in emergency cases.

Tom: Yes and me take the responsibility of having broken that glass and justify it to somebody else. Yes.

Alex: Presumably that would come back to the Caldicott Guardian or would it, that would be the person made aware?

Tom: Yes although I think there's much more, there are now more sophisticated sort of systems coming through which look at irregular use of a system so this is Darren Lloyd, Information Governance told me about systems that can monitor systems all the time and you can see a peak of activity or some other you know something which is quite sophisticated to say this person wouldn't normally look at those results let's have a look.

Shada: So you can see on those systems the person accessing what kind of information, the information and the person accessing it?

Tom: Yes.

Shada: Ok.

Tom: And I think up until now it's obviously not been sophisticated enough to look at all the background noise but I think we are getting more and more.

Shada: So you think that's handy in terms of the access.

Tom: I think the bottom line is if you really need it you need to be able to get it, it shouldn't be going back to an organisation in an email through a help desk or something else which is going to take a long time basically.

Shada: So going back to the braking glass mechanism, the information what do you think, well first of all how sensitive is the information that you are dealing with when treating the patient?

Tom: Most of the information, the individual patient is not that, for me, wouldn't be that sort of sensitive.

Shada: Ok, confidential may be.

Tom: Well it's all confidential isn't it? I think you know if you were doing a lot more work with Paediatrics, with section medicine, HIV about medical genetics and inherited core things, those are clearly much more sensitive areas such as social services, abuse whatever you know all of those areas are labelled as being much more sensitive, my patients just have cancer and you know they, you know they would want you to have access to the clinical information that would enable you to make a clinical decision.

Alex: And would you want to limit it the braking glass to certain rules?

Tom: Yes ideally

Alex: Would it be someone in your position or how far down the chain would you go?

Tom: Well I think that's just a matter of judgment isn't it. The person, for me, as I say I just keep coming back to the fact that it comes down to a much more professional responsibility and that I don't mind if I have to make a decision that is not just a routine review of a case note but I know, somebody will know an e-mail or a message will go to

somebody saying I have looked at these notes and I would be happy to then be able to justify that.

Alex: Yes I was thinking more if you looked there's a team.... would it apply to all members let's say would it apply to registrars?

Tom: I think what you need is a balance of access and then you know levels of seniority and responsibility but you always need a speedy way of accessing clinical information. I think as consultants I think yes.

Alex: Down the tree a bit.

Tom: Yes well I think trainees come and go and they have different rules they are not necessarily ongoing but seniors, nurses are managing patients almost as much as consultants are, ward clerks, well it 's probably too low you know, but what I am also saying its more, sometimes you could develop a system that was very very sensitive information that only one person in out patients can do that, but as long as I can go up to somebody within a reasonable amount of time for clinical care with some minutes and say I would like this clinical information can this one designated person get it for me? One person in a GP practice possibly, one person in a radiology department can access that information, that would be reasonable as long as there is always one person there who can get that information. I think in a practical level for cancer care the consultant should have that privilege.

Shada: Yes.

Alex: One of the things I investigated at one stage on this was if your at the stage in the tree one person, if you're coming down the tree, this is for giving permission, three out of five you can do something like that, and if you can get that you can cover the fact as you go down the tree for access. It was something we looked at for a completely different problem, but it is not something that has ever been adopted because it does depend on your hierarchy of your organisation.

Tom: Yes, yes I'm sure.

Shada: So I think that's important for me to know that we have an answer to it, if you would classify the information in your cancer or your area and the people how would you, the information being top secret you know something like that or senior people and asking, if you were the one who was given the choice to say who accesses what kind of information how would you say?

Tom: I think that needs to be in a discussion between a sort of claim or an explanation for what is needed and by whom and then somebody in authority to be able to allocate priveleges and I am sort of frequently asked around that as a Caldicott guardian and using

CaNISC I would say that, so we have had allergies and risk alerts, and it could be HIV risk alerts or something along those lines and for me its anybody managing the patient. So at that level the juniors, the specialist nurses on the ward who or anybody who is prescribing chemotherapy treatment certainly consultants should have access, not necessarily ward clerks or you know other people, allied health professionals, you would just have to have those different levels.

Shada: Ok, so you said that there must be someone there owning that information coming from different places. Ideally do you think that's the way it should be or do you think may be you should own that information because you generate that information, or record it and then you have control over it, do you see it that way or?

Tom: You could have that from an operational level but from an accountability level everybody has to be accountable to designated people and in the health service at the moment its through Health Boards and Trusts but mainly now Health Boards through to the Executives.

Shada: Ok. About the information I mean, this is ideally may be how it should be or may be how it is right now, because people have different perspectives about some people say it is the patient who is owning the information so I just get confused really because it is not very clear to everyone who owns that kind of information.

Tom: I don't think ultimately the patient can own the information they may be able to have access to it.

Shada: Why? Do you link the ownership with control?

Tom: No just from a practical level, I don't know how you would own the information without running the system, I don't know how that would work.

Shada: Ok.

Tom: Ownership means that you could take it away from the person and they can't, you shouldn't be able to access all information without being granted that access.

Shada: Ok.

Tom: I mean I'm for patients can read everything they like about their records, I've got no problem with that, but they can't walk into a hospital and take it but they have to apply to have it and you have to have a good reason in fact if you haven't there probably isn't a good reason not to give it to them.

Alex: If you look at some of the things that are coming out of the States where people are holding their own personal medical record and it's coming in this country as well, and they own that to some extent.

Tom: Yes I can see that they're walking around with it and may be your adding some bit on to them, but that isn't really either practically, or I suspect if I really thought, I don't know you can think about it longer than I can, in terms of true accountability, that doesn't exist at the moment.

Alex: If there's going to be a tension in the Trust in the future, but it's probably too far for what we're wanting to look at. Can I just ask a question in this ownership, what we mentioned just a second ago was Swansea create a record, they let you have it for the MDT, it goes out urgently in another hospital and in each of these stages bits can be added to it, now if I understand it correctly you're saying this one here owns the record because they originally created it.

Tom: It depends I think. At the moment the system is that each provider puts parallel pieces of information together which is collated all in CaNISC and each provider health organisation owns their bit of the information for their record so when I've got a CaNISC patient with a number an NHS number and then you've got provider organisations for that disease and every time a provider goes in they enter into their section of the case record and own that section.

Alex: Ah so there's separate sections. Yes that's what I...

Tom: I Have access to all of those if I am a referrer and we are trying to get rid of that we are trying to make it from a patient centre point of view it would be better to have the disease and then we put in sequentials, partly just because of ease of access information unless you really know your way around the system it is quite difficult to find relevant information, but also there is duplication of information that is put in at the moment, so when you want to stage a patient each provider puts in a stage diagnosis and the problem then for data quality is what happens when they vary...

Alex: Or you make a mistake...

Tom: Yes you make a mistake. I don't think that's resolved actually because you know for clinical care we get frustrated with multiple records and clinical audit and data quality in fact also from an ownership point of view, Cardiff and Vale can only own what they put on to the system and how do separate?

Alex: That's actually something we suspected but didn't know if it was true.

Shada: Thank you so much for that this is really useful. What about the protection they put on, I mean they own it, they give it to you, they put it in their own partition, you are someone who is actually receiving that information. Let's talk about your information, you're providing your information to them do you tell them how you want it to be protected in your partition, in their system, you know, or have you never thought about it that way at all?

Tom: Not really. If we want to change any information you have to have edit access, you have to have edit rights, so those.

Shada: Do you have edit access to your part but not others?

Tom: Well I haven't tried to be honest, I suspect I do have edit access but I suspect also somebody could switch it off if they wanted so I suspect that the system could stop me editing any information.

Shada: So that means they could have control.

Tom: I suspect because of my role they've probably given me edit access to everywhere I suspect because I keep asking for it.

Alex: But what we are trying to see is when you share the information you are giving a copy of yours as we are understanding now, into their partition. Do you still ask them to maintain the sort of controls you had here, or are you just assuming?

Tom: I would say my guess is that we assume they do, and I suspect that people are very aware that this is a very real issue for people who care about it.

Shada: But do you think, have you ever thought about it.

Tom: Well I do because people tell me it's a problem. I don't worry about it.

Shada: Well do you think, because you are assuming that when the information goes there it is going to be protected as good as it is in your local system?

Tom: I think if we're talking about CaNISC its the use by other healthcare organisations is only slowly evolving so my gut feeling is that there would be no risk to other healthcare organisations even opening up my side of the record, because these will be low level cancer servers and works working in their own sort of silo in their own section. If you ask me am I worried, yes I wouldn't want them to come in and edit my records obviously without my knowledge.

Shada: That is their section that is in your system do you mean?

Tom: It's only one system so technically.

Alex: Also with CaNISC we've got the problem we're actually thinking about, it's more if somebody is not on CaNISC let's say you've got someone across the border and they are on a different system to CaNISC and they share the information with you and you share information back to them would you want to be reassured that they are protecting what you give them at a reasonable level, similar level to you?

Tom: Yes we would and an example of that is in national audits and we will send information from Wales on an all Wales basis from CaNISC gut loads of data and there would

be information governance and data sharing agreements by which they could not edit or alter that information as a secondary user. I don't know if that helps?

Alex: So it would be defined as a secondary user and you would be relying on their equivalent of protection.

Tom: Yes I think there would be safeguards in as it's a file that's been taken out of the live system I don't think, you know even if they did alter the files, it wouldn't have any implications.....

Alex: But if the patient was going back and forward between the things because of the state of the treatment there might be issues as to what's happening.

Tom: You're talking about inside and outside the country I don't think there's any, there's no system that does share across borders as far as I know in terms of clinical systems.

Shada: What is the border exactly, how do you where do you see the limits to that border?

Tom: Wales.

Shada: Wales all Wales oh yes.

Tom: Well we are talking about lots of IT systems here but certainly around CaNISC it is a Welsh system and doesn't go into England at all in any way.

Shada: So as long as there is just...

Alex: So you don't get any referred patients? I know sometimes the border you're treating people ....

Tom: We are, when they came and be treated here and they were being managed here we would register them on CaNISC but when they went out to into England, you know on the border in Hereford and Chester and all these places they wouldn't use CaNISC at all.

Shada: They would take the information of the patients and just go on.

Tom: You would write a letter you know.

Shada: You don't enforce any kind of protection of that information because you think that you just don't own it any more may be, because they're going to take it, they're going to keep it there?

Tom: Yes but I'm not really sure what, there's no danger to that that I can see. Taking it as an external file either on a piece of paper or in an e-mail or scanned or some form of..

Alex: Or stick or something.

Tom: But it is in an isolated system it's not inherently back in the system so the danger is they would alter it for themselves but it wouldn't alter.

Shada: So the danger is if they have remote access to the local system?

Tom: Yes.

Shada: So if they do, let's say they do, I mean how theoretically would you like to control the access and how do you protect it?

Tom: For me it would be the same as two organisations in Wales if they have been trained in using CaNISC you just trust that they would do it responsibly, you would be able to audit it and you wouldn't want anybody altering information that I've altered without rules and governance around that.

Alex: How long have you got.

Tom: I've got to chair a meeting we are nearly there.

Shada: Yes you've covered lots of the things. That's really helpful you know.

Alex: Have you got the urgent things from this.

Shada: Yes, some of them you've just you know bounced around.

Alex: But you have actually revealed some of the things we suspected which people were denying was going on, that it's

Tom: The other things is because I work in a lot of these areas, there were other people who may have either more knowledge or different views to me about CaNISC, so for me it would be Janet Warloe, I mean e-mail me and I will copy her back in. She is Cancer Information Framework Manager for Wales uses CaNISC across healthcare organisations and data quality and data governance would be a massive thing for her. She probably would have a slightly different view to me, she doesn't have to technically manage patients and would be much more important and accuracy quality and governance than clinical care.

Shada: Just one last question, why do you think a Caldicott guardian should be a Medical Director and Information Officer for example? Is it not too conflict with the needs of sharing because they don't understand it thus not being medical doctors?

Tom: Do they have to be medical doctors?

Shada: I mean it says on this [laughter].

Tom: Does it for me? A Caldicott guardian for me has to be medical.

Shada: A nurse or a medical director but they didn't mention so I just wondered about that.

Tom: Yes, I don't know, I'm glad they are though.

Alex: You're glad they are?

Tom: Yes. Because for my background everything I sort of said at the start I think the intrinsic things is around accessing clinical information for the needs of the patients responsibly. This is not a technical review saying this is information that we hold and we will allow you to have it, you know, permission. So there is already too many barriers that the potential for us not to have the right information at the right time I would imagine would be huge.

Alex: It is actually what I expected you to say. What I feel myself, I feel that the IT people shouldn't dominate illness.

Tom: I think there's still not enough is made of patients, I think you need to know patient's views and what they think. Are they frightened of their clinical information going to the wrong person or are they more frightened if they knew about it that the clinician looking after them doesn't have the information they need to make the right decision.

Alex: That's a key question here, it is the one.

Tom: And I think you could go back to the European Court and Human Rights around that, around patient's access to the best healthcare available and if somebody else is putting an artificial barrier up to that healthcare by not allowing access to information then that's a really worry. We get, or at least we get too much of, is the rules and regulations around information sharing which put blocks and that don't for us, appear rational in terms of accessing clinical information.

Alex: Yes there's a tendency sometimes for the computer system to dominate instead of the patient's needs.

Tom: Absolutely.

Alex: That to me, working with unclear 49.43 this was always our you know, it's always been how we are trying to look at the system and just to summarise I think you said that at the start, Martin Murphy and Darren Lloyd, I think we would like to approach them and ask them to see their prospective on that. Should we do it through you or should we just get in touch with them.

Tom: Well they're pretty high people so you probably won't get to them. Martin Murphy we can never get hold of him. Darren Lloyd you may he's a very nice bloke and knows all around this.

Alex: Dave Murray suggested somebody who's come in or who has contacted us...

Shada: Stuart Davis.

Tom: Stuart Davis.

Alex: Is it worth contacting him?

Tom: You are more likely to get hold of him.

Shada: But is he, I mean does he look at...

Tom: He's a sort of manager of national systems. He doesn't focus on the governance side.

Alex: But he is wanting to make contact with us to carry on the sort of link we had with Dave, that's clear.

Tom: I am not sure, he is certainly not a Dave character.

Alex: No no I understand.

Tom: We are just appointing a new Information Lead which is really replacing Dave Murray we are interviewing in a couple of week's time so may be that...

Alex: I mean I certainly think we'll want to come back to you. And just from my personal it was Dr Khan you suggested wasn't it.

Tom: Dr?

Alex: Pharmaceusters.

Tom: Kumar. Satish Kumar. Yes.

Alex: Is it alright if I just give him a call?

Tom: Yes absolutely.

Shada: Thank you so much for the meeting.

Appendix B

Interview with Normal Breast Cancer MDT Coordinator (Ms. Mital Patel)

B.1 Interviewee's Role

The first interview was conducted with Miss. Mital Patel (in the rest of this appendix, she will be referred to hereafter as Mital). She plays the role of an MDT coordinator in Llandough Hospital and UHW. There are two breast cancer MDT reviews: Normal Breast Cancer MDT, and Metastatic Breast Cancer MDT. The former has an average of 35-40 patients per session, reaching 50 patients in some weeks. This MDT is represented in the "Happy Pathway" selected as the main treatment scenario in this research. The latter MDT review, on the other hand, has fewer patients with normally under 30 patients in total per review, and is not included in the research scenario.

Mital is the coordinator for the Normal Breast Cancer MDT review but she also covers for other cancer MDTs in those hospitals. Her job includes gathering all information from the clinical appointments for the patients so that they can be discussed in the MDT review. This information normally includes results from triple assessment involving: referrals, consultants' patient case notes including history and examination, pathology results, and radiology results. Once all the information is available for the review, the patient case is discussed with the aim of devising a treatment plan indicating the next step in the treatment which the coordinator records in CaNISC.

B.2 Interview Aim and Structure

The interview with Mital was held in Llandough hospital for a total of 35 minutes immediately following a regular two-hour MDT review. The interview aimed to evaluate the usefulness of the SHarE prototype system from one of the users of the current breast cancer care support systems. In the first 13 minutes the research was presented along

Table B.1: Interview questions with breast cancer MDT coordinator.

Category	Questions List
Interviewee role in healthcare organisation	What are the role(s) you play in the healthcare organisation(s)? Give more details about each role.
Information needs	What types of information do you need/use/manage as part of your job?
	Is it of a sensitive nature? [Give a number between 1-10]
	How are you normally asked to look after this information?
Information sharing needs	Do you share this information with others/ receive it from others? How?
	On what basis is the sharing is done? (Need-to-know? Role?)
	How are you normally asked to look after this information?
Research problem	Do you agree on the research problem? Any additional problems you face to do your job?
	What do you think about the missing functionalities? Any additional functionality you suggest is missing?
SHarE and Controls	What do you think about the proposed system?
	Do you think it has the potential to address the identified issue?
	Additional comments? Recommendations?

with a demonstration of SHarE. In this presentation the research problem was introduced through a breast cancer treatment scenario in which the interviewee plays a role, then its research aim, and its main requirements were represented. Following this SHarE was demonstrated live and through a number of screenshots. In the remaining 22 minutes, the reactions of the system were evaluated through a set of open questions, shown in Table B.1 below.

B.3 Questions List

The questions are classified into five main categories as shown below in Table B.1

B.4 Interview Synthesis

The duration of the interview with Mital was only 35 minutes in total and, therefore, the presentation was very brief and questions were direct, to the point and limited to the core of the research. Besides, this was the first interview, and thus it helped shape the following interviews in terms of the richness of questions. Interview synthesis is based on the categorisation criteria of the questions asked as follows:

General information needs. After understanding Mital's role, she was asked three main questions to gain a better understanding of the information she generates as part of her job. This was before elaborating with further questions about the information sharing needs in the collaboration context. Initially, and before the MDT review, Mital's job is to make sure the right information is available at the MDT review. Since consultants' patient case notes are mainly paper-based, Mital collects the filed patients' case notes from the ward. These notes include an average of 35-40 patients which makes them massive, and thus, she stacks them in a trolley to be physically available for consultants in piles for the MDT discussion. In addition, the pathologists and the radiologists use two different healthcare systems, therefore Mital liaises with them to ensure they know the patient list for the upcoming MDT review. This is to make sure they prepare the results and bring the right information along with them for the review to be discussed.

On the meeting day, the pathology results are available in printed paper format for the pathologist to brief on the results, while the radiology images are displayed on a screen in the MDT room for the radiologist to show the ultrasound or mammogram image with labeled areas of concern. The results are discussed with the consultant who decides the treatment plan. This discussion is carried out with consultants, nurses, pathologists, radiologists, oncologists, and the coordinator. It is necessary to reach a decision on a treatment plan indicating the next step in the treatment pathway. As the discussion is underway, Mital collects the pathology and radiology results, and the referral details. Since the average number of patients in every Normal Breast Cancer MDT review is fairly high, this makes it hard for Mital to record this information live into CaNISC (namely, the cancer information system used across Wales) during the review, therefore, she takes hand-written notes during the review then records this information along with the treatment plan after the MDT review into CaNISC. In addition, benign patients are not recorded into CaNISC as it is time-consuming with the large number of patients. Furthermore, since most patients in the Normal Breast Cancer MDT review are diagnosed with cancer for the first time, these patients did not exist in CaNISC before this point in time. Eventually, this information is recorded in Llandough Hospital in that hospital's partition in CaNISC in a new MDT module.

Information sharing needs. Further questions about information sharing needs in the collaboration context were asked in the interview. Questions related to any information Mital passes on to other CT members or information she receives from them. In response to this set of questions, Mital explains that if a surgery or chemo treatment option was chosen in an MDT review held in Llandough Hospital, Velindre Hospital will need to have access to patient information from Llandough Hospital's partition that Mital recorded. This is critical to inform the CT members working at Velindre Hospital about the

treatment plan and recent results, as some of the treatments are carried out by those CT members in Velindre Hospital. Although CaNISC is also used in Velindre Hospital to record and access cancer-related patient information, CT members in Velindre do not have access to information recorded into other hospitals' partition of CaNISC unless they were granted that access from that other hospital. Therefore, in order for Mital to share MDT treatment plans and results with CT members caring for the patient in Velindre, their referral needs to be added to the patient's case note. Once this is done, Velindre healthcare professionals will have access to that partition and will be able to see Mital's notes from the MDT as well as her referral back to them for treatment purposes.

Furthermore, when Mital was asked about the sensitivity level of the information she processes as part of her job, she said "it is very sensitive information because you are playing with people's lives." However, when speaking of information security, she expressed extreme concern about information accuracy in particular, which she finds difficult to preserve in the context of collaborative cancer care. Mital further expanded in the interview by referring to an incident, saying that in the last MDT review, the pathologist did not have some patients' results while the breast care nurse did. In such a case, normally the consultant who examined the patient attends the MDT review and he/she makes the decision as to to whether the results from the nurse should be considered, or the patient's case should be rescheduled for the following week's review awaiting the pathologist's results. However, the consultant's absence made it worse. Therefore, Mital had to make that decision but she did not know what the right action to take was in this very confusing situation that she claims had never happened before now. She was not sure to decide whether "the results were ready or not ready, but technically they were not ready and then someone came out with the results" as she said. In the end, Mital put the said patient onto the following week's MDT list regardless. Although this decision causes delays to the patient's treatment due to reconfirming the diagnosis, it has far fewer risks on the patient than recording the wrong diagnosis. Additionally, Mital said she made this firm decision because she said: "I am not just going to leave them [those patients]. You cannot leave them hanging nowhere, that is the problem." Although such cases are very rare, they still happen and it is critically important to deal with them in a professional manner. When I asked Mital about any reasons causing such an incident in her opinion, she said: "the main reason why this happened is because the pathology department was basically in both Llandough and in UHW. They have now all moved to UHW, so they are having a lot of problems over there." This indicates that the usage of different information systems at geographically distributed hospitals that are not integrated in a collaborative care is disadvantageous in terms of the accuracy of information. Therefore, there is a demand for a mechanism to address this inaccuracy issue which CT members cannot afford to experi-

ence. Additionally, there is the need for a system that enables the coordinator to prepare all the information herself through the system so that only patients with ready results are scheduled for the week. This would enable the system to pull all the information in an automated manner. The interviewer has been to a number of MDTs and witnessed 15 patients without ready results in one of those reviews. As such, they were all rescheduled for the following week. SHarE is capable of handling such situations because it is web-based, which increases the availability of information between hospitals regardless of their location.

Research problem. The interviewer moved on to concentrate on the research problem by asking Mital whether she agrees with the fact that patient information is sometimes not available at the point of care because current systems may block the flow of this information with the patient. She agrees that this is an issue to some extent. She agrees that it can be problematic to make treatment plans and results available in CaNISC in a timely manner following a Normal Breast Cancer MDT review. This results in the system not being updated, especially if those patients discussed in the MDT have appointments with the consultants on same day. In such cases, Mital would not have enough time to make this information available for the consultant to discuss the treatment plan with the patient. Mital explains this saying: "the breast cancer MDT works a bit differently to the other MDTs; it would be a bit harder if you diagnosed a patient today and then went straight onto our database because the patient won't be there." Mital justifies the reason why this is happening in her MDT by saying: "because there is such a big quantity of patients, you just do not have the time to do that. Also, to reduce workload, benign patients are not recorded. The thing is if you notice today a quarter of them are benign and are not going to be on the system anyway so you would be basically reversing what we are trying to get rid of in the first place so there would just be no point. They leave a lot of it to me to put the patients onto MDT." This supports the fact that breast cancer is one of the most common cancers in women today. On the other hand, "other MDTs type in the MDT live so their information is available within half an hour," Mital explained, then added, "their patient would already be on the database regardless of whether they are malignant or benign. Like with sarcoma cancer patients, they will put them on regardless and then say they came to clinic they would have the information in front of them."

Nevertheless, Mital believes that information should be available among CT members once they are granted access to other hospitals' partitions on CaNISC. She explains that if any CT members claim that the information in not available, this is most probably because either they do not have the time to find it and would like someone to perform this task for them, or because they are not experienced in finding their way into the system to find what

they are looking for. She explains this by saying: "the problem with information access is that you will have two tabs in the current system at the top and consultants do not understand where the other page has gone. For example, after I update CaNISC system at my endpoint in Llandough Hospital, CT members in Velindre still say that we do not understand what happened to this patient. The patient is on the system, why are you not looking?" Mital believes "it is not so much that the information is not there, I think people are not willing to look for that information." However, "although there are different places where you look for information, people want the information to be handed to them whereas you have not got the time for that. Our system is generated for all hospitals, every hospital uses it like the Gwent, the Royal Glamorgan. So the information does flow; it is just not available because people think it is not available, I think! Or they assume it is not there. So I think the information is there if people used it but people are not willing to use that information." So I asked Mital if it is not mainly to do with the system but with people's behaviour in terms of accessing the information. She responded that: "people know that they have got the system and they have got the information available but I think a lot of people do not have time to look for that information." Mital went on to say that "if they find an easier way to find information they might even use it."

SHarE and its functionalities In the interview, SHarE was demonstrated and a number of questions were asked to get to know what Mital thought about the proposed system and if it has the potential to address the identified issue. Mital responded by saying that an automated referral will help solve the information availability issue we talked about. However, she also said that "the only thing is you have also got to realise it is the accuracy as well because you are passing this information on to five/six different people. So the first person that inputs this information should be accurate. You cannot afford to have any mistakes." When we mentioned the amendments functionality maintains the accuracy, she agreed it will help. Furthermore, Mital thought the breaking-glass functionality would be useful, and reflected on it by justifying, "you need to know all the information. You also need to know if the patient has any problems previously which you can only really say in whether it is sensitive or not sensitive." (Mital suggests that the sensitivity icons label patients with problems to make it easier to spot.) When I asked whether to let the breaking-glass at each care point access everything in one go or just relevant information for that point, she responded by saying that: "you do not want to overwhelm them with information, so only the basics. But if you will need to justify at each point you break a glass, then the system users will not want to use the system." She added: "justification may actually put off the users." Mital said that "I can see that they are not going to want to use it, are they; because they are going to have to justify everything". Therefore, I suggested that justification happens at the end of the session of breaking-glass incidents

to make it easier, and she thought it would be easier.

Adoption of SHarE When I asked Mital about the potential for SHarE to be adopted, she responded by saying: “it looks for me quite easy to use but you have got to understand that the consultants are all in their fifties. So even your system is making things easier, I think possibly the same because these consultants some of them are quite happy to use anything on the computer and then you have got others that have been trained and do not touch it. So your system seems fine but your system might not be the problem.” She continued, “if you came to our office and you said this is the new system; say you were selling it to us; I think half of my office would literally turn around and say I would use it, because we are all quite fast at just using different systems so I do not think anyone would have a problem. But you are trying to get this information for everyone to use it on the computer so that no one has to go on paper or no one can see a patient without the information.” She continued by saying: “some of the older consultants might find it problematic not because they are older, it is just they are so used to their system that change is not something they want." Moreover, “the amount of times I have trained them, they have not appreciated it once but I have done it because I have decided I am not doing it the other way. I do not want to do it the other way." Mital then goes on to say, “I think if they had a firm, if their Director of Management turned up and said you have to use the system, they would not have a choice really. And eventually they will have to.

Security in collaboration Mital made the following comment about security in collaboration by saying: “as long as you have got user name and password and it is not given out to anyone else; so long as you have all got your own and it is not given out to anyone else, I do not think there should be any issue. Obviously there is the confidentiality issue and you cannot let other people who are not, first of all, not from the Trust, second of all, who have not got the user name or password, to be using a system like that." She added: “I have people asking me if they can get information off CANISC and I said no because if they have not got a user name or log in, I am not giving them access." However, “we have all got our own user name and log ins, so once you are in, you can access anyone’s. Obviously, we work in the Trust; if one of us did not work in the Trust, you would not be able to do it regardless. So we are trusted to do our jobs regardless but obviously different people use the system for different things." On the one hand, within the same trust, “Velindre has follow up tabs which we do not use. I have got the ABS module on the system that I use." This indicates that the current system has everything inside it and everyone logs in to do their job, but all functionalities are available for all. On the other hand, across trusts, “if I am their UHW log in, I cannot change anything on Velindre’s login. You have not got

access to change other hospitals' so you only look at it and that is it". However, when Mital tried to update the Velindre system, she explained that, "Velindre's is one the worst I think for updating it because they do it all differently; the CANISC screen will tell you that you have got to do it this way so the other hospitals all do it that way and Velindre just does whatever she likes." This, however, indicates a common interface for everyone is an easier way of operating. She also explains: "the only other thing is obviously you would give GP surgeries access to your system, right. GP surgeries are pretty rubbish because they have access to clinical portal now so if you have your blood test done at the hospital, they now have access to those results. But some GP surgeries still refuse to use clinical portal. They just say they do not have access but they do have access and they just do not do it. I think it is change they are not willing to do further work."

Changes to SHarE Mital recommended adding some details to the information recorded. She said: "I did not notice in your MDT bit a plan because the MDT's main point is to plan what treatment the patient needs. Because that is what you want, if you have got the plan from the MDT and then here they are having primary chemo, then once Annabel accesses it, she will know that that patient is now for primary chemotherapy and is not going for surgery first. So you need your plan to be in there somewhere under the MDT bit because it is the decision made by the MDT."

B.5 Full Interview Transcript with Normal Breast Cancer MDT Coordinator

Shada: This is recording. So what I am trying to do is actually to develop something that can help increase or help with the information sharing. So I am going to talk about a treatment scenario, talk about my research problem mainly and the aim. We identified as part of our research a couple of requirements that we think is important to address the problem. And there is a system that is based on that, and I will ask you a couple of questions.

So a treatment scenario, this scenario was taken from Annabel's notes so she gave me this that says: "a GP going to triple assessment radiotherapist, pathologist and a surgeon, and then there is an MDT and then if they decide operation which is most of the cases then the operation happens and then another MDT post-operation and then if no further surgery then it is going to be chemotherapy by an oncologist. So this is the scenario I picked. So going to the GP, the GP is suspicious he sends

the patient to a specialist who is a surgeon. They collect information, they share information and then they start the triple-assessment. Then there is the radiologist who does the ultrasound, the pathologist for biopsy and then the results are discussed in an MDT. After the MDT if it is going to be surgery then there is the surgery which I think in a different system. So a different system collects information about the patient and there is a post-operation MDT review and then oncology is different. So different colours here indicates a different information system is used to collect the information for the different stages. Palliative care if there is management of end of life care in case the patient relapses years later."

The problem is that we believe these are legacy systems or we were told that these systems are isolated. They are discreet, they are legacy, and they do not help the flow of information with a patient. So if the patient goes from one hospital to another sometimes the information does not flow. This makes the information not available at the point of care. Now we think that because a disease centric these were developed at a disease centric stage you know like era before when information sharing was not a priority. And there was no internet it is pretty old so now there is a patient-centric care which means these legacy systems should really come together and they should share information electronically. This means integrated care, health care professionals working as care teams. They share decisions and there is a need for cross-organisational information sharing. Like you taking the trolley a lot of information from this hospital, from there it has to be paper-based, now it has to be cross-organisational information sharing electronically. So this is what I focus on.

We believe the main problem why the information does not help with the flow is to do mainly with information security. So if you take one of these systems you will find in order to protect the information you need to consider three things: confidentiality of information, integrity, and availability. They have same level of importance but in order to attain that balance between these three you need to create a security policy that consists a set of rules. Now in order to implement that in a system you need information security controls which is technical things that enforces policy and thus the balance so that information can be available confidential and still at the same time consistent and accurate. Finally these security controls and policy will ensure harmony between the different systems that are discrete and they are different, isolated.

When you see the different systems you see that each of them has different control and the control represented by a lock. Now the aim is to help these legacies, it is just ideas in our PhD so it is just a proof-of-concept that if we support legacy systems with additional functionalities then we will fully support cross-organisational information

sharing that can help the adoption of patient centre care. That is what we are trying to do.

Mital: Okay.

Shada: Help legacy systems to share information securely and have that balance. Now we identified a couple of requirements needed for this collaboration thing. So we know each organisation works by its own, we do not have a problem with that and we encourage in our proposal to keep what is going on today but have additional things on top of it to help with cross-organisational information sharing. So I will mention the requirements that we identified and then this is exactly what my system does.

Mital: Okay.

Shada: It does not interfere what the system does it is just something that bridges the sharing; it is just something on top of it that will work with the legacy systems. So you can log into this and you can still log onto the main system. The first requirement is to organise information differently from what is happening today. You need it in chronological order so the patient had been seen in this care point, and then this is the first point. Then if he is referred to another hospital then this is the second point. So it is history. Then you time-stamp each point of care with the date, time, the role of the person who saw the patient and the location so it was in this hospital, that hospital, it helps track the information. So this is number one.

Number two to automate referrals so no one needs to chase the information, the information goes to the right place, to the right person with the right information. So when the patient moves this is already available as information needed for the point of care. So automated referrals to named care team member or his/ her role that can be picked from the other end with all needed information okay. So as the patient goes to treatment this part of the breast cancer treatment guidelines published by Map of Medicine, so the patient goes down all information is available.

The third requirement is to filter and gather information from the system's database so I do not link to the interface I go directly to the database and collect the information that I need in my interface which is a different interface from the systems to help collect the right information. If anything does not make any sense to you please let me know.

Mital: Okay.

Shada: And finally and this is major to my research if extra information is needed so we are automating referrals.

Mital: Yes.

Shada: We are making information available at the other end but if there is extra information that is needed we give trusted care team members an ability to access any information they need. Because they are trusted people and we know that if they need to access information it will be for the benefit of patient care. So we give them the ability to "break the glass" as a concept, access extra information in the role they normally do not see or maybe at this case they do not see or we did not think that they needed it but they think they need it then they need to access it. They need to justify it and the system logs it so everybody knows who accessed what at what point. Finally if the information was already recorded then there is the ability for them to change that information afterwards.

Like today when they said okay is it the left breast or the right breast. It was the right one but in their notes it said left so amending that after the sharing is important. This is one of the things that we want to do. So yes information access is based on patient needs not the organisation needs. Okay?

Mital: Yes.

Shada: This is everything, this is my system it follows this and these are the people in my system. You log onto an internet based one so you log into this and then you type in, for example, Hessah is a GP in my system and when she logs in she sees all the patients waiting for her.

Mital: Okay.

Shada: If she needs a new patient then she needs to create a new case. To make it easier I have screenshots of the system. This is Hessah logging into the system, this is what she sees. She creates a new patient; she searches for the patient because it needed to be registered to the system. And here you can see the hierarchy, the chronological order of information who accessed what and what is going on, the treatment itself. So search for the patient if it is found then she enters medical information. She needs to enter how sensitive it is. This is just a concept it is not real but we want to introduce that idea and we think how useful it is going to be for you to use it as an MDT Coordinator. So as a GP she enters the information whatever she needs and she decides how sensitive it is. Sensitivity of that information will help us predict it better. Okay because the person entering that information is the person who knows best how sensitive it is. So we just selected three different types.

Mital: all right.

Shada: So medical history examination. After the GP it refers to a surgeon which says here after the GP it goes for the triple-assessment starting with a surgeon on my

system Carl is a surgeon. The surgeon logs in on a different page and she sees here that this patient is waiting for her so she clicks on that and it is outstanding. And now if she clicks on it she starts seeing the patient and filling the information for that patient at the point of care. So that is the start of triple-assessment. It starts here and she fills more information whatever is needed for her. Whenever you click on one of these it will tell you the time it was completed, the time the patient was seen for all the hierarchy so every single point. Now it goes to the pathologist so my pathologist logs in see the patient is there. So you know that the information will be there for you whenever she clicks on it she will see whatever information she needs, we believe she needs from the guidelines and then she enters more information. After the biopsy there is the radiologist it is referred to Amal, Amal logs in and so forth. Okay but I will go to the MDT quickly so you can see the point where you are involved. After the radiologist there is the mammogram taken, recorded, Claire is my MDT Coordinator who collects the information.

Mital: Okay.

Shada: So she will see that Susan is there. I tried it out yesterday so it says the time and date and that is outstanding. Now it is referred to Claire and this is the information we believe she needs from the all the people up there. So primary care history and examination, secondary care history and examination for example we can add here any information but this is what we believe she needs. And there is the biopsy, the imaging all the information so she just clicks a button and the information comes out something like this.

Mital: Okay.

Shada: And this is what has been collected from the stages before. When she is done it is automatically referred and the decision was positive, no abnormalities and then is it malignant or benign and then sends a letter to the GP for example to inform him. So it just a kind of concept that this is the MDT people, information collected from them and everyone who logs in can see that what happened to that patient where is that patient going and what time. This is Carl so if it is a different person then it would have their name there so you know who actually has seen the patient. Okay so that is my system it is a pretty long one but because we do not have time I am just going to stop here. I just wanted to ask you a couple of question about what you think about such a system that can help with the information availability. So I will start here are the questions. First of all what is your role in the Health Care Organisation and what hospitals do you work in?

Mital: I work here Llandough Hospital and UHW. This is not the only MDT I do we cover

each other as well.

Shada: Okay.

Mital: And I also do other bits and bobs here and there. My main role is as an MDT Coordinator.

Shada: What does a coordinator normally do?

Mital: The coordinator is there based to get all the information from the clinic appointments for them to discuss in MDT. I liaise with the pathologist and the radiologist and make sure they know what patients are on MDT for today and so they can bring the right information along with them to be discussed.

Shada: Okay.

Mital: It is basically just for results really. Or if there is a patient that has had a scan that they think that might have meds in it, it is just to discuss and then to plan forward for the next treatment.

Shada: Okay excellent. What kind of information do you usually need/ use/ or manage for that job as you say maybe results?

Mital: Yes because basically if they get diagnosed in our MDT first time around then they go onto our system so you need the pathology results and the radiology results and the referral as well so you can put them onto our database.

Shada: Yes.

Mital: Once they have had their surgery obviously they go onto our database for waiting time purposes because obviously they have to be treated in a certain amount of time. Once they have had their surgery or maybe they go for primary chemotherapy then Velindre will need to access that database so that they know what the results were in the first place.

Shada: Absolutely and you share that with them?

Mital: Yes.

Shada: You help them access...

Mital: ... they have got access to the same system. So once they have added their referral to my case note they can see my referral as well.

Shada: Okay excellent. What about the paper based, the notes that you are carrying around?

Mital: They are mainly just for the consultants use so they know. When the patient comes to clinic, what we are trying to do in the future is to get them to use the computer because the notes are all going...

Shada: ... that is one step towards patient-centred care...

Mital: Exactly they are trying to get everything with mini-computers basically which I do not think half those consultants are going to be able to do. Because half of them do not even know how to use a computer [laughter] so it is quite difficult.

Shada: Was it not from the beginning introduced?

Mital: No and the problem is that you will have two tabs at the top and they do not understand where the other page has gone and there is a tab at the top what word do you not understand.

Shada: Okay just click the tab [laughter].

Mital: It is things like that because mainly they could do it now actually. They could use our database in clinic and go through each patient but because the breast cancer MDT works a bit differently to the other MDTs it would be a bit harder if you diagnosed a patient today and then went straight onto our database because the patient won't be there.

Shada: Yes okay.

Mital: Whereas other MDTs their patient would already be on the database regardless of whether they are malignant or benign.

Shada: Okay is this because of the large number of patients?

Mital: Yes because there is such a big quantity of patients you just do not have the time to do that.

Shada: You cannot do it because it is limited time?

Mital: Yes. With sarcoma cancer patients they will put them on regardless and then say they came to clinic they would have the information in front of them but obviously no one uses the information in front of them.

Shada: Okay.

Mital: But the paper notes are going.

Shada: What about the average number of patients you have normally every week?

Mital: I would say about thirty-five to forty for MDT.

Shada: Okay. What about the others?

Mital: Under thirty.

Shada: Okay. Excellent so how sensitive is the information you normally collect? You do not have to answer all my questions if you do not want to.

Mital: I would say it is very sensitive because you are playing with people's lives are you not really when you think about it?

Shada: Absolutely.

Mital: It is the accuracy that I think if you notice today the pathologist did not have some results but the breast care nurse did. Now I did not take any of that because I have not got written information that says what you just told me. This is what I told the secretaries upstairs because obviously the consultant was not in that the patient belonged to. So she...

Shada: ... it normally helps when he is there?

Mital: Yes because she is not going to know now that the results were ready or not ready but technically they were not ready but them someone came out with the results. So you do not know what is right and what is wrong.

Shada: So what happens in such situations do they discuss it again next week?

Mital: It has never happened until today.

Shada: Really. I was lucky I caught a case.

Mital: Basically I will just put them on next week regardless because I am not just going to leave them. You cannot leave them hanging that is the problem.

Shada: But why did the other system not have the results, is it timing, what went wrong?

Mital: The pathology department basically they had one in Llandough and one in UHW. They have now all moved to UHW.

Shada: So they are moving around.

Mital: So they are having a lot of problems over there.

Shada: Okay it makes sense. How long are you asked to look after that information? Is there anything particular that they ask you to do to look after that information or just common sense part of your role?

Mital: Common sense should not be part of my role but apparently it is because this is the other thing if you went to, I do not know if you went to anyone else's MDT last year? Did you go to anyone else's?

Shada: Yes, Dr. Tom Crosby's.

Mital: Because theirs is so much different than mine.

Shada: They all typed in I noticed.

Mital: Yes.

Shada: It was different and is this...

Mital: ...the majority of the patients in my MDT I just do not have the time to type, I do not think it would work. The thing is if you notice today a quarter of them are benign and

are not going to be on the system anyway so you would be basically reversing what we are trying to get rid of in the first place so there would just be no point.

Shada: Absolutely.

Mital: No they leave a lot of it to me to put the patients onto MDT but they are getting better at just emailing and saying can you do this or can you do that.

Shada: Okay you mean the consultants?

Mital: Yes the consultants.

Shada: We mentioned a couple of requirements and the problem mainly the flow of information, do you agree on that problem that it exists and it is a problem today or is it a minor, little tiny problem?

Mital: I do not know because we obviously update our system and Velindre will still say that we do not understand what happened to this patient. And it is on the system why are you not looking. I think it is not so much that the information is not there I think people are not willing to look for that information.

Shada: Are there different places where you look for information? Is there paper...?

Mital: Exactly and I think the people want this stuff handed to them whereas you have not got the time for that. Our system is generated for all hospitals, every hospital uses it like the Gwent, the Royal Glamorgan.

Shada: What is the system you are talking about, is it CaNISC...?

Mital: CaNISC yes. But people are not willing to use that information now if you use the information...

Shada: ...so the information does flow it is just not available because...

Mital: ...people think it is not available I think [laughter].

Shada: okay.

Mital: Or they assume it is not available.

Shada: Okay.

Mital: I think it is there if people used it but people are not willing to use it.

Shada: So the information most of the time is actually there?

Mital: Yes.

Shada: Okay but what the other MDTs in the electronic one?

Mital: Well they type in the MDT live so their information is available within half an hour.

Shada: What about patients coming from different, anywhere outside South Wales? Do you have problems with their information not being available and flowing?

Mital: You very rarely get ones out of South Wales unless they have moved here. We have had people move from Oxford and things but in that case they have sent proper information in the referral letters you have got all the information.

Shada: Okay so going back to the problem because it is important. Mainly it is not to do with the system it is mainly to do with people's behaviour accessing the information?

Mital: People know that they have got the system and they have got the information available but I think a lot of people do not have time to look for that information.

Shada: Okay so if the system helps them get the information easier. For example, if they do not like the tabs then we can find another way.

Mital: Yes.

Shada: Because the system should really adapt to the practice and not the practice adapting to the system?

Mital: Exactly and if they find an easier way to find information they might even use it.

Shada: Like a click of a button like I showed you there.

Mital: Yes.

Shada: This is this patient's information if you just click on it you will see everything that is relevant to it. Do you think that that is going to be more helpful to help with the information availability?

Mital: I think it will be. The only thing is you have also got to realise it is the accuracy as well because you are passing this information on to five/ six different people. So the first person that inputs this information should be accurate.

Shada: Should go to the hierarchy?

Mital: It has to be accurate. You cannot afford to have any mistakes.

Shada: No it is people like you said. That is why we are having the hierarchy thing. So you can see who actually went there and if it is wrong and he amended it you can see everyone affected with it, actually can see that information changing. I did not actually show it to you but it is just that if you change the information then the time stamp where you change it you will see that this person has changed that information. And there is an alert so everyone who was involved in the treatment can actually click on it and see what has been happening. But nothing is deleted so even the amendments they will still have all the information in there. This is the old one,

this is the new one. So everybody who made a decision based on the old one will still be able to change things. That is one of the things that we considered just to make a time stamp because you know different times people access the information and they do make different decisions. So you make sure that is the most recent information that you have.

Mital: Yes.

OK. Do you think there is anything we missed out from because of the tab thing and people cannot access information we had the break glass. So it is like a little button I will show it to you now. If for example we go down here you will see that every single person who accessed that information here for example this is the GP. Let us go to the MDT, this is the MDT person. This is Annabel the oncologist. So there is information that has to be entered that she cannot access. So there is a button here at the check history and examination, at this point Annabel wanted to access that information. She believes there is information that she needs and once she clicks on it then a justification, like a place where you can justify why you need to access that information to help overall and after the justification all the information is listed there that she needs from that point. And then there is the icon saying this is sensitive, this is less sensitive. Whatever the person who has recorded the information has described it. Do you think that is useful?

Mital: I think yes it would be because you need to know all the information. You also need to know if the patient has any problems previously which you can only really say in whether it is sensitive or not sensitive.

Shada: Yes that kind of thing. Some people suggested that we actually put this at each stage so this is one stage, the very first stage. We can put it at each stage and whenever you click on that you access everything from top. From the very beginning and then down. Or do you think that is going to be too much information for the person to see?

Mital: It depends on what you are looking for and it depends on who it is.

Shada: Okay.

Mital: I do not think...

Shada: ...you do not want it to be overwhelming.

Mital: Yes you do not want a lot. You want the basics in there.

Shada: So do you suggest that we put a button for each thing and that it only includes information about that point instead...?

Mital: Instead of everything in one go.

Shada: But you will still have to justify it every single point because you are accessing...

Mital: ...I can see that they are not going to want to use it are they because they are going to have to justify everything.

Shada: Exactly. Or maybe they can access whatever they want at the end of all the access they can justify once?

Mital: Maybe yes that would be easier.

Shada: Thank you so much. Do you think that we missed anything about the information security or anything?

Mital: I did not notice in your MDT bit a plan because the MDT's main point is to plan what treatment the patient needs. I do not know if I missed it.

Shada: Maybe I did not put it there. We can add any information.

Mital: Because that is what you want, if you have got the plan from the MDT and then here they are having primary chemo then once Annabel accesses it she will know that that patient is now for primary chemotherapy and is not going for surgery first. So you need your plan to be in there somewhere under the MDT bit because it is the decision made by the MDT.

Shada: So whether it is benign or malignant after that when you send a letter to inform the GP, for example, there is...

Mital: ...there should be a bit in there that says what your next step is.

Shada: Okay what normally does that information include?

Mital: If they have been diagnosed with cancer and the patient is agreeing with surgery then your first treatment would be surgery. Sometimes if they are heavily no positive you can go to plan your chemo.

Shada: Who decides that plan?

Mital: The consultant.

Shada: At the meeting?

Mital: Yes.

Shada: Okay. So it is an MDT plan before the letter. Do you see any potential for SHarE or such an idea?

Mital: It looks for me quite easy to use but you have got to understand that the consultants are all in their fifties [laughter].

Shada: Is it less complicated than the current system than you see, they have problems with tabs for example?

Mital: I think possibly the same because these consultants some of them are quite happy to use anything on the computer and then you have got others that have been trained and do not touch it.

Shada: Okay.

Mital: So it is not really, like your system seems fine but your system might not be the problem.

Shada: It is just that I am trying to make information more available and accessible.

Mital: If you came to our office and you said this is the new system say you were selling it to us I think half of my office would literally turn around and say I would use it.

Shada: Really.

Mital: Because we are all quite fast at just using different systems so I do not think anyone would have a problem. But you are trying to get this information for everyone to use it on the computer so that no one has to go on paper or no one can see a patient without the information.

Shada: This is eventually going to happen.

Mital: Yes they are all going to panic [laughter].

Shada: It is going to be part of the resistance of... like change resistance.

Mital: And hopefully I will not be working in the NHS then [laughter] and I will be a multi-millionaire.

Shada: What type of people or roles in the organisation that would find that hard to use that is very important to me? Is the consultants?

Mital: Some of the older consultants might find it problematic not because they are older it is just they are so used to their system that change is not...

Shada: ...going to happen overnight.

Mital: The amount of times I have trained them they have not appreciated it once but I have done it because I have decided I am not doing it the other way, I do not want to do it the other way. I think if they had a firm, if their Director of Management turned up and said you have to use the system they would not have a choice really.

Shada: Yes. Eventually they will get there.

Mital: They will have to.

Shada: Thank you so much. What about the security issues do you find anything that you could add to this, any comments about first of all...

Mital: ...so long as you have got user name and password and it is not given out to anyone else so long as you have all got your own and it is not given out to anyone else I do not think there should be any issue. Obviously there is the confidentiality issue and you cannot let other people who are not, first of all not from the Trust, second of all who have not got the user name or password to be using a system like that.

Shada: What about people who take over roles? If you are the MDT Coordinator today for another MDT that you are not used to because your colleague is not there. How do you log in, do you log in with your name or her name normally?

Mital: Mine.

Shada: So you are still given the authorisation to actually access any MDT?

Mital: Yes because we have all got our own user name and log ins so once you are in you can access anyone's it is not...

Shada: ...restricted?

Mital: Yes but obviously we work in the Trust if one of us did not work in the Trust you would not be able to do it regardless.

Shada: But does anyone else who is not an MDT Coordinator can log in and do your work, for example?

Mital: No I have people asking me if they can get information off CaNISC and I said no because if they have not got a user name or log in I am not giving them access.

Shada: Even if they have a user name, for example, I do not know I cannot really think of an example, if anyone in the Trust who is not an MDT Coordinator?

Mital: If they have got a login and user name because you fill out the security forms before you even get them anyway. If they have been given one...

Shada: ...no but maybe I did not phrase the question right. So once you are logged in you are authorised to use the system, does it matter what you do in the system? If you log in as a coordinator then you will only be allowed to do the coordination things and if you are a nurse you only do the nurse thing or you are trusted to do your job regardless?

Mital: Yes you are trusted to do your job regardless but obviously different people use the system for different things.

Shada: That is exactly what I am saying.

Mital: Like Velindre has follow up tabs which we do not use. I have got the ABS module on the system that I use.

Shada: What ABS do you use?

Mital: It is just for breast cancer whereas no other MDT would use it.

Shada: So different views will be different from users too.

Mital: Yes.

Shada: So that is what they think you need to do your job?

Mital: Yes. Also if I am there UHW log in I cannot change anything on Velindre's login.

Shada: Okay.

Mital: You have not got access to change other hospitals so you only look at it and that is it.

Shada: And do you think that is helpful in terms of you...

Mital: Velindre's is one the worst I think for updating it.

Shada: Why?

Mital: They do it all differently the CaNISC screen will tell you that you have got to do it this way so the other hospitals all do it that way and Velindre just does whatever she likes [laughter].

Shada: Okay. This is what I am talking about they are different systems they do work differently and they have different ways of doing things and you do not want to be frustrated by following their own rules so we have this common for everyone.

Mital: The only other thing is obviously you would give GP surgeries access to your system right. GP surgeries are pretty rubbish!

Shada: Why [laughter]?

Mital: Because they have access to clinical portal now so if you have your blood test done at the hospital they now have access to those results.

Shada: Good.

Mital: But some GP surgeries still refuse to use clinical portal.

Shada: Refuse to use why?

Mital: Because they just say they do not have access but they do have access and they just do not do it.

Shada: Is this part of the resistance that we were talking about?

Mital: I do not know because my GP surgery the number of times they have asked have you had your blood test this year. And I will say I did it at the hospital because I work there and they will say we do not have clinical portal and I say you do have clinical portal [laughter]. I could log in for you and show you but I am not allowed.

Shada: They are not trained maybe?

Mital: I do not know. I think it is change they are not willing to do further work.

Shada: That is very important in health care. You still want them to do their job. If you work in a company and you just decided you do not want to do a job because it is not the way that you like or are comfortable to do it then maybe you cannot do it. But in health care it is difficult because you need to keep caring for the patient regardless of whether you like it or not [laughter]. The patient life and death factor and their lives is the most important I think the priority here is different from anywhere else. So you need to keep them moving using whatever it takes to treat the patient. Thank you very much for your time.

Mital: That is okay.

Shada: I really appreciate it and I am so sorry for this asking you...

Mital: ...I have a job here to do.

Shada: I know you have a job here to do and I am taking probably more than I actually need but this is really helpful to get my degree. This is so much and it is really nice to meet you.

Mital: That is all right.

Shada: I will just stop this.

Appendix C

Interview with Clinical Nurse Specialist in Breast Care (Ms. Helen McGarrigle)

C.1 Interviewee's Role

Ms. Helen McGarrigle is a Breast Care Nurse and Key Worker in breast cancer care for patients in the University Hospital of Llandough, Cardiff and Vale Breast Centre. Helen's job is to look after patients throughout their breast cancer treatment journey and mainly interpret the results for them. She is normally immediately involved at the early stages of the patient's treatment pathway once they are referred from primary care to a surgeon in secondary care. This means her first involvement would be when the surgeon sees the referred patient and onwards at all stages of their treatment pathway, including: radiology imaging, pathology results before, during, and after their surgery, and the MDT review. Therefore, according to Helen, she is the closest to the patient and considered a key CT member with significant input at the beginning. Moreover, she works closely with the surgeons rather than for them and Helen explains the nature of her job by saying: "the surgeon says to the patient: 'you have got breast cancer. This is what we are going to do, and these are the choices you have to make,' and a lot of our job is interpreting what that actually means in the real world." In addition, the oncologist may delegate his/her role to Helen when the patient is scheduled for chemotherapy and the oncologist is on leave. For example, "sometimes they'll see an oncologist, sometimes they'll see a nurse instead of an oncologist," Helen stated. Eventually, Helen summarises her role in patient care in one sentence by saying: "we are patient advocates, the patient is our priority."

There is no wonder the information Helen collects and processes as part of her job includes, "everything, everything," as she claims. She explained by saying: "well, we want to know breast history, general medical history, surgical, have they had surgery before, family details, social history, that type of thing, what medications they are on. We would want to know about their specific situation, everything like the size, the presentation, the side, everything!" In order to access this massive amount of information, Helen uses dif-

ferent information systems where this information can be located. She also records other information about the patient at the different stages of treatment.

C.2 Interview Aim and Structure

The interview session with Helen lasted 84 minutes. As with the previous interview with the MDT Coordinator, this aimed to evaluate the usefulness of the SHarE system. Fortunately, the long session provided ample time for detailed questions to be put to the interviewee, which was hard to achieve in the previous session due to the limited time allowed. It took approximately 18 minutes to demonstrate the research problem through a breast cancer treatment scenario in which the interviewee plays a role, along with the research aim and the main requirements. This also included a demonstration of SHarE through a number of screenshots with an emphasis on how the seven functionalities are provided. The remaining time was spent asking open questions as listed below in Table C.1.

C.3 Questions List

The questions are categorised into a number of main categories as shown in Table C.1

C.4 Interview Synthesis

Interview synthesis is based on the categorisation criteria of the questions asked in the interview, as follows:

Information access needs. Helen's job requires a great deal of information recording and access on a daily basis. This information is recorded and collected at different points of care following the patient's treatment pathway, and has different formats; some are paper-based and others are in an electronic format. According to Helen, most of the information she gains is from MDT reviews where she takes hand-written notes from the discussions. Thereafter, information "comes piecemeal," and Helen goes on to explain that, " you do not get it all straight away." She continued, "so we often organise the system to get the rest." However, currently, this information is not stored in one system, but rather in different isolated systems, each serving the healthcare professional using it to store and manage his/her information silo. Therefore, Helen accesses mainly three other

Table C.1: Interview questions with clinical nurse specialist in breast care.

Category	Questions list
Interviewee role in healthcare organisation	What are the role(s) you play in the healthcare organisation(s)? Give more details about each role.
Information access needs	What types of information do you need/use/manage as part of your job?
	Is it of a sensitive nature? [Give a number between 1-10]
Information sharing needs	Do you share this information with others, or receive it from others? 1. CaNISC system users? Probably from another NHS Trusts? Any problems? 2. Non-CaNISC users? For example GP or Palliative care? Any problems?
	On what basis the sharing is done? (Need-to-know? Role?) In referrals for example, is the patient referred to a named CT member or a role?
Research problem	Do you sometimes find it hard to access/receive this information? Or receive it later? What do you do in such cases?
	Do you agree on the research problem? Any additional problems you face when you do your job?
SHarE	What do you think about the proposed system?
	Do you think it is useful?
	Do you think it will help in terms of information availability at the point of care?
	Do you think it has the potential to address the identified issue?
	Any additional information in the system that we missed?
	Do you think SHarE has the potential to change your behaviour?
	Additional comments? Recommendations?
Controls and Requirements	For each of the functionalities: 1. Does current system provide it? 2. Is it important? 3. How it can be improved? 4. Challenges? Comments?
Future	Finally, if the patient is to have access to their information electronically, do you see this system as being suitable?

information systems as part of her daily job to access the rest of the information she needs to care for the patient. These systems are:

- Patient Management System (PMS) which is more than a medical system for outpatients who are admitted to the hospital; medical details can be accessed and certain information can be checked,
- Clinical Portal to access test results and doctors' letters, and

– CaNISC for when the patient has gone to the oncologist.

Information sharing needs. In this category, the interviewer asked Helen a number of questions to gain a better understanding of the nature of information sharing happening in the context of cancer care from her point of view, and on what basis the sharing is occurring. Helen started by stating that she needs to share information with other healthcare professionals across systems. However, she confirmed that "now, most of these systems are not connected," and agreed that it would be a good idea to help these systems to talk with each other. Moreover, CT members playing other roles in breast cancer care use different information systems; for example, the surgeons use CaNISC and Clinical Portal, while the radiologists use Clinical Portal and RADS. The pathologist and radiologist use very little of CaNISC, and Helen commented by saying "we do not use CaNISC very much here at all, we use Clinical Portal." However, at some point later in the interview, she highlighted the fact that "in the future, I think we are moving towards CaNISC."

Moreover, Helen explained the means of sharing used in breast cancer collaboration by saying: "it is sometimes variable. Sometimes it is face-to-face discussions in the MDT, other times it is emails and getting things in and out of computer systems." She was also asked on what basis this sharing happens (for example, whether on a need-to-know, role basis, or both) and she confirmed that, currently, information access in the breast cancer context it is on a "need-to-know" basis. This is justified by the fact that cancer care is complex; there are those who treat the patient but sometimes others playing same role but not caring for the patient may need to access the information. Such cases occur when the one caring for the patient is busy or on leave. Therefore, these healthcare professionals will need to access information in such cases and should be able to gain access to it. Helen explains that by saying: "for the one oncologist that is looking after [the patient], would be the need to know. The other oncologist who is not looking after them, we do not know which one it is necessarily going to be, because it depends on who is on leave that time or how much busier we were at that clinic." This is the main reason why patients are not referred to a specific name, but just to a role in the hospital since it is not clear who will play that role of caring for the patient.

Research problem. After understanding how CT members exchange information with Helen, the main focus in this category is on the issues or difficulties that Helen faces in terms of accessing the information she needs, and, most importantly, to see whether she agrees on the problem this research is addressing. Initially, Helen did not question the fact that the systems are isolated, and this sometimes blocks information flow with a patient. She also added that the information is sometimes hard to locate not only between different systems sharing the information, but sometimes even within the same system. However,

according to Helen, the former is more common: "both perhaps, but mostly not sharing the system. I think not having access to all the different systems." In such cases, Helen normally has to communicate with the person by e-mail to gain access to information in another system, a process which is immensely time consuming. Helen elaborated through an example by saying: "if there's somebody who's been seen at Velindre by the oncologist, at the moment we should be able to access in CaNISC, because they do go right in CaNISC like real time. So they are very good at that, but because I, as yet, am not kind of up to speed with that [CaNISC usage], I would probably email the oncologist and say, what happened with this one? How did this go? Or it's that type of thing."

Nonetheless, Helen has some difficulties using existing systems to find relevant information she needs for patient care in a timely manner. Starting with CaNISC, there are a number of factors hindering Helen's usage of this system as highlighted from the interview. First and foremost, Helen describes CaNISC as a slow user-hostile system that requires intensive training to be properly used to locate relevant information. CaNISC makes it very difficult to find information: "it's hard work," Helen complained, "CaNISC is not easy!" she added. She described how: "CaNISC is very slow, even when you know what you are doing, it is quite slow, and when you do not know what you are doing, it is really slow. At the moment, I do not have time for really slow, and the rest of my team, because they have got a little bit more time, perhaps they have been practising and using it more often." Helen has had training on using the system twice so far but still finds it hard to find her way around the system to locate information she needs in a timely-manner. She clarified by saying: "I've actually been trained in CaNISC about a year ago, and I haven't used it yet. I've been retrained about a month ago, but I will use it now. Because if you don't practice it, you won't; use it or lose it." Helen added, "one of our consultants uses CaNISC a lot and he's very good, and he's very computer literate, but watching him go through to get the information he wants on CaNISC when we're sitting in the clinic here, it's just like, and that's somebody who really knows what they're doing with it. He's very used to it." Despite these factors, Helen finds no way out of this situation without practicing and using CaNISC more often, because she stated that, before CaNISC, everything was paper-based and admitted: "I think we're moving towards CaNISC," and thus, "we are beginning to use CaNISC a bit now." Helen concluded by demanding a system that should be an easy one to use, and she justified that by saying: "it has to be for us, because we are not very kind of IT literate as a rule. We can do things, but the easier it is for us, the better. CaNISC is not easy!"

Additionally, there is evidence that Helen and fellow nurses working outside Velindre suffer from an organisational division that hinders their usage of CaNISC. CaNISC was fully developed in-house for cancer care, and Velindre NHS Hospital is the home of its devel-

opment. Although it is intended for Wales-wide usage, Helen and fellow nurses working outside Velindre suffer from access inequity with fellow nurses working within Velindre NHS, lack of communication with the development team, and even a clear neglect in the development process. Initially, Helen claims not to have the same access rights as other fellow breast cancer nurses working in Velindre NHS Hospital which she personally finds unfair. She explained by saying: "certainly, all the nurses in Velindre work directly onto CaNISC, whereas we do not." When I asked Helen about the reason behind that, her response was: "I think it is just because we have never been involved in CaNISC really. They have been quite precious about who gets access to it; at the moment we have access to it, but we cannot put anything on it. We are not actually able to change anything." Consequently, Helen is prevented from using CaNISC to record her information. Therefore, it is not surprising that Helen claims: "CaNISC has not got our information on it." This is mainly because Helen and her fellow breast cancer nurses working outside Velindre NHS Hospital seem to lack communication with the development team, and complain about the fact that they are being neglected and excluded from using CaNISC as much as they would like since they work outside Velindre Hospital. This was evident from the interview as Helen did not know that treatment plans decided in the MDT reviews and other MDT information are recorded into CaNISC by the MDT Coordinator. Therefore, she takes hand-written notes herself to record that information from the discussions at the meeting.

In regards to Clinical Portal, although it does not have the same issues CaNISC has, it has more of an organisation-based access control system making Helen's access more of an issue. The Clinical Portal is not an entirely new system as Helen claims to have been "using it for between five and ten [years]. It could be a lot longer." She commented by saying that Clinical Portal "is not a bad system" and she added, "Portal is OK. Portal is quite quick," in contrast with CaNISC. Nonetheless, "the biggest problem [with] Clinical Portal is getting into it in the first place." According to Helen, this is mainly "because if you don't have the hospital number, it doesn't like letting you in just with a name. It will sometimes, and you have to find out the right address."

SHarE. In this category, the interviewer wanted to know Helen's opinion about SHarE in general by asking a set of questions regarding its usefulness, and potential to address the problem. Helen said, "I think anything that makes sharing information between the relevant people easier, has got to be a great idea." Helen commended the system's usefulness, and continued, "I suppose there is the opportunity for the allied professionals like physio and people like that, to input to that, because really it is like case notes, isn't it? And you just want them, all the information in one place or accessible so that you can get all that information." Moreover, Helen believed that SHarE is an easier system to

understand, easier to use and more useful than current systems, especially in regards to locating patients' information, by clearly stating: "it looks quite user friendly."

Furthermore, Helen believes that SHarE will assist with the information available and has the potential to address the problem, as she commented by saying: "I thought it would save me time," and continued, "we want something very simple, because as you can see, we are very simple people. You know, we're nurses and we're doctors, and we're not, none of us is stupid, but that's not our priority. This is supposed to be a tool for us. Need to be able to just help us do our job, not learn somebody else's job and we don't have much time to learn how to make it work." Helen strongly agrees on the fact that healthcare systems should really adapt to her practice, and that it should not be the other way around where Helen should learn how to use the system and adapt her practice to fit the system; she commented by saying: "Absolutely, absolutely. That's the whole point, is that we, and that's why, as nurses, it's taken us a while to get round." This is because the current systems are perceived to be user-hostile and staff were not involved in their development. Finally, there is the potential for nurses to use that system to access the information they require to care for the patient.

Controls and functional requirements. Generally speaking, Helen found SHarE a useful system. However, the interviewer had to ask further questions to elaborate on the controls and functionalities that SHarE has. This was to assess their usefulness and acceptance, to know whether current systems provide them, whether there is scope for improvements, and finally whether there are any potential challenges in their adoption.

- ***Information access is patient-centred based on the patient's condition and treatment stage and neither organisation nor disease-centred.*** Initially, Helen agreed that changing the type of information access to being beyond the disease or organisation towards being more patient-centred is very important. She added that current systems are trying to provide information this way, to be fair to a certain degree. For example, according to her, the way the information is organised in the clinical portal is based on the type of information: "There is a list of results, list of referral letters, and so on." She said that any one accessing a patients record can see all test results for that patient even if it is not cancer related. She said: "I can go in the Clinical Portal here, and have all the results now. It's not just the breast ones, by any means; it's everything that she's had done." Although this might not be good from a privacy perspective, Helen explained how useful she found this model because it helps show comorbidity easily by listing all tests, for example, which can be checked to pinpoint any other problems the patient has been having. She said: "You are trying to find something and you might think, well there's quite a few bone profiles here. Why are we looking at these bones? Why are we doing

this? Why are we worried about this woman's bones so much?" Helen added: "You know what to look for, but you also sometimes find out about some tests that you did not know they had done, which maybe the GP's organised, or they have been admitted for something else, which you could then link and think, well actually, I did not know about that, but that is actually quite relevant to what we are doing here, because somebody else has not made that jump of, or maybe the breast care bit has come afterwards, but because I have got past results as well, that you think, well, she's been complaining of bone pain. Has she got bone secondaries. So you go looking at things like that." However, this patient centred view is only limited to the tests done for that patient in the hospital being checked. Therefore, in order to see all tests and get a real holistic view, Helen would have to log into other hospitals and check any other test results for that patient separately. As such, it partially meets this requirement, and would need to be improved to extend the view across organisations such as SHarE would do. According to Helen, Clinical Portal makes it easier to find relevant information about the patient since once you access to it, you can see everybody's results. This is much easier than CaNISC.

– ***Information organisation in chronological order (in a timeline format) with a stamp showing date and time of care point, and who saw the patient.*** Current systems organise information differently. CaNISC, for example, organises information on the provider basis. Therefore, the patient's casenotes are divided into partitions in which each provider stores treatment-related information. This system was not designed to show this information based on the history of treatment points, therefore it is harder to locate most recent test results or treatments unless the user is well-trained and very familiar with the system. On the other hand, Clinical Portal organises the information based on its type. Once a healthcare professional is logged into the system, different lists appear on the right side of the screen: for example, results list and letters list. Helen commented on the how the Portal organises each type of information in chronological order. She explained by saying: "normally the latest information is at the top, and you work your way down, and I think the good thing about this is that normally they would be in chronological order. So, as it happens, it looks like almost everything that's been done recently, is just with us, but if she was also going to a diabetic clinic in between times, you see, that would come through. So it would be like breast, breast, diabetic, breast, breast, diabetic, renal. So you would get that in chronological order, chronological order with this generally." She gave an example by saying: "she'll have seen in 2013, she saw our surgeon, and then, now, that's oncology Annabel Barley, Peter Bartley and Annabel Barley (BPA) that's still our surgeon, but he sent letters to the GP and to the

oncologist. So that's accessible to both of them, but if she had seen an orthopaedic surgeon in the middle, then there would be a letter to the orthopaedics from Mr Stephenson's, I think, renal, urology." Although each category is listed chronically, it still does not show the most recent treatment points and so there are no test results that can be listed. Since Helen is familiar with the breast cancer treatment pathway, she can ascertain the most recent treatment points, but this is extremely difficult when it comes to other conditions, whereby Helen has to establish and make assumptions regarding what happened to a patient receiving treatment for another condition.

The interviewer asked Helen whether she believes that organising information in the system on a treatment point basis, in a timeline format, is an important one and her response was "I would have thought so, very important yes," for easy to read and accessible information. Helen added, "in current systems, you have to go and find the information," and this is mainly because the system does not show it in an obvious and user-friendly way. Although current systems do not provide this, Helen said: "because I'm used to using it, so I don't have a major problem with it, but it's not the easiest way of doing things." Furthermore, Helen found the chronological order of treatment points with the details of the CT member's name seeing the patient helpful. When asked why knowing the CT member who saw the patient with the date and time was useful, Helen explained that other CT members can look at it and say "alright, so she was seen last Tuesday, so I know she'll have this done, so we can sort that out or we can look for these results." Finally, a concluding question was asked regarding how this functionality can be improved, and Helen answered by saying: "just by having a list of who saw what, who saw, or who did what, when to the patient, or what happened to the patient at any particular time," and she asked for bigger writing: "just make it nice and easy to pick up things, and when somebody, when they've done breaking glass [for example] you want something that kind of be quite obvious, or when the new information comes out, so you want something you can pick at easily."

– ***Automated referral to a named CT member or a role that is picked up by the recipient with all information needed.***

The first question this functionality raised is when referrals happen and whether they are to a named person, or to a role, and Helen responded by saying:"Generally to a named person." She explained the reason behind this is because there is a fixed number of people: "I suppose it depends, because we're talking about going from perhaps surgery to oncology, then it is to the consultant oncologist, but there is only two of them, so they put somebody, stroke, then the other one. So put both their

names on them," and whoever is free would pick it up. Helen also said: "we usually know when she's on leave. That's because it's quite a small unit, so we will know what's happening with each other." However, Helen commented by saying: "it might be better not to have a specific name, but just to have a role." This is because the referral may go to a named person, such as Annabel, who plays an oncologist's role in cancer care for example, but the patient sees Helen instead because Annabel is on leave. She explained: "if we sent out a letter directly to the oncologist that is the first person that does contact, and then that's perhaps handed out, that might be delegated to one of the other doctors or to a nurse then." She further clarified: "So they are still under the auspices of the oncologist. So Annabel would still be in charge." This makes this functionality more effective in bigger communities where the CT includes a large number of members and it is hard to keep track of who is on leave and who has delegated their tasks to other members of the CT.

Subsequently, the interviewer asked Helen about current system automated referrals, and to explain in detail how referrals happen. She mentioned that referrals in current practice are not automated as current systems do not automatically refer the patient to the CT member in charge. As such, referrals from the GP are faxed and some of them complete a proforma with all the necessary information, including the last 10-15 visits to the GP, medical history and current medication; this is then sent "to our coordinator, who then books them into clinic, and then when they come to clinic, they are booked for the surgeon, and the surgeon just turns up," Helen explained. She went on to add: "what happens with a referral, you get the referral. You look at the breast information that you need. You would flick through and see if there is anything relevant in the rest of it, and then you just ignore that, because it is not relevant. When the surgeon does his annotation, he is dictated, and then he would say about this patient, and he will say, who I note has congestive cardiac failure or da, da, da, and then talk about the breast issue. So it is kind of noted that there is certain medical history that may be relevant." According to Helen, this information is recorded on paper rather than onto a computer. On the other hand, later referrals, for example, from an MDT to an oncologist, are dictated letters and she explained they are: "using a dictation system that is as accurate as typing although it is causing the secretaries a trouble when they dictate the letters and that is not the word they said at all. Because at the moment, that is what they do. The doctors see a patient. They dictate into a machine and say, I have just seen this lady, and then the secretaries pick up the machine, the tape, and they put it into a machine and they play it back, and they so type it in." However, she is not sure whether it is manually typed or automatically through a dictation system. All in all,

it is clear that the current systems are incapable of handling referrals; neither means used today for referrals is practical and both require improvement.

Subsequently, the most obvious question was whether it is better to automatically make the referral instead of using a fax machine or dictated letters. Helen responded that, as long as the information is there, it is not important, but she believed that if "it's through the system, that will be easier and a lot quicker." Furthermore, when Helen was asked about ways of improving this functionality in SHarE, she at first misunderstood the purpose of the system and said: "I suppose the only other thing you could do is having something that you could actually, so that, without logging into this system, that there is some flag that they should log into the system. I suppose it's like if you're not spending all your time on the computer, because that's the thing, you're sat at the desk, it's OK, but if you're actually out doing clinics and things like that, and doing, moving around and physically not in front of your computer all the time, then actually to know at some point that there's something that you have to do," but when I explained to her that the system is used at the point of care when the patient is to be seen at clinic, she said that there would be no need for this suggestion.

– ***Filter and gather needed information from the different systems at the point of care based on clinical guidelines.*** Initially, Helen believed that "any kind of clinician looking after that patient should have access to everything that is not ultrasensitive, but does not necessarily have to plough through it all to get what they need for that, there should be some kind of, I know that Dr. Tom Crosby was saying about the boxes. So you do kind of want some kind of boxing off of some kind of organ, something to do with the breast situation." Furthermore, she commented on this functionality by saying: "yeah, it's just knowing, it is getting the filter right, I suppose. I think it should be like a basic filter but with access to the whole lot if, certain effort." This suggests that she prefers having access to everything and having this organised for her to easily retrieve information. She explained the reason behind it by saying: "so you can get the information if you want it, and, because some people, there might be something that is actually quite obscure, some kind of quite obscure connection between one disease and another, that your filter's not going to come through with, or your average person is not going, the average consultant might not make the connection, but you've got somebody who says, well actually in very rare cases, such and such is." This highlights two possible conclusions: either this need reflects Helen's lack of trust that any system would provide her with the necessary information, or she simply does not know what she wants or needs until she accesses the entire information resource.

Moreover, Helen was asked about the best way of organizing the information for her, and the interviewer suggested organising information based on the treatment point, in other words, based on the CT member caring for the patient at that treatment point: GP's, surgeon's, and MDT's information, for example, rather than organising the information based on its type: tests, referrals, letters and notes. She responded: "I think so, but it depends on what you want to know," and continued: "because you kind of know what's likely to happen each time." This way, one would know what information to expect at each point based on the treatment pathway against that particular point. Finally, Helen emphasised how all breast care team members should have access to all information. She would prefer to have full access to all information even if it is overwhelming, rather than there being filtered information which may omit information she may be interested in. This can be improved with a more organised way of showing this information to her. However, the interview shed light on the fact that the only information normally recorded into the system in this context is mainly cancer-related information that is relevant to the whole team. For example, the GP's faxed referral letter is not recorded into the system; only the relevant information is dictated by the surgeon who sees the patient after the referral. This is perhaps why Helen did not recognise the idea of filtering the information in this context. SHarE may have a better use for the filtering when multiple ICPs are integrated into the same page for a more holistic patient-centred view at that point when the filtering will be a necessity.

– ***Information can be amended after sharing by originator and this will automatically alert everyone involved.*** Initially, Helen thought this functionality would be very useful by commenting: "yes, I think that would be very useful." Moreover, although she was not aware of whether current systems could amend information after it was shared, she said "I don't think there is anything like that, where you could like put a little kind of red flag up everybody can see," and she commented on the way SHarE deals with such situations by alerting everyone in such incidents. Finally, Helen agreed that the amendments should only be done by the original person to check whether this information is actually correct or wrong, and she explained this through an example by saying: "I think they should really go back to the original person, because the original person might say, oh no, I have checked my notes, and I'm absolutely sure. There might be something else on the left side [of the breast], but it was definitely the right side I was worried about, and if there is nothing, because it could be the right side that was worried, and then they find an incidental left side, and you can find that somewhere down there, where the surgeon normally will say, yeah. Left side was fine, but incidentally right finding on

mammogram of a small tumour, yeah."

– ***If extra information is needed at any point, trusted CT members could break-the-glass and access all information they need, then they have to justify it.***

It was clear from the interview that Helen struggled in some cases to access patient-relevant information using current systems, either because she cannot find her way around the system to locate the information she is interested in, or because there was a bad referral without the information flowing with the patient. Therefore, this functionality is designed to deal with such situations to help CT members caring for the patient to have speedy access to information and force the system to show that information instantly. However, Helen was not sure why there was the need for this access to information that is not there if it is not part of the treatment pathway. Therefore, she agreed it could be useful if the CT member was not provided with the information due to a badly executed referral, for example. She agreed that the breaking-glass feature may be useful in cases when there is something wrong with the system, such as not providing information, causing this automated information-sharing process to be broken. Consequently, the use of breaking glass feature would only be in very extreme cases.

The interviewer then asked Helen if she thought that the breaking-glass feature should be used only for super sensitive information; she did not actually comment on this although she said that anyone in the breast care team should be able to access all information automatically without the need to break or justify access into information. As such, this highlights the fact that, for CT members, information sensitivity is not an issue, as the rule is such that if they require information, then they should be able to access it regardless of how sensitive it is. On the other hand, information of an especially sensitive nature should be hidden from those who do not require to access it for their role. However, in terms of other reasons, such as the Portal especially, Helen thought the breaking-glass feature would be mostly useful with extremely sensitive information although she is not sure who would decide what is sensitive and what is not. This highlights the need to establish how to make a link between sensitive information and the breaking-glass feature.

However, Helen highlighted the fact that among the current systems, "Clinical Portal deals with very sensitive information by hiding it behind a glass." This glass feature is implemented by having a red exclamation mark in the results list that, when clicked, should reveal very sensitive results that are normally not related to cancer. Therefore, Helen never thought she would need to access that information. However, when asked whether she thought this feature was important to protect

sensitive information, she said: “I think if there is information that we are not supposed to see, and I don’t know who decides what becomes highly sensitive and what is not, but I know things that are.” She continued: “the only one I can think off the top of my head is HIV, and if that is deemed not everybody has access to it, then I have no worries, I do not need to know that.” She then added, “it has never been in my patient, you see. It has never been something I need to be concerned about.” This highlights a confidentiality issue in the Portal, as Helen said: “if you have access to Clinical Portal, you have access to anybody’s results,” she explains, and continues “so I could access the results on any patient in this hospital,” meaning that, “there are things that lots of people could access and find out,” as Helen stated. However, Helen also believes that “you have to trust your health professionals.” Despite the fact that the Clinical Portal can breach patient’s privacy, it also deals with very sensitive information in that pool by hiding it in a box and limits access to the absolute minimum, but this is only implemented in the results list and not for the whole system. Helen explained this by saying: “there is a little, the red exclamation mark, and you know you do not go into that, that is where it’s things like HIV testing. It is very, very sensitive testings, stuff that you are not allowed to know, unless you have got a good reason, and I would have no reason to know that information.” Helen said this mark is like the breaking-glass concept in terms of how to treat super sensitive information. Similarly, Helen never clicked on that icon to gain access to the information behind the glass, and when she was asked about the reason behind this, she said: “there is no information that I need! That tends to be in that extra, behind that glass, if you like, because the kind of information that I usually need, which is all the cancer information, but that is not seen as things like HIV results and so it should be hidden. That is the kind of thing that is hidden at the moment, because that is not something that I tend to have to into.” When the interviewer elaborated by asking whether Helen agreed that knowing what is already behind the glass about HIV or any other infectious disease is crucial so Helen can take extra precautions, she said: “you should treat everybody as if they have got HIV, just because they have not had a test, does not mean to say they have not got it. Or worse, they’ve got hepatitis something, C something, which is more infectious than HIV anyway. So our rules are, ’treat everybody as if they have got some.” Therefore, this information would not change the way they look after the patient, although only “whoever is looking after somebody at that particular time” can see this information, and as Helen stated, “it is where they have sent off for that result at the time.”

The interviewer then wanted to understand the best way to justify a breaking-glass

incident without interrupting the practice. Therefore, the interviewee was asked whether it is preferred to justify it before or after the information was accessed, and Helen offered an unexpected response when she said: "if you have got an oncologist who should have access to all the information, rather than them having to break glass because somebody has not given them a good referral. Could there not be certain people who are just given an automatic breaking glass, without having to justify it, because it is going to be time consuming to break the glass and even justify it? Well, there's certain people who should just be allowed access to all the information relevant to that patient. Well, they should not have to justify why they do it, just the fact of their role maybe should allow them to have access. They should not have to go in and say, well I want to know the mammogram, because I want to know, you know, I want to see the side of it or something like that." She continued: "because if I kind of thought, oh I want to see this woman's mammogram results, because she's coming to clinic tomorrow, and I'd like to be prepared, because I know I have got certain things to put, to find out, it is going to be bad news. The same with the pathologist. There are certain things I need to do, that I would not have to do, and if I am going to have to make a justification every time, it is going to be, I'm going to have a set sentence eventually, after, where I'm just going to be spewing out. So it is not actually practical. It's going to be meaningless." She added, "if the system already tells you who broke the glass, then why bother those people to justify it?" Helen believes the breaking glass action and its justification is actually a waste of time to some roles who should have access to everything as part of their role, just like the oncologists. However, when Helen was asked what the use of a breaking-glass feature would be if all care team members should have access to everything, her response was: "I think, apart from on these very, very sensitive things, I do not know if there is, because there is not many people within the team who should not have full access too."

Helen was then asked about how she would like this functionality to help her access information, whether by breaking the whole box and having access to everything that has been done for that patient treatment-wise up to that point where information has been broken into, or only to break into information for that particular point. Helen preferred the former by saying "only what she wants really, then she should only click on that," and then justified by saying: "because otherwise they just spend ages working, wading through all the stuff to see what they actually need." The drawn conclusion is that Helen thinks that the breaking-glass and its justification may be a good idea but not for those who would need to access all information related to the patient, such as the oncologist or anybody in the care team, as this

should be an automated task with no justification. Justifying access to those people may be meaningless and time-consuming. The interview shed light on two potential uses of this breaking-glass feature: firstly, to limit access to extremely sensitive information by putting this information behind the box. Hiding this information should not affect the treatment, but still only a handful of trusted CT members should have access to it if they need it. Secondly, the breaking-glass incident can happen in cases when the information is not available at the point of care, and a CT member caring for the patient at that point requires rapid access to all the information. These are two different scenarios, and Helen was asked which one has a potential need for the breaking glass. She said: "I think it is very important that in the second situation, that everybody who's in that care team should have access to everything, including information in CaNISC and the portal and every system and get everything for you to read". She found this more important than protecting sensitive information as she said it is political. Finally, in regards to any possible improvements, Helen suggested: "just make it nice and easy to pick up things, and when somebody, when they have done breaking glass [for example] you want something that kind of be quite obvious, or when the new information comes out, so you want something you can pick at easily."

– ***Labelling the sensitivity level of patient-identifiable information and communicating it to all healthcare professionals as a technique to raise their awareness.*** In regard to the sensitivity level of information stored in these systems, Helen responded by saying: "it's a difficult one, because to us, it is our day-in day-out stuff, but it is whether somebody has got cancer or not, so that is fairly sensitive I would have thought, to the patients it is highly sensitive." She added, "to us, to a certain extent, we are dealing with it on a daily basis, so it is still very sensitive, but it is routinely highly sensitive." Therefore, on a scale of 0-10, she would choose 8 to reflect how sensitive the information she processes would be.

Future considerations. Helen suggested improvements to SHarE by including the nurses in it as well. Helen explained by saying: "we would like to be able to do our own annotations, so that anybody can, like whereas I can see that this woman's been seen by the oncologist, I can see that the nurse in Velindre has done such and such with her, and some, this kind of interaction with her." She added: "and they can see in the hierarchy if the patient says, right, I haven't seen my breast care nurse, they can look and they can go into the system and say, you actually saw her on that day and that day and that day." Therefore, Helen was asked if what she actually needs is two different entries: one from the oncologist's point of view, and one from the nurse's point of view. She responded: "well, it depends who they see. Sometimes they will see an oncologist. Sometimes they

will see a specialist nurse instead of an oncologist. So whoever has that interaction with the patient, should have the ability to input into it to do an annotation, so that anybody in that care team can then go into it and then say, alright, so she was seen last Tuesday, so I know she will have this done, so we can sort that out." Moreover, the system should consider delegation. For example, when the oncologist goes on leave, he/she can delegate the treatment point to a nurse, so the person who should log into the system to retrieve the patient's outstanding referred case is the nurse and not the oncologist. This is mainly because it is such a small community and maybe this needs to be addressed in a more professional flexible manner to fit a cancer care community of any scale. The delegation means that each must have different views regarding their jobs and they cannot perform without delegation. Therefore, systems in the context of cancer care collaboration should provide the option of delegation, which SHarE does not currently have.

Another key discussion in the interview shed light on the fact that most of patients in our ageing population have a comorbidity, when the patient suffers from one condition that results in him/her following more than one treatment pathway. This means that CT members need to share as much information about the patient as possible to collectively paint a big picture showing the holistic condition of the patient to support shared-decision processes. Helen explained by saying: "well, they are older, so everything, heart, blood pressure, diabetes, everything, arthritis, thyroids, gynae, everything." This thought led to a further question about whether it is important for Helen to know about all the conditions from which the patient suffers in order to care for the patient, and she commented: "well, you do not necessarily have to, but it is useful to know that, because it is all about holistic care. So there is no point just dealing with the breast, if the woman cannot walk because her legs are so bad. So you need to know a bit of, but to be honest, you can sit and talk to the patient, she'll tell you that. You might not need to look at all of that." However, following further discussion on that matter, she agreed that some of the patients may not be able to remember "and there is a lot of people who do not understand. Like I say, even if they have very good English, they do not understand or do not remember or forget. So, you need to have that as well. You do not necessarily have to use it, but you need to have it, you need to have access to it." Furthermore, Helen gave an example supporting why it is important sometimes to know about other conditions, when she said: "we would normally do a CT scan on patients, but if they have got renal disease, so in fact, there is the contrast that they inject for CT scan, is probably, would not be broken down by the kidneys. So we cannot do it that way. So you have to have some awareness of what, if you are having surgery that renal disease is quite serious and in this case it is reasonably severe renal disease, but you look at somebody and you would not know he has got the disease from looking at him, so you could very unwittingly just arrange something which could

actually be quite detrimental to his health without having access." She added, "you have to look at it obviously, but it is useful, and sometimes it is actually by glancing through something, you think, well hang on! Why is she having that done, and that alerts you to having to actually, there might be more to this person than you realise, because they do not all the time, because a lot of chronic conditions as well, they are kind of so used to. There are certain things that they know they can do and cannot do, but anything's a bit more obscure, and so used to having this disease, that they do not consider it as something to be considered, that it's going to make any difference. It's just the way they are."

One of the challenges in adopting SHarE is how the information will be recorded with having two systems used at the same time: SHarE and the currently used legacy system. Therefore, this meant raising a number of questions with Helen which eventually helped both the interviewer and interviewee agree that the information should not be recorded twice into each system separately because this would be ineffective as well as extremely time-wasting. Therefore, one of the suggestions is to use SHarE at the treatment point and record information at that time for that purpose; this should automatically store that information in the current systems' database for synchronisation. This information can then be viewed on the current system once logged in to remain up-to-date with the treatment. Moreover, she suggested considering the usage of a dictation system with SHarE, as it is used today, to dictate referrals letters. Besides this, Helen mentioned requesting a change in the order of treatment points mapped into SHarE to reflect current practice: "the surgeon would send them [the patient] for an ultrasound and mammogram, and under ultrasound, they would have a biopsy." The prototype could pick up the treatment in the wrong sequence by having the patient's biopsy done before the scan, which is not the case. This comment suggests the need for more involvement of healthcare professionals to double check all the mapped treatments into SHarE to ensure it follows the guidelines. Although this is time-consuming, it would be beneficial in the long-run.

To conclude the evaluation session, the interviewer asked Helen if, say in the future, a patient is to be involved in accessing information through the system. Helen was asked whether she thought that this would help them see where they are going and who is accessing their information or whether she thought that the patient would not be involved and the system would not help them. She did not hesitate and responded promptly, as if she was expecting the question and had already thought about it: "you have got to be very, very careful about patients accessing the information because mostly it needs to be interpreted. Because this is what you find all the time, with people who go on the internet, or get information, and then try and work out what to do with it, because it is not. They do not understand where that fits into the big picture of what that means to them, then they for example Google things or they go on the internet and get various different things, and

they come back with very quiet misleading ideas. Oh yeah, it is more negative than positive yes, always." The interviewer commented on her statement, asking whether maybe it is useful to involve patients in the current system as well, perhaps by giving them a box, not accessing everything, at least to see where they are going in the treatment, such as the hierarchy. Helen said: "I'm not sure if that is something that I can see. You are talking about younger generation where they want to be heavily involved in this, and then they are going to not like being kept out, and they hack into it and get into it anyway, and I think then you have got to be very careful about people accessing other people's information, because that would have to be very, very strong, wouldn't it?!" Helen is well trained to interpret the data in a language that the patient will understand, and the patient trusts them. This is Helen's main fear regarding patients' access to their information, because they will lose the interpretation element. Intelligent patients will not likely accept it and would like explanation.

C.5 Full Interview Transcript with Clinical Nurse Specialist in Breast Care

Shada: Yeah, remember I was doing PhD to help information sharing in medical collaborative environments, I'll show you my system, and I'll give you a little bit of background of my research, so you understand where I'm coming from, because I never discussed this with you before. OK, so, I'll talk about SHarE, which is the system's name. I'll start with a scenario, and then the research problem and the aim, what we are trying to do. In the research we identified a couple of requirements that can address our problem, and then I'll show you a screen shot of SHarE and ask you a couple of questions.

Helen: Sure.

Shada: OK. Good. So I'll start with the treatment scenario. You remember this treatment scenario we discussed last time we met? So the patient goes to a GP, and if he's suspicious then he will refer the patient to a specialist, who's a surgeon in this case, and then the surgeon starts the triple assessment. So he collects information about examination and history check. There's the pathologist, who does the biopsy, and radiologist doing ultrasound or a mammogram. At any point, if you feel that there's something missing, or I'm saying something that is not correct, please correct me.

Helen: I would change three and four round.

Shada: three and four?

Helen: Otherwise.

Shada: OK.

Helen: Because it is the surgery, the surgeon, who would send them for an ultrasound and mammogram, and under ultrasound, they would have a biopsy.

Shada: OK.

Helen: So it would come in opposite.

Shada: Excellent.

Helen: Yeah.

Shada: OK. Are they the same system they use, or different systems?

Helen: In what?

Shada: When they record the information. Is it all CaNISC?

Helen: No, none of it. Very little of it is CaNISC here, yet!

Shada: OK, yeah, yeah.

Helen: Yet.

Shada: This will help with my research, thank you. So the result from the three assessments will go to our, will be discussed in an MDT and a treatment plan will be planned.

Helen: Yeah.

Shada: And then if we know it's operation, then the patient will go to a surgeon. The patient will be referred to a surgeon, and there is a post-operation MDT, and then maybe chemotherapy. This is the "happy pathway" on most of the cases, and in the patient relapses years later, he will go, or she will go to end of life care. My problem is that, that we see from discussions and interviews with people and from literature, that these systems are actually isolated.

Helen: Yeah.

Shada: So these systems are actually discrete. They're isolated legacy systems. They were built at the time when they were not in the habit of sharing information. So there is nothing wrong with them, it is just they are old, and we see that because they are isolated, sometimes this blocks information flow with a patient.

Helen: No question!!

Shada: Good, excellent. So you agree with the problem, and we believe the main reason that we investigated is because there are security rules, we are looking at things from a security point of view. So there are different rules.

Helen: Data protection, yeah.

Shada: And they are not in harmony, because each system has its own rules, and as a result, information is not available at the point of care sometimes.

Helen: Yeah.

Shada: So that is why it compromises on information availability, because different systems have different ways of protecting the information. So the aim is, we know that there is a shift from a disease-centred care, which we call them when the systems were not sharing things towards a patient-centred one, when they come together and share the information. This is the new trend, and we know that there is emphasis on integrated care, where care professionals come and work together as care teams. They make shared decisions, and this means across-organisational information sharing, OK. The different colours here indicate the different systems.

Helen: Systems, yeah, fine.

Shada: OK. So here is where we come from. What we want to do is to help evolve the, what the current systems actually do, with additional functionalities to help them support secure across-organisational information sharing. So we're not saying that we wipe the systems. We are saying that the systems need a couple of functionalities to help with the across-organisational sharing, and that is exactly what we're doing, and the requirements that we identified is actually the missing functionalities that we believe is missing, and the main reason I am here is to check that these are missing, and maybe there is anything else that you think is also needed.

Helen: OK.

Shada: So, the requirements. First of all, as the patient goes down a treatment pathway, this is just part of the guidelines.

Helen: I like that.

Shada: So there are different people, different systems involved, different information collected, and different tests done.

Helen: Yeah.

Shada: So, we believe, it is important that the information is organised differently, to reflect the treatment points in chronological order.

Helen: Yes.

Shada: So the information is actually stamped. So whenever a patient sees a doctor here, there is a stamp here saying, OK this doctor has seen this patient and this is the information collected, and then the next stage, when the patient is referred to the second one, then another stamp, another care point. Depending on history.

Helen: Yeah.

Shada: The second thing is that we automate referrals. So these are not done whenever the doctor sees the patient. He presses a button. It will refer to a different, it will refer the case to another healthcare professional. It is all decided in the guidelines, or when we said at the beginning, we can decide who the information goes to or referred to. So this is, because I know that you know where the information go, or who, what are the care points. So if they are automated, we think that this will help to make the referral to a named person or a role, and the other person at the other end collecting the information. So we refer the case and the information with the patient, so this will help make the information available at the point of care, the next point of care.

Helen: OK. Sorry, what is CT?

Shada: Care Team.

Helen: Care Team, yeah.

Shada: But when referrals happen, are they to a named person, or are they to a role?

Helen: Generally to a named person.

Shada: Why is that? Is it because they're normally fixed people in?

Helen: Yeah.

Shada: OK.

Helen: And because there is, I suppose it depends, because we're talking about going from perhaps surgery to oncology, then it is to the consultant oncologist, but there is only two of them, so they put.

Shada: OK.

Helen: Yeah.

Shada: So it is either this or that?

Helen: somebody, stroke, then the other one, you know.

Shada: OK.

Helen: Put both their names on them.

Shada: OK, and whoever is available will pick it up?

Helen: Yeah.

Shada: OK, excellent. So, yeah, there are for the patient with the information that we believe is needed, but sometimes mistakes happen in healthcare, and continuity of patient care is the most important thing. So we filter the information, based on what we think the next person will need. You know, if it's from surgery to oncology, then the oncologist, we believe that this information he needs, and we refer that, we filter that information to him. So he is not too overwhelmed with too much information, and it's still automated, but if mistakes happen and not all the information is available there, then we give the chance for this trusted healthcare professional to access relevant information.

Helen: Right.

Shada: So he does it, by breaking glasses, just a concept.

Helen: Fine, yeah.

Shada: So he can access whatever he needs. If you see the history, you can pick where the information you think is missing. For example, these results are not there, so and then he break the glass and see the information,

Shada: Fifth is we believe that this way we will make information access, is based on, is more patient-centred than organisation-centred. So that is for the patient benefit, regardless of the location of the treatment...

Helen: Yeah.

Shada: and finally, is that information can be amended. So if the oncologist receive the patient, and she believes that there is an error there, so she can contact that person. He can automatically amend that information, and anyone who is involved or based a decision on these notes can, is automatically alerted.

Helen: Right, OK.

Shada: So this is one of the things we believe is missing, but I'll show you the system now, and then you can tell me if you think there's anything extra that we can do.

Helen: OK.

Shada: So, this is the scenario mentioned.

Helen: Yeah.

Shada: The GP. So we have a couple of people. So we have like named people, and the GP is named Hessah, and this is the list of people.

Helen: OK.

Shada: And, so yes, the GP is Hessah. She logs in. It is an internet-based one like the portal.

Helen: Right.

Shada: So you log in with your name, and because Hessah's a GP, she creates a new case.

Helen: Right.

Shada: So she create a new case with a patient, and, so this is the very start of the whole treatment scenario.

Helen: Right, yeah.

Shada: So now Hessah starts by finding the patient in the system, in order to start writing notes and everything. So she writes her NHS number or something.

Helen: Yeah.

Shada: Find the patient. After it is found, then history check and examination starts.

Helen: Yes.

Shada: OK. She fills in. These are the guidelines. So we are trying to remind Hessah about the things she needs to collect.

Helen: OK.

Shada: Just to help with what is needed. Maybe that is not important, but this is in the guidelines.

Helen: Yeah.

Shada: And so she puts, she enters the medical history.

Helen: Yeah.

Shada: She decides how sensitive the information is. We believe this is important to, so the system can see how to protect that information whether it is very sensitive or less sensitive, or maybe she believes, Hessah believes that only care team should see that information or maybe it is not very sensitive. So it depends. She is, because she is the one who enters information, she knows the content, she knows how sensitive it is.

Helen: Yes.

Shada: and maybe it is very, very embarrassing, very confidential, then she selects "highly sensitive".

Helen: Yeah.

Shada: So when we come stages later, we deal as a system with more sensitive information differently from none since it is free text.

Helen: Yeah.

Shada: OK. So medical info, medical history and examination here and in both sensitivity, it is all cases, all people. Anyone who enters information should decide how sensitive it is. Now after the GP sees the patient who is Susan, OK, it goes to Carl, who is the surgeon.

Helen: Right.

Shada: OK. So the surgeon, so Hessah's done here. Carl should log into the system. When she walks in, she will see Susan's case there, and she just picks it up.

Helen: Yeah.

Shada: And it says the date and what's going on. It says here that Susan's case is outstanding, meaning she needs to pick it up. So it starts here that the surgeon starts to check history and examination, enters information and sensitivity level as well, and then if you just, just hover over any of the hierarchy list, then you will see the date and time entered, so more details about the treatment point.

Helen: Yeah.

Shada: So you know when the patient, Susan, is seen by the GP and everything, and then after she's done with the surgeon with the checking and everything, she is referred to, you told me the radiologist first.

Helen: Yes.

Shada: I have here the pathologist, so I am going to change it.

Helen: Yeah.

Shada: But it, so my pathologist is a different person. It is Kate. She logs in. She picks up, you know, Susan's case, and then she puts in information, and so on for all the cases. Radiologist, and then she picks it up, puts information, chemotherapy, depending on her age, because of her age, she's older than 35, then it is a mammogram, and you know, it is done, more information.

Shada: Now the MDT in our case, she's Claire. She logs in, picks up. At MDT, she clicks the button for the information she wants to receive from everyone, and then she receive that information, and then we know the decision of the MDT and the treatment plan is recorded, and then a letter is automatically sent to the GP (Hessah).

Helen: Yeah.

Shada: Just for the note and everything. Although if it is automated like this, no need for Hessah to receive a letter, because she cannot see what is going on, but anyways.

Helen: But they probably need a trigger, don't they?...

Shada: Yeah.

Helen: ...To make them look for it.

Shada: Yeah. So because there was a decision made, it is where it was not really normal.

Helen: Right, yeah.

Shada: There was cancer, then there is alert here.

Helen: a red cross icon, yeah.

Shada: Everybody sees that there is alert here, that it was actually malignant, and then refers back to Carl, the surgeon, for operation. After the operation, another MDT will start (a post-operation one) and then picks it up, collect the information, records chemotherapy in this case, in our scenario, it is chemotherapy after the MDT. Then oncologist would logs in, Annabel would pick up the person and then write a report with the treatment and everything. This is a simple scenario. It can be altered. It is just a concept.

Helen: Yeah, yeah.

Shada: So this is what we believe the system can do in order to facilitate the information sharing. You can still use it with current systems. So you can log into both, but this is just a different way to organise things between the different systems, and if you enter anything here it is still recorded in the other system, because it links all to the same database.

Helen: Right, OK.

Shada: OK.

Helen: Yes, because you would not want to put this information in SHarE, and in CaNISC.

Shada: Yes, yes, you want it everywhere. It is just this mainly, we believe, is going to be like on top of the legacy systems. So these work independently and this helps with the sharing bit, so this is on top of it, and works with it. So the first functionality, we mentioned that it is in chronological order. If you hover over these treatment points, you will see the date and time and everything, but this is showing how it is organised,

and it goes to Amal. So you can know that Amal is the person who picked up this case. So you know who has seen and the time.

Helen: Yeah, you've got names, that is useful, yes.

Shada: OK, and an automated referral, as you mentioned that whenever a person logs in, you can see the case waiting for him to pick up, with the right information. The breaking glass concept that we talked about, for example if Annabel, the oncologist, did not see some details from the GP, then she can break the glass. Hessah is the GP, she recorded information and it was referred to a surgeon. So at this stage, anyone down there can actually break the glass if Hessah did not provide the right information, or maybe it was not automated. So breaking the glass will help Annabel access that information, and so she has to justify why she wants to access that, because it is normally, it should be there, but if not, then she shall have to justify it, and then after that she access the information that Hessah recorded with a sensitivity level. So she knows that it is very sensitive. So if she can, you know, it rises the human awareness about how sensitive that information is. After the event, everybody knows that there was a breaking glass. This happened at this point of treatment, after Annabel has seen the patient. So it's just, it could happen anywhere at this point, but it's just happened at this time.

Helen: Yeah, just in this case, yeah.

Shada: So this is what I think, and being able to amend the information and alert everyone, I did not actually implement that fully, but it's just the same concept. Only owners of the information like the GP, she can access her records, and actually amend that information. So the oncologist cannot do it for the GP, because it has to be the person that recorded it, otherwise it is going to be a missy situation, I think. I do not know what you think about that, but it is just the person who recorded the information can actually amend it. After he clicks on that "dynamic control/ amendment" link, wherever the treatment is at that point, he/ she can access the information, and everybody is alerted, like the breaking glass, like this has been amended. It is not the left breast, it is the right breast. So everyone.

Helen: So if Annabel broke the glass and picked that out, because she realised there was a mistake perhaps, she would then have to contact the GP and say: "you said left and it is right," for a GP to change it.

Shada: Is it for changing the information?

Helen: Yeah.

Shada: Or is it for breaking the glass or changing?

Helen: To changing.

Shada: Changing here, we are talking about the GP accessing her information. Oh, yes, yes, I understand you know! yes, she has to contact Hessah because she needs to contact Hessah to get to know why the information is wrong. So if Annabel does it, maybe it's the right side, and everything will be, she needs to contact the person who recorded the information to confirm that it was wrong.

Helen: OK, yeah.

Shada: What do you think that is the case, or do you think she can, she should be able to change it?

Helen: Well, no, I think they should really go back to the original person, because the original person might say, oh no, I've checked my notes, and I'm absolutely sure. There might be something else on the left side, but it was definitely the right side I was worried about.

Shada: OK.

Helen: And if there is nothing, because it could be the right side that was worried, and then they find an incidental left side, and you can find that somewhere down there, where the surgeon normally will say, yeah. Left side was fine, but incidentally right finding on mammogram of a small tumour, yeah.

Shada: Good. So that is what we think about the, yeah. I just want to ask you a couple of questions.

Helen: OK.

Shada: In general. These are the questions. I'm sorry it's a long list, but it is going to really help me understand what you think about the system. You've been really, really helpful. Thank you. So I'll start with the first one. If you can tell me please about.

Helen: Right. What are the role, what role I play. Well I'm a breast care nurse, and key worker for the patient.

Shada: OK.

Helen: Which is the same job really.

Shada: Excellent, and you work at which hospital?

Helen: At University Hospital of Llandough, Cardiff and Vale Breast Centre.

Shada: OK, so different ones. OK, what type of information do you normally gather? You see the scenario. Which part of the scenario are you involved in?

Helen: I'm usually involved, once the GP sends the letter to the surgeon, the surgeon arranges for the mammogram, and at that point where they have a, the patient arranges for the mammogram and ultrasound. If the surgeon has a suspicion, then I usually get involved then. A biopsy is taken and sent off to the pathologist, but that then is another week probably, a few days certainly, before the results come back. So my first involvement would be when the surgeon sees them, and they do their imaging, the radiology.

Shada: Imaging, yeah. Early in the triple assessment?

Helen: Yes.

Shada: Yeah, OK.

Helen: And, so I would see them at that part, and then again when they come back for the pathology results, and then before surgery and probably during surgery, and then after surgery, and then when they come back for the results. The MDT again, we have quite a big input with them at the beginning.

Shada: Yeah. So you're the closest contact with the patient?

Helen: Yes.

Shada: And, so if I ask you about the type of information that you normally collect to do your job, what kind of information is it? Is it the result, or maybe the...

Helen: Everything, everything. Well we want to know breast history, general medical history, surgical, have they had surgery before, family details, social history, that type of thing, what medications they're on. We'd want to know about their specific situation, everything like the size, the presentation, the side, the size, the greyed east, yeah everything.

Shada: Everything, wow.

Helen: We need to know everything, yeah.

Shada: And do you normally log into the system and see that information, or do you take it from?

Helen: Mostly from the MDT.

Shada: From MDT.

Helen: But then it comes piecemeal, so you don't get it all straight away. So we often organise the system to get the rest.

Shada: Excellent, excellent! and if I would ask you to give me a number between one and 10 about the sensitivity of that information that you normally see, which number would you give me? If you don't want to answer any question, just say.

Helen: Yeah, no, it's a difficult one, because to us it's our day-in day-out stuff, but I mean, it's whether somebody's got cancer or not, so I mean, that's fairly sensitive I would have thought to.

Shada: To the patient?

Helen: To the patients it's highly sensitive. To us to a certain extent, we're dealing with it on a daily basis, so it's still very sensitive, but.

Shada: This is the kind of...

Helen: It's routine sensitive, yeah.

Shada: Yeah, routine sensitive.

Helen: Routinely highly sensitive. Does that make sense?

Shada: Yeah absolutely, but you still didn't give me a number.

Helen: OK.

Shada: So it varies.

Helen: Eight.

Shada: Eight, OK. Oh, OK. I wasn't expecting that.

Helen: No?

Shada: Thank you. OK. If you share information with others, like I know that there is CaNISC and there are different other systems that are linked to it, and there are systems not linked to CaNISC at all, like the GP and the palliative care. So do you share information with people outside CaNISC?

Helen: Yes.

Shada: Like who?

Helen: Because we do not use CaNISC very much here at all. We use Clinical Portal.

Shada: You use the Clinical Portal?

Helen: Yes.

Shada: Wow, OK.

Helen: Yes.

Shada: Who else uses the Clinical Portal from the scenario that I talked about?

Helen: The surgeons, although, see we're beginning to use CaNISC a bit now. The radiologists use Clinical Portal and RADS.

Shada: So how many systems do you use in your daily job?

Helen: Well I, we just go into it. There's PMS, which is kind of an outpatient, about patient management as in outpatients where they're admitted, that type of thing, but for the results and things.

Shada: Is it administrative more than.

Helen: Yeah.

Shada: OK.

Helen: More than medical, although you can get medical details on there as well, check certain information. The results and things that we tend to get and the like doctors letters, that type of thing we get from Clinical Portal.

Shada: Yeah, OK.

Helen: Clinical Portal.

Shada: Clinical Portal. So what do you use CaNISC for?

Helen: Well, just for when they've gone to the oncologist.

Shada: And the MDT is there recorded as well, right? No.

Helen: No.

Shada: Oh, I thought the MDTs are recorded at CaNISC.

Helen: Not generally at this point. Well I think, I think it's recorded. I'm not sure.

Shada: Sorry.

Helen: I'm not sure if our coordinator might do it. She might record it in CaNISC, actually.

Shada: OK, OK.

Helen: But we don't see that.

Shada: So the information that you collect at the MDT or for the MDT that is mainly the information, the big piece that you use...

Helen: Yeah, what I take away from is...

Shada: ...From the portal?

Helen: Well it's mostly from the MDT.

Shada: Yeah.

Helen: And the portal.

Shada: Oh, so you hand write it.

Helen: I hand write it, yeah.

Shada: And which system do you recorder it in? the portal?

Helen: On a piece of paper [laughter].

Shada: In the future. Yeah I know everything is going electronically in the future, but in the future do you think it's going to be...

Helen: Well I think we're moving towards CaNISC.

Shada: CaNISC, OK, OK, more of the unified way?

Helen: Yes.

Shada: And is the portal connected to CaNISC or no? No! OK. That's the kind of thing we're talking about, different systems, different hospitals. I know they're getting there, and my research is actually focusing on this problem, because it's an existing one. It should be an existing problem that I talk about, and it's just how we can help them talk to each other. That's the main thing.

Helen: That would be great.

Shada: Yeah, OK, excellent. On what basis the sharing is done normally between the systems, from your job's point of view? Is it on a "need-to-know" or "role" or both?

Helen: "Need-to-know" really, I guess. It's, because it is, well sometimes it's variable. Sometimes it's face-to-face discussions in the MDT. Sometimes it's emails and getting things in and out of machines, but it's out of the...

Shada: The computer.

Helen: ...The computer systems, but I think the people who need to know that, so for the oncologist, the one oncologist that's looking after, would be the need to know. The other oncologist, who is not looking after them, we don't know which one it's necessarily going to be, because it depends who's on leave that time or how much busier we were at that clinic wouldn't get that information, but could access that information, and I would say should be able to access that information.

Shada: Yeah, yeah. That's why I'm talking about, breaking glass. I mean, if they're normally not given access to it, then they should find a way to access it because they need to access it for patient care.

Helen: But I think it would be there for them. They just wouldn't access it, because they wouldn't need to.

Shada: OK, OK.

Helen: But it would be there available for them if they want it.

Shada: OK, excellent, OK. We answered that question. Do you sometimes find it hard to access or receive information?

Helen: Yes.

Shada: Yes. Can you give me an example please?

Helen: Well I think the results, histology results, but that's sometimes because, sometimes because they're not put on the system, so.

Shada: So they were done, but they were not recorded, and since they were not recorded, you can't access them?

Helen: Yeah.

Shada: OK.

Helen: Or they take a long time to be on the system.

Shada: Yeah, yeah, OK.

Helen: And.

Shada: So the referral happens, but the test results don't follow with the patient?

Helen: Because the basic, is it cancer or not, comes through, but when there's an oestrogen receptor positive, and that type of thing takes longer to do, and sometimes we will get a verbal report on that, but it take another week.

Shada: OK. Is it an error, yeah.

Helen: Before it to action, and it's a case of somebody, I don't know, somebody actually typing the report into the computer, somebody else verifying, or the first person, the actual pathologist verifying it, and then it gets put into clinical portal and that seems to take an awful long time sometimes.

Shada: Yeah, OK. So the problem is not mainly in the system not being linked, it's just in the people delivering...

Helen: Putting it into it in the first place, yeah.

Shada: ...Put into the system, OK, OK.

Helen: We don't have, I mean, with CaNISC I use very little, but I have now been signed up to CaNISC. That's in the last month, and I just haven't really got my head round it very much.

Shada: Yeah, you need time to get used to the system.

Helen: Yeah, because it's quite slow.

Shada: Yeah, OK.

Helen: Even when you know what you're doing, it's quite slow, and when you don't know what you're doing, it's really slow. At the moment, I don't have time for really slow.

Shada: Yes, yeah.

Helen: These last three or four weeks has...

Shada: I can totally understand that.

Helen: ...Three or four weeks have been extremely busy, so it's like I will get into this, because I know I have to.

Shada: Yeah, in order to get the information.

Helen: But, and the rest of my team have been, because they've got a little bit more time, perhaps they've been practising and using it more often.

Shada: OK, yeah.

Helen: But it hasn't got our information on it.

Shada: Why?

Helen: Because it's not put on.

Shada: OK.

Helen: And that's another thing, because all our paperwork and certainly all the nurses in Velindre, work directly onto CaNISC, whereas we don't.

Shada: Because of the large amount of patients, right?

Helen: My, oh no, they've got a large amount of patients as well. So I don't think that would be it. I think it's just because we have never been involved in CaNISC really. They've been quite precious about who gets access to it...

Shada: OK, OK.

Helen: ...And at the moment we have access to it, but we can't put anything on it.

Shada: OK, OK. How did it work before you had access to CaNISC? I mean, how did things work? Was it only paper-based?

Helen: Paperwork, yeah.

Shada: So now you're moving electronically, these are the problem facing the electronic system, but it's going to get it in time, it's just, but you still need to access the information. There is no question about that. OK, excellent. So. OK. Do you agree on the research problem, that information sometimes does not flow with them?

Helen: Yes, absolutely.

Shada: Is that when we talk about different systems, sharing the information, or are we talking about the different care points, even if it's the same system, it's just that.

Helen: Both perhaps, but mostly not sharing the system. I think having, not having access to all the different systems...

Shada: Yeah, so normally how do you have to communicate with the person to get access to information in other system?

Helen: Yeah.

Shada: OK, which is time consuming, I think.

Helen: Yes.

Shada: OK, can you give me a case, like an example of such cases?

Helen: Well I suppose, if there's somebody who's been seen at Velindre by the oncologist, at the moment, whereas now, we should or I should be able to access in CaNISC, because they do go right in CaNISC like real time. So they are very good at that, but because I as yet am not kind of up to speed with that, I would probably email the oncologist and say, what happened with this one? How did this go? or its that type of thing.

Shada: And before that it was still email, but now because they noticed a problematic thing, then they are actually giving you access to the system straight away, because you need that information. OK, excellent.

Helen: But as I say, we're not actually able to change anything.

Shada: Change anything, but it's still.

Helen: But it's a start.

Shada: Yeah. So in the future do you want still to change things and type things in? How do you want?

Helen: Well we would like to be able to, I think what we're going to have to do really is to be able to do our own annotations, so that anybody can, like whereas I can see that this woman's been seen by the oncologist, I can see that the nurse in Velindre has done such and such with her, and some, this kind of interaction with her.

Shada: Yeah. At the nurse level, that, yeah, OK. So you want to see what happened.

Helen: And then they can, because you each have your tab, and then they would also be able to, sorry not a tab, but in the.

Shada: Yeah, yeah, I know, the different.

Helen: Thingy, map, kind of, what you call a tree.

Shada: Like a hierarchy.

Helen: Yeah, then they can also, they can see, so if the patient says, right, I haven't seen my breast care nurse, they can look at and they can go into the system and say, you actually saw her on that day and that day and that day.

Shada: OK, OK.

Helen: And she said this.

Shada: If we want to improve this system that I just show you, how do you think it's going to help you with your job? I mean, I didn't include anything to do with the nurses in particular, but it's part of the oncologist and, so how do you think it can be improved?

Helen: Well by including the nurses in it as well.

Shada: OK. Is it like a different stage or without stage?

Helen: Without stage.

Shada: Without stage. So it's like two different entries, one from the oncologist's point of view, and one from the nurses point of view?

Helen: Well it depends who, if they see, but sometimes they'll see an oncologist. Sometimes they'll see a nurse instead of an oncologist.

Shada: So whoever.

Helen: A specialist nurse.

Shada: Ah OK.

Helen: So whoever has that interaction with the patient, should have the ability to input into it.

Shada: OK.

Helen: To do an annotation, so that anybody in that care team can then go into it and then say, alright, so she was seen last Tuesday, so I know she'll have this done, so we can sort that out...

Shada: So the referral.

Helen: ...Or we can look for these results or.

Shada: If we said the referral goes to a named person, like Annabel for example, but she sees a nurse instead, then do you think we should not really indicate who the patient should be seeing? I mean, you don't want it to go to Annabel, but Annabel's not, may be on leave, and a nurse sees the patient.

Helen: But I think that that's then, well one we usually know when she's on leave. That's in a, it's because it's quite a small unit, so we will know what's happening with each

other, but that would then be, generally if we sent out a letter directly to the oncologist, it's, that's the first person that does contact, and then that's perhaps handed out, that might be designated, not designated, delegated, sorry, to one of the other doctors or to a nurse then. So they're still under the auspices of the oncologist. So Annabel would still be in charge.

Shada: So the person delegates. Who delegates? Is it the person like.

Helen: Annabel.

Shada: Annabel herself, OK, that's excellent. So we should maybe consider that in here, that the person is not going to receive the patient. They think it's delegation like, OK.

Helen: I mean, it might not be. It might be better not to have a specific name, but just to have a role. I don't know.

Shada: A role, OK.

Helen: Or.

Shada: So, a role...

Helen: The ability for both, yeah.

Shada: OK, so, and it goes to the nurse or the... So if the nurse does the job, then the oncologist doesn't have to actually do anything about it, OK, OK. I'll try to find out a way for us for this to be done. So you do agree, OK. So in general, what do you think about this system?

Helen: Right.

Shada: I mean, do you think if it's there...

Helen: I think anything that makes sharing information between the relevant people easier, has got to be a great idea.

Shada: Good, good, and do you find that easy to understand, because it's...

Helen: Oh yeah, I can understand what you're getting at.

Shada: ...Is it easier to use and more useful than just using the current systems and trying to find your information?

Helen: Yeah.

Shada: OK, OK. So you think that there's a potential for nurses to use that system to access the information and see the patient, and everything?

Helen: Yeah.

Shada: OK, brilliant.

Helen: Definitely.

Shada: OK. So it's going to help with the information available problem?

Helen: Yes.

Shada: OK.

Helen: Yeah.

Shada: OK. Do you think it has the potential to address the problem?

Helen: Yes, I would have thought so.

Shada: OK. Any additional information this proposal has missed? like you mentioned the delegation thing, and you think there is any detailed information, because this is from the guidelines... I didn't meet anybody to discuss the information in detail about each care point. Is there anything major that I missed?

Helen: I don't think so.

Shada: So it represents reality?

Helen: Yeah.

Shada: In treatment.

Helen: I suppose there's the opportunity for the allied professionals like physio and people like that, to input to that, because really it's like case notes, isn't it?...

Shada: Yeah.

Helen: ...And you just want them, all the information in one place...

Shada: Yes absolutely, absolutely.

Helen: ...Or accessible, whatever...

Shada: Yeah absolutely.

Helen: ...So that you can get all that information.

Shada: Yeah.

Helen: Yeah.

Shada: Good. Do you think it's going to change your behaviour, in terms of doing the job, because you're trying to find the information? Do you think it's going to change in a positive or negative?

Helen: I thought it would save me time.

Shada: Good! and that's what I like to hear [laughter].

Helen: [laughter] And that's wonderful...

Shada: OK.

Helen: ...Absolutely wonderful.

Shada: Before we finish to this system, do you think, do you have any additional comments or recommendations?

Helen: No, it looks quite user friendly so far.

Shada: Yeah.

Helen: You know, and it has to be for us, because we're not very kind of IT literate as a rule. We can do things, but the easier it is for us, the better. CaNISC is not easy.

Shada: It's not easy. Let me ask you a question that I believe personally from my research, that the system should really adapt to your practice, and not you adapting to your system...

Helen: Yes.

Shada: ...Is that true? because you know I'm computer scientist, yeah.

Helen: Yes, if you can do that, yes.

Shada: So for me, I mean, I build the computers, for example, but I have to also put the needs and the practice of the people I'm building the system for in account, and trying to twist the system in a way that can meet their needs and still support their practice, and not the opposite. It's not that I have to train you a lot on the system, and I want you to do what the system can does. OK, so you agree with that?

Helen: Absolutely, absolutely.

Shada: OK, good.

Helen: That's the whole point, is that we, and that's why, as nurses, it's taken us a while to get round. I mean, I've actually been trained in CaNISC about a year ago, and I haven't used it yet. I've been retrained about a month ago, but I will use it now. Because...

Shada: If you don't practice...

Helen: If you don't practice it, you won't, use it or lose it.

Shada: Absolutely. It's like a language, like, yeah, if we see a friend for a year and then you stop using it, then you'll just not get into it.

Helen: Yeah, and if you, because it's hard work, because one of our consultants uses CaNISC a lot and he's very good, and he's very computer literate, but watching him go through to get the information he wants on CaNISC when we're sitting in the clinic here, it's just like, and that's somebody who really knows what they're doing with it. It's very used to it.

Shada: It's very difficult to find information in the current system, and very slow. What about the portal?

Helen: Portal's OK. Portal's quite quick.

Shada: How's it, how is it outlined? Is it like CaNISC or is it more like?

Helen: No. I mean, the biggest problem clinical portal's gotten into it in the first place, because if you don't have the unit number, it doesn't like letting you in just with a name. It will sometimes, and you have to find out the right address.

Shada: OK. When you say, you mean like the organisation, is it?

Helen: Hospital number.

Shada: Hospital number, OK.

Helen: Sorry, hospital number. I'm going to log into the Portal now but it will take a minute or two, but the, you go into clinical portal, and you sign in, and...

Shada: Do you want to click enter on the screen? That kind of thing we're talking about [laughter], because otherwise it's not going to move. I'm so sorry!

Helen: No, that's fine, that's good [laughter].

Shada: OK. It's just the usefulness of the system.

Helen: Yeah.

Shada: You can't imagine how much helpful this is.

Helen: Is it?

Shada: Really, very much! You don't understand how it's important to go and speak to the people who have a system that we're devolving for them, and you saying this is useful is just a great thing. So, yes.

Helen: But I mean, it's great for me, because we just get presented with something and kind of got on with it, and for somebody to ask us, well what do you like about this, or how does this work, or why. How would that be useful?

Shada: It's very simple.

Helen: We want something very simple, because as you can see, we are very simple people.

Shada: And you don't have time to learn, you don't have time.

Helen: You know, we're nurses and we're doctors, and we're not, none of us are stupid, but that's not our priority.

Shada: No, this is not what you're supposed to do.

Helen: This is supposed to be a tool for us.

Shada: Yes, it's like a, exactly.

Helen: Not what we have to.

Shada: Exactly. You don't have to learn how to make this chair work.

Helen: Yes.

Shada: It should be easy for you to make it.

Helen: Exactly.

Shada: Yeah, it's, I totally understand. That's why we need to meet you.

Helen: Need to be able to just help us do our job, not learn somebody else's job.

Shada: Exactly, exactly, and this is the problem with new systems and everything. It has to fit your practice, and what you do, but it's like the opposite. Now we've got other things too, it's OK.

Helen: OK.

Shada: So that's the questions about the system itself. We go back to the portal to see how different and easy to use the portal is. I have a sixth requirement, and they're in this very first page. If you can just open it and for each one, I just want to see if it's important. Does caring system provide it or any of the systems? How it can be improved in your opinion, and if there are any challenges or comments about it.

Helen: OK.

Shada: these six of them and I'll be done with the interview.

Helen: OK. Information organisation and... put it in terms of... on a patient.

Shada: So this is when we, when we said that this is the hierarchy and it's in chronological order. Do you think that this is important?

Helen: Well I would have thought so, very important, yeah.

Shada: Because I remember when I met Dr. Tom Crosby, that he said that the systems are actually organised in boxes for like partitions. So it doesn't show the time. It shows the organisation itself, and this is not the way that he wanted it to be.

Helen: Yeah, you have to go and find things from...

Shada: It's not at this point what happened and then where the patient goes. So that's very good. So these current systems do not provide that.

Helen: No.

Shada: OK.

Helen: I don't think so.

Shada: OK. How can it be improved, in your opinion in general? You've answered that already, but?

Helen: Yeah, just by having a list...

Shada: A list!

Helen: ...Of who saw what, who saw, or who did what, when...

Shada: OK, OK.

Helen: ...To the patient, or what happened to the patient at any particular time, and...

Shada: OK.

Helen: In time.

Shada: OK, but are you talking about current systems or this one?

Helen: Well the new one.

Shada: The new one?

Helen: You're saying, what, how could it be improved, you said?

Shada: Yes, yes. I mean, this system!

Helen: How could this be improved?

Shada: Yeah, because we already tried to do that.

Helen: Bigger write.

Shada: Yeah, bigger writing, yeah, OK. This is just a squeeze.

Helen: Yeah, I know, but, yeah, just make it nice and easy to pick up things, and when somebody, when they've done breaking glass, is there breaking glass on there?

Shada: Yes, it's...

Helen: Because it's...

Shada: ...Yeah, there.

Helen: Because you want something that kind of be quite obvious, or when the new information comes out, that's this bit here, is it, is that, when you have change because of the breaking glass...

Shada: Yeah.

Helen: So you've got, yeah, so you want something you can pick at easily.

Shada: Yes, because of the items icons we're using?

Helen: Yeah, that's OK.

Shada: I put the plus, because it will have two things. It will have the breaking glass at each point.

Helen: Right.

Shada: And the dynamic control, which is changing the information.

Helen: Right.

Shada: But the breaking glass, everybody can see but not the person logging in. So Annabel, when she logs into her system, everybody else can break into her information, because it's her information and she has access to it already.

Helen: Right.

Shada: But the dynamic control which is changing the information, can only be done by the person.

Helen: By the person who recorded it in the first place.

Shada: yeah.

Helen: Yeah.

Shada: So everybody can see it, yeah.

Helen: So this, this here tells your breaker history one, so that's why you look up here.

Shada: Yeah, you broke that information at this point.

Helen: Yes, so then you would press the...

Shada: And you see the time and date...

Helen: ...Plus button, and that would.

Shada: And even if you break it again, it will go on and on, but some people suggested, a researcher suggested that you put a breaking glass after each point, that's what we want to do. We want to break glass at each point when the information was actually collected, OK.

Helen: Right.

Shada: But one of them said, if you break the one down, you access everything up.

Helen: Yeah.

Shada: And someone else like me tell the MDT coordinator, she told me, it's better if he breaks only that information, because you don't want him to be overwhelmed with it.

Helen: Yeah.

Shada: So what do you think? Is it with the first option or second option?

Helen: So, well what would be the point of breaking glass every week? Is that just to.

Shada: It's because, for example, a person here for, this is Annabel for example. She wants to see the mammogram details or report or anything, then she can't break. If it wasn't given to her at the beginning, then she can actually break that glass and access that information, but do you want her to access only this information or everything above that information?

Helen: Only what she wants really.

Shada: So she knows.

Helen: If she knows that she wants that mammogram.

Shada: She will only click on that.

Helen: Then she should only click on that, because otherwise yeah, they just, you spend ages working, wading through all the stuff to see what you actually need.

Shada: OK, OK. Do you suggest, you suggest that the breaking glass only access the information at that point?

Helen: Yeah.

Shada: And what about the justification? Is there before accessing the information or after just accessing the information, because it's time consuming to justify it.

Helen: Yeah.

Shada: So do you suggest before or after, or it doesn't matter?

Helen: If you've got to do it sometime, you've got to do it, haven't you? So.

Shada: Yeah. I mean, because this is...

Helen: But would you...

Shada: ..This is the breaking glass.

Helen: ...Why would she not have it? That's the thing. Why would she not have that information anyway?

Shada: Because it wasn't in, when she, when she logged in and picked up the patient, this information wasn't in the information provided to her for any reason.

Helen: Right. Just because it was badly done.

Shada: Yeah, exactly.

Helen: Yeah.

Shada: Or maybe that person did not enter it at that point when he referred the patient, but he entered it later, for example. So...

Helen: I mean, wouldn't it be because you think, if you've got an oncologist who should have access to...

Shada: All the information...

Helen: ...All the information, you know, should have access to all the information, couldn't, rather than them having to break glass because somebody hasn't given them a good referral, couldn't there be certain people who are just given an automatic breaking glass, without having to justify it, because it is going to be time consuming?

Shada: The justification and everything?

Helen: Yeah.

Shada: So we should break the glass anyway.

Helen: So really if you get certain people, well there's certain people who should just be allowed access to all the information relevant to that patient.

Shada: So it's not, it's not at each one.

Helen: But he shouldn't have to make, they shouldn't, well they shouldn't have to justify why they do it, just the fact of their role maybe should allow them to have access. They shouldn't have to go in and say, well I want to know the mammogram, because I want to know, you know, I want to see the side of it or something like that. They should be saying...

Shada: Yeah, so you don't see a use for it in justification?

Helen: ...Well I'm just thinking, they should, there's certain people who...

Shada: And you know already who done it.

Helen: Yeah.

Shada: So it's already there. It says here that I didn't actually include it, but you can see who actually broke the glass.

Helen: Broke the glass. So why, why bother.

Shada: If it's a problem, they can actually talk to them, because there's someone monitoring the system, who can see that..

Helen: Because there's certain people that, because if I kind of thought, oh I want to see this woman's mammogram results, because she's coming to clinic tomorrow, and I'd like to be prepared, because I know I've got certain things to put, to find out, it's going to be bad news. The same with the pathologist. There's certain things I need to do, that I wouldn't have to do, and if I'm going to have to make a justification every time, it's going to be, I'm going to have a set sentence eventually, after, where I'm just going to be spewing out.

Shada: Or just put a number or anything.

Helen: Yeah, yeah. So it's not actually. It's going to be meaningless.

Shada: It's not practical. OK, yeah.

Helen: It's going to be time consuming and meaningless, because people will not...

Shada: Excellent, so no justification?

Helen: Yeah, I'm not sure if there are any, I think that certain people should be, you could if you wanted, limit who has access to that information, so that it wouldn't be, but one of the things with clinical portal, it can take a long time, is that if you have access to clinical portal, you have access to anybody's results.

Shada: Really?

Helen: Yeah.

Shada: And do you think there's a problem? You mean, all the patients, or all test results for the same patient?

Helen: All the patients.

Shada: All the patients.

Helen: So I could access the results on any patient in this hospital.

Shada: Is that a good thing or a bad thing?

Helen: Depends what they want to know. It's.

Shada: It's easier for anybody who.

Helen: It's easy.

Shada: Yeah.

Helen: But it's a case of, I suppose it's, you have to trust your, your health professionals.

Shada: You always have to trust them to do their job, but you said you don't want everything very open.

Helen: Yeah, although, but there's thing, and again it's when you're talking about the sensitivity, so maybe a, it was too high for that because there's things that lots of people could access and find out. We already have on clinical portal, there's a, on the results just, I think it's on the results, list of results that you get, where it says, there's a little, the red exclamation mark, and you know you don't go into that...

Shada: Oh, what is that?

Helen: And that's where its things like HIV testing, or...

Shada: So it's very, very sensitive...

Helen: It's very, very sensitive testings, stuff that you're not allowed to know, unless you've got a good reason, and I would have no reason to know that information.

Shada: Same like breaking glass.

Helen: Yeah.

Shada: I mean, sensitive things, because the reason I put the breaking glass, is for to deal with more sensitive information differently, and we know healthcare, we trust that they would want to access that information for a reason, but it's not available there. It's that if they don't find it, then they can access it, and then justify it, but maybe no justification is needed in this case, but they put more sensitive information behind the glass, and put this exclamation mark, and then what happens if you break it?

Helen: I don't know. I've never done it.

Shada: OK, but don't you think that sometimes you need that information?

Helen: Oh there will be. I mean, I.

Shada: I don't know.

Helen: There's no information that I need! that tends to be in that extra, behind that glass, if you like, because the kind of information that I usually need, which is all the cancer information, but that's not seen as...

Shada: OK.

Helen: ...It's things like HIV results.

Shada: Should be hidden.

Helen: Yeah. That's the kind of thing that are hidden at the moment, because that's not something that I tend to have to into.

Shada: Yeah, who would need that information you think?

Helen: I suppose whoever's looking after somebody at that particular time. It's where they've sent off for that result at the time.

Shada: OK. Anything to do with that?

Helen: Yeah, if it's relevant to that particular issue.

Shada: But doesn't it concern you if the patient has HIV when you deal with them?

Helen: You should treat everybody as if they've got HIV.

Shada: Really?

Helen: Yeah.

Shada: OK. You deal with them that way, so you protect yourself.

Helen: When you're talking about, yeah, because you don't know. Just because they haven't had a test, doesn't mean to say they haven't got it.

Shada: OK.

Helen: So, or worse they've got hepatitis something, C something, which is more infectious than HIV anyway. So our rules are.

Shada: You always.

Helen: Treat everybody as if they've got some.

Shada: But knowing that information won't change the way you speak to them or deal with them.

Helen: Oh no, not how you deal with them.

Shada: No, I mean, I mean, in terms of sensitivity, you know that they're sensitive from that part, so you avoid talking about such, certain things or anything. Does it have an effect now?

Helen: No.

Shada: OK. So you think the, the exclamation thing is important, to hide sensitive information?

Helen: I think if there's things that we're not supposed to, and I don't know who decides what, what becomes highly sensitive, and what's not, but I know things that's, the only one I can think off the top of my head is HIV, and if that's deemed not everybody has access to it, then I've no worries, I don't need to know that.

Shada: OK, OK, OK.

Helen: It's never been in my patient, you see. It's never been something I need to be concerned about.

Shada: Yeah, but if we put here, for example, breaking glass only for very sensitive information of that kind, and you make everything is available, do you think that's going to help with the system, to eliminate the amount of information there will be in the glass.

Helen: Yeah, because if you start saying, and I suppose that's where again, looking at my eight was probably way too high, but if you, anybody, any of the healthcare professional in our team, in the breast care team, for example, should have access to every single bit of that, without having to break glass.

Shada: OK, OK, yes, yes. So the use of breaking glass is going to be in very extreme cases.

Helen: Yes.

Shada: When there's something wrong with the system not providing information?

Helen: Yes.

Shada: OK, OK, excellent, OK. So what about the automated referrals, does that happen today in the systems, yeah, does it happen?

Helen: So, you're talking about from when something gets sent from us to another?

Shada: Yes, sorry, no, I meant this one. We're talking about here, automated referrals. So you see the person picking up.

Helen: Yeah.

Shada: And you can see the patient waiting, patient case waiting for us to pick it up for, at treatment point. So this automation of referrals, does this happen today in the systems or no? I mean, how does referrals happen? Is it manually done, I mean the information?

Helen: Referrals, yeah, the referrals are faxed from the GP, for example, to our coordinator, who then books them into clinic, and then when they come to clinic, they're booked for the surgeon, and the surgeon just turns up...

Shada: What about the information, because we've been talking about referral, talk about the information needed to do the...

Helen: It's on that piece of paper.

Shada: OK. So it's faxed?

Helen: It's faxed, yeah.

Shada: But if it's automated through the system, that will be, is that important?

Helen: As long as you get the system, as long as you get the information...

Shada: So it doesn't matter if it's fast or automated by a system?

Helen: Automated, no, because people will only put in so much information anyway.

Shada: But.

Helen: And some of the, some of the GP referrals will send us, we have a proforma, and they'll fill that in, and then the back will be a list of the last 10, 15 appointments they've had with the GP, some kind of vague thing. It's a one line thing about...

Shada: Yeah. Does that, this is what the GP provides to you?

Helen: ...And all the medication that they're on and things like that.

Shada: Everything...

Helen: And medical history.

Shada: What do you do with that information? Do you record it into the system?

Helen: We would, not onto a computer.

Shada: Not onto a computer. Maybe that's because you work with paper...

Helen: Yeah.

Shada: But what if you were...

Helen: Well I wouldn't anyway, it would be the coordinator, I guess, but then it's, what happens with a referral, you get the referral. You look at the breast information that you need. You would flick through and see if there's anything relevant in the rest of it, and then you just ignore that, because it's not relevant.

Shada: It's not relevant, OK.

Helen: Or, you know...

Shada: Yeah.

Helen: So then when, when the surgeon does his annotation, which goes in...

Shada: He still do th...

Helen: He's dictated, OK, he's dictated, and then he would say about this patient, and he will say, who I note has congestive cardial failure or da, da, da, da, da, and then talk about the breast issue. So it's kind of noted that there's certain medical history that may be relevant.

Shada: What about from the MDT, for example, to the oncologist and this is the GP case, but what about other cases?

Helen: MDT, like for when we have it in MDT and they go to the oncologist?

Shada: Yes, is it automated?

Helen: That's a dictated letter.

Shada: Dictated letter, OK. So it's still letters?

Helen: Yeah.

Shada: Do you think if it's through the system, that will be easier or no?

Helen: I would have thought so. It would be a lot quicker, wouldn't it?

Shada: Yeah, OK. So it is important to have automated referrals between the different, at the different points of care. So when the patient's seen by Doctor A for example, and then he's referred to Doctor B, then this is automatically done.

Helen: But somebody has to put it in though, don't they?

Shada: But it's automated then the information already appears on the other system. That's what we're trying to do here. So.

Helen: So, you mean, there's a bulk of information that just follows them round, and it's added on to by the new...?

Shada: Automated, yeah.

Helen: Yeah, yeah.

Shada: So if he refers the patient to Doctor B, then it's, when he presses a button, the information that he recorded in, are in the system that he wants to share it with the other doctor, and all the case notes and everything will automatically.

Helen: Yeah, so what came from the GP, and then what he's added on to it.

Shada: Is automated.

Helen: Is automatic.

Shada: But maybe the information coming from GP, is not as valuable as for example, notes coming from oncologist, for example.

Helen: No.

Shada: So it depends on different cases, but if it's automatic, all the information needed is already in the case, and it's with the press of a button, then the other person can pick it up from their system. They don't have to record it again and do anything, and if it's in the system, do you think that's important, and will same time and everything?

Helen: Yes, I would have thought so.

Shada: OK, what about, so the current systems do not do that?

Helen: No.

Shada: No, OK. Do you think, OK, here we do it this way, that the person come and click on the patient, when he logs in, and then he sees the information that is available about the patient, then he records whatever it is and do the test or whatever it is he is doing, and then clicking "next" or "done." When he clicks done, this happens to the next person, I mean the next one. Logging in, he can see the same patient with the results that he's done, and then he can pick it up. So do you think there's a way to improve it? I mean, is this how we think it should be, but.

Helen: Yeah. I suppose the only other thing you could do is having something that you could actually, so that, without logging into this system, that there is some flag that they should log into the system.

Shada: Ah, OK.

Helen: Yeah, that there's something, I don't know how you'd do that.

Shada: It's OK, but just tell me about the concept or the idea.

Helen: It's just that, I suppose it's like, if you're not spending all your time on the computer, because that's the thing, you're sat at the desk, it's OK, but if you're actually out doing clinics and things like that, and doing, moving around and physically not in front of your computer all the time, then actually to know at some point that there's.

Shada: That there's a patient waiting for you.

Helen: That there's, well there's something that you have to do.

Shada: OK. Well maybe the hospital have the lists of patients being automatically referred, for example, if it's automatically referred, then there's a sheet coming out to the hospitals saying, I don't know who is responsible, but I can say, OK, this is a list of patients for this doctor, or maybe it can be, send an email to the person who should pick it up anyway, to inform him that there's someone waiting for them.

Helen: Well there would be, I mean, if the next step is for them to go to clinic, then they would come to clinic without really, I mean, that would kind of be arranged by the.

Shada: This is where we thought the case is that it's a point of care, so the patient will go and see the doctor. Then the doctor.

Helen: So this is just whether they want to see that patient?

Shada: Before they see them, yes.

Helen: Right, OK, sorry, yeah.

Shada: So, no need for that.

Helen: It's not, no. I thought it, so that they have to have an appointment.

Shada: No, this is only, this is when they will see a patient, and then when they see the patient, maybe five minutes before, they click on this and see the information and then they see the patient, and then record whatever it is they need or do their tests or anything, record their results there and then click "done". So there is no need for any alert or anything like that.

Helen: No, no, no, sorry.

Shada: No, it's OK, absolutely fine.

Helen: Yeah, I know what you mean there.

Shada: I like how you think about things. Excellent.

Helen: That's very scary.

Shada: Any challenges or any comments about the referral thing?

Helen: Well, it's just a case of, people would have, really need to do the entering there and then, because at the moment, they talk into machine and somebody else does it for them.

Shada: So you need a dictation system in here for them to, OK. How accurate is that?

Helen: As accurate as typing...

Shada: It saves some time. That's good. I never thought that they used a dictating system to write.

Helen: Yeah, they do.

Shada: Do you know the brand or the name of the company?

Helen: It's a fairly new one, because they've changed it recently. I don't.

Shada: I know Dragon is one of the very well known dictation systems in the medical field.

Helen: Never heard of it.

Shada: Doesn't ring a bell?

Helen: I don't know, but I know recently, there's a, like a digital, a slightly different system, which is, the girls have had to have consecutive.

Shada: OK, they install it into the computer and then they just use the mike to dictate anywhere.

Helen: I, do you know, I honestly don't know how it works, but I know it's, they have different, different handsets now that they dictate into, and I know it's been, it has caused the secretaries a bit of trouble.

Shada: Why?

Helen: I don't know.

Shada: OK, OK.

Helen: I don't need to know, so I don't want to know.

Shada: Yeah, maybe you don't need to know, but it's, do you think it's going to help, if you have a dictation system?

Helen: But if you've got something where...

Shada: Because dictation system can actually work around any application, anywhere that there is, it depends, because I've done in my undergrad, a dictation

system. So you have different types. You have like filling forms, kind of dictation system. This has to be trained where to go on the form, but if it's free text, it's fine, because you just and it's just trying to find the right word that you sent. So in that kind, that type of dictation system, it can go, it can type anywhere that you put the mouse in, or maybe it has to be, you can dictate the system, put it somewhere and then you copy and paste it, that's it, but it's so, there are many systems that can do that.

Helen: Because at the moment, that's what they do. The doctors see a patient. They dictate into a machine and say, I've just seen this lady, and then the secretaries pick up the machine, the tape, and they put it into a machine and they play it back, and they so type it in.

Shada: OK, so there's someone manually trying to, taking, OK.

Helen: I'm not quite sure what happens with this new system, because it's very new.

Shada: Maybe that's why they want to change it, because it's going to go direct through here.

Helen: Maybe if they don't actually type it in. Maybe they just log it in somehow. I don't know.

Shada: But dictation system for a medical field. I think that's, that's important.

Helen: Yeah.

Shada: Excellent, OK, yeah.

Helen: I mean, I know there's, because you can see in lots of things, well it's the same as you see some of these programmes where they have subtitles, and you think, that's not the word they said at all.

Shada: Yeah, sometimes it does not recognise the right word.

Helen: It can be wrong.

Shada: That's why the person's saying...

Helen: But then that happened to a secretary as well. They, you can read their letters, you think, yeah, that wasn't right either.

Shada: I now that doesn't, yeah, yeah, OK, OK, yeah, yeah, excellent. OK. What about filtering and gathering the information from different systems? So at the point of care, we put the information that we believe is relevant, and that's why we have the breaking glass, in case we miss something. So based on the guidelines, it says that this is the kind of information that this person should see, but maybe it's not detailed enough, because Mital told me, the guidelines as I say, about the treatment

plan field is missing. So we have to add it, but do you think it's important to filter information, and not have everything in there?

Helen: Yeah, it's just knowing, it's getting the filter right, I suppose. I think it should be like a basic filter but with access to the whole lot if, certain effort.

Shada: So it's organisation more than filtering. So you're organising in a way that is easy for anybody to read?

Helen: Yes.

Shada: But it's like everything is there?

Helen: Yes.

Shada: I mean, so not filtering organisation of the information, OK.

Helen: Maybe yeah. So you can get the information if you want it, and, because some people, there might be something that is actually quite obscure, some kind of quite obscure connection between one disease and another, that your filter's not going to come through with, or your average person is not going, the average consultant might not make the connection, but you've got somebody who says, well actually in very rare cases, such and such is.

Shada: These rare cases may kill the patient.

Helen: Yeah.

Shada: So we need to consider all the of the cases.

Helen: Yeah, so I think that everybody, somebody, any kind of clinician looking after that patient, should have access to everything that's not ultra-sensitive, but doesn't necessarily have to plough through it all to get what they need for that, there should be some kind of, I know that Doctor Crosby was saying about the boxes. So you do kind of want some kind of boxing off of some kind of organ, something to do with the breast situation.

Shada: So in my case, in my case, these are, could be like little boxes.

Helen: Sorry.

Shada: Good. You know, when you share that information, if you categorise it into different, like for example, if Annabel's here, and she wants to access Amal's, Kate's, Carl's and Hessah's notes, then we categorised based on the care point, rather than the information itself. Do you think that's, that's the best way of organising things? So.

Helen: I think so.

Shada: Yeah, OK.

Helen: I think so.

Shada: OK.

Helen: So I suppose it depends on what you want to know, doesn't it?

Shada: I really can't.

Helen: It's hard to know, you know.

Shada: Yeah, yeah, but, can you think that's a good way organising information, in a way that can help the healthcare professional do their job, or does his job?

Helen: I would have thought so.

Shada: OK.

Helen: Because you kind of know what's likely to happen each time.

Shada: Because it's free text. You want the system to be smart, but you don't want them to be too smart, that it may actually end up in a messy way.

Helen: Yeah.

Shada: You know, a situation. So if he categorise, if the system categorise the information that this is what received from GP, this is what received from a surgeon, this is what received from an MDT coordinator. So it's all organised, and you can see the different information. This is how I think about the organisation, but do you have any other ideas, about how to organise information?

Helen: No, I think that...

Shada: It's not too overwhelming, no?

Helen: Yeah.

Shada: OK, OK.

Helen: Without actually being stuck in the middle of it, it's hard to, I would have to come across a problem, before I realised it was...

Shada: Yeah, yeah, yeah.

Helen: There might be things that come up, but at the moment, I can't.

Shada: Yeah, absolutely, OK. If, yeah. The breaking glass thing, you mentioned a couple of comments about it, that no justification.

Helen: Yeah.

Shada: Maybe only just for very sensitive information.

Helen: Yeah, I think.

Shada: Only ultra-sensitive, because you said they all need to access...

Helen: I think everybody in that care team should.

Shada: OK. So who, who think may have like, I'm not sure how to say this, so if everybody should access everything that is organised in a way to help them access the information, or see or find the relevant information, maybe there is no need for breaking glass?

Helen: I think, apart from on these very, very sensitive things, I don't know if there is.

Shada: Yeah, OK.

Helen: Because really, there's not many people within the team, who shouldn't have full access to.

Shada: So two things we're talking about breaking glass, putting very, very sensitive, ultra, extremely, super, super sensitive information in that box, that we think is not going to affect the treatment, the care, but still only very numbered people should access it, and we're talking about breaking glass in cases that the information was not available at the point of care, and we need to access it rapidly now, so it's all the information. So we're talking about two different things. Which one do you think is important and which one is not?

Helen: I think it's very important that in the second situation, that everybody who's in that care team should have access to everything.

Shada: So maybe the breaking glass, if it's not referred here, then they can access CaNISC and the portal and everything and get everything for you to read.

Helen: Yeah.

Shada: OK. So breaking glass from the other systems.

Helen: Yeah.

Shada: OK, OK, and the ultra-sensitive thing, you can see how it's important to the patient maybe, yeah, yeah.

Helen: I think that's kind of a political thing actually. I think they have to say, we're not allowed certain things.

Shada: Yeah, OK, OK.

Helen: For example, this is , I can't do a fictional one unfortunately, because otherwise it wouldn't come up, there'd be nothing.

Shada: So that's to.

Helen: So this is to give you an idea. You go in, you get the details, and then for results, for example, I can go in the Clinical Portal here, and have all the results now. It's not just the breast ones, by any means, it's everything that she's had done.

Shada: OK. These all, that's why, that's good way of organising information, you know, that these are test results.

Helen: So, you can find things, and it is, because sometimes you look and you think, well, you're trying to find something and you might, you think, well there's quite a few bone profiles here. Why are we looking at these bones? Why are we doing this? Why are we worried about this woman's bones so much.

Shada: As a nurse, you have to check them all?

Helen: I wouldn't necessarily, but you, I would think, why are we looking at this woman's bones so closely.

Shada: Yeah, do you question that, yeah.

Helen: Why are we, why is this woman, I mean, that's just over and above, I suppose. It's not something I'd necessarily want to go. I know that this is the histology. You know how to find them. You know what to look for, but you also sometimes find out about some tests that you didn't know they had done, which maybe the GP's organised, or they've been admitted for something else, which you could then link and think, well actually, I didn't know about that, but that's actually quite relevant to what we're doing here, because somebody else hasn't made that jump of, or maybe the breast care bit has come afterwards, but because I've got past results as well, that you think, well, she's been complaining of bone pain. Has she got bone secondaries.

Shada: OK, and you have to find the information relevant to that, to see more details about them.

Helen:

Shada: So, I can understand that the systems are actually organising the information, based on their type. These are the results. These are the letters. These are the, but they're not organising it in chronological order.

Helen: No.

Shada: Like we said.

Helen: No.

Shada: So do you think chronological order is more important than this way, or is better way?

Helen: I don't know. I'm used to this, I suppose. So I don't have a problem with this way, because as long as, because what you do find sometimes is, yeah, 1913, 2013, 2010, 2010, 2013.

Shada: You can...

Helen: So depending on the type of, type of letter it is, they're not necessarily in chronological, although they should be, but there's two 2010 ones that have come from nowhere. I don't know what they're doing there.

Shada: They should be organised by something.

Helen: They should be down here somewhere, shouldn't they, but as I said, because I'm used to using it, so I don't have a major problem with it, but it's not the easiest way of doing things, and it's not, because, so this is chronological. So she'll have seen our surgeon, and I've no idea what this is.

Shada: So this was in 2010.

Helen: This is the, no this was in 2013, she saw our surgeon, and then, now, I don't know what this is. I don't know what this is, BPA. Oh I know! That's oncology. That's Annabel Barley. Peter Bartley and Annabel Barley (BPA).

Shada: Yeah.

Helen: So that's still our surgeon, but he sent letters to the GP and to the oncologist. So that's accessible to both of them, but if she had seen, I don't know, an orthopaedic surgeon in the middle, then there would be a letter to the orthopaedics from the, so you would, so that would be in, Mr Stephenson's, I think, renal, urology.

Shada: So when you look at the patient, you find it hard to find the relevant information or maybe the latest information, or.

Helen: Well, normally the latest information is at the top, and you work your way down, and I think the good thing about this is that normally, I don't know where these 2010 ones that's come out, come out of nowhere really, I don't know what's happened to them, but normally they would be in chronological order. So, as it happens, it looks like almost everything that's been done recently, is just with us, but if she was also going to a diabetic clinic in between times, you see, that would come through. So it would be like breast, breast, diabetic, breast, breast, diabetic, renal. So you would get that in chronological order, chronological order with this generally.

Shada: OK, OK. This is when the patient has two different conditions?

Helen: Well, that's right, and most of them have.

Shada: Yeah. What are the common ones with breast cancer?

Helen: Well they're older, so everything, heart, blood pressure, diabetes, everything, arthritis, thyroids, gynae, everything.

Shada: Oh my God, and this effect, you have to see both to...

Helen: Well you don't necessarily have to, but it's useful to know that, to see the patient as, because it's all about holistic care, isn't it?

Shada: Yeah, exactly.

Helen: So it's no point just dealing with the breast, if the woman can't walk.

Shada: But does it...

Helen: Because her legs are so bad, you know.

Shada: So you need to know what's happening.

Helen: So you need to know a bit of, but I mean, to be honest, you can sit and talk to the patient. She'll tell you that. You might not need to look at all that.

Shada: But some of them may not be able to remember, for example.

Helen: No, or they may not be able to.

Shada: They always ask me about the medication. I just don't know. They live under the system, because they're all English, and they're too medical terminology for me, I'm a computer...

Helen: Yeah.

Shada: Student, so I don't know about medical things and terminology. So for me, it's really hard to recall medication, otherwise I have to take a picture of them, because I'm going to my doctor, I picture the medicine for him to know. So I really can't say. So maybe some of them don't even speak English, the patients.

Helen: Yeah, we've got lots of them.

Shada: So maybe it's easier to ask their permission through the record, right, or anything like that. OK.

Helen: And there's a lot of people don't understand. Like I say, even if they have very good English, they don't understand or don't remember or forget. So, it's, you need to have that as well.

Shada: Yeah, absolutely, absolutely.

Helen: You don't necessarily have to use it, but you need to have it, you need to have access to it.

Shada: To everything that is relevant to a patient, you think, and if you want to access, then you can access if you think you need it otherwise, yeah.

Helen: I mean,

Shada: Yeah, you have to read about it or ask.

Helen: And he's foreign. He does speak English, but he's.

Shada: He didn't tell you unless you ask.

Helen: You don't hold all the information, without a bit of work. So things like that, because you could very unwittingly just arrange something which could actually be quite detrimental to his health.

Shada: Yeah, yeah.

Helen: Without having access. You have to look at it obviously, but it's useful, and sometimes it's actually by glancing through something, you think well hang on, why is she having that done, and that alerts you to having to actually there might be more to this person than you realise, because they don't all the time, because a lot of chronic conditions as well, they're kind of so used to. There are certain things that they, they know they can do and can't do, but anything's a bit more obscure, and so used to having this disease, that they don't consider it as something to be con, it's going to make any difference. It's just the way they are.

Shada: So you need to know about it all this.

Helen: So you do kind of need to know about the whole lot.

Shada: Yeah, absolutely, which is the patient-centred eventually. Yeah, that's.

Helen: I know I don't answer any of your questions straight [laughter].

Shada: No, you answered all of them straight [laughter]. You were the easiest person for me to interview, seriously. I met others, it's really difficult to get the information. So it is important to have information access that is patient-centred, not organisation-centred?

Helen: Yes.

Shada: Excellent, and the systems currently don't do it that way? They try to.

Helen: They try to, to be fair.

Shada: They try to. So, to a limit?

Helen: To a degree.

Shada: Yes, to a degree, yeah, a certain degree, which is the portal mainly trying, mainly because it's a new system. OK.

Helen: Although the clinical portal's not a new system.

Shada: Well, because I thought the clinical portal is one of the initiated ideas, to help with patient central care.

Helen: Oh, depends what you mean by new. We've been using it for about 10 years.

Shada: Really.

Helen: I think so.

Shada: OK, OK.

Helen: Yeah, clinical portal's not new.

Shada: Maybe they try, maybe they pick the clinical portal to try to link the other systems to it.

Helen: Maybe.

Shada: So the idea is there, but it's an old system that this, as a starting point, 10 years!

Helen: Maybe, I don't know. I'm not good with that. Maybe five years.

Shada: No, but it's not something new?

Helen: But it's not, it's definitely not new.

Shada: No. my knowledge and reading, it doesn't really give me that ondication, OK.

Helen: It's not, no. it's, I wouldn't say less than five years.

Shada: OK.

Helen: It could be between five and 10. It could be a lot longer.

Shada: Well thank you very much Helen. The last, very last thing, is it very important to give the chance to amend information that automatically alerts everybody who made a decision, based on that point?

Helen: Yes, yes, I think that would be very useful.

Shada: OK, and does the current systems do it? I mean, does.

Helen: Not that I'm aware of.

Shada: OK.

Helen: Don't think so.

Shada: Do not think so. OK.

Helen: I can't think how you would do it. Well again, I don't know so much about CaNISC, because I don't know enough about CaNISC to see that.

Shada: OK, yeah.

Helen: I don't think there is anything like that, where you could like put a little kind of red flag up everybody can see.

Shada: Yeah, yeah. It's the same like the breaking glass, when you see that they're working the same here, that at this point, at this point, there is an amendment that happened earlier in this stage. So you need everyone who made a decision and went down the treatment pathway, should actually consider these amendments, and if there's anything they need to do, then they have to do it, otherwise, for example, the right breast or the left one, then maybe they should check the other one and do the assessment on the breast for example.

Helen: Yes, yes.

Shada: OK, excellent. I had all my questions, and it's really, really helpful. You don't understand how much it's helped me to know the information. One more thought in the future, if a patient is to be involved in accessing information through the system. Do you think that's going to help them see where they're going and who's accessing their information? Or you don't think that the patient will ever be, and the system maybe does not help them.

Helen: I think it's, you've got to be very, very careful about patients accessing the information.

Shada: Why is that?

Helen: Because mostly it needs to be interpreted.

Shada: Because they won't understand, like myself, I don't understand the terminology used or.

Helen: Because this is what you find all the time, with people who go on the internet, or get information, and then try and work out what to do with it, because it's not.

Shada: Their case.

Helen: Well, it may be their case, but because they don't, they don't understand where that fits into.

Shada: The bigger picture.

Helen: Into the big picture, of what that means to them, then they, they for example Google things or they go on the internet and get various different things, and they come back with very quiet misleading ideas.

Shada: Misleading!

Helen: Ideas about what's happening.

Shada: Is it more negative than positive?

Helen: Oh yeah, it's more negative than positive yes, always.

Shada: OK. So maybe because they go out trying to sort out information, maybe it's better to involve them in the current system, maybe by giving them a box, not accessing everything, just a box that has some, summary of things for them, or at least to see where they're going in the treatment. They see that, the hierarchy. Do you think that's going to be something?

Helen: I'm not sure if that's something that I can see has been, I don't know.

Shada: I just thoughts.

Helen: I'm in the wrong generation.

Shada: Because it's all in the future.

Helen: You're talking about younger generation where they want to be heavily involved in this, and then they're going to not like being kept out, and they hack into it and get into it anyway, and I think then you've got to be very careful about people accessing other people's information, because that would have to be very, very strong, wouldn't it.

Shada: Yes, yes, absolutely.

Helen: The firewalls, but I think, I think information like that has to be explained.

Shada: In a different way.

Helen: And it's something that you would, no, face to face, if possible on, somebody has to interpret it, whether it's some kind of professional, has to, or some health carer, has to interpret what that means.

Shada: To the patient?

Helen: To the patient.

Shada: OK.

Helen: I mean, that's what I do all the time. Because the surgeon says, you've got breast cancer. This is what we're going to do, and these are the choices you have to make, and a lot of our job is interpreting what that actually means in the real world.

Shada: Because you're the closest to the person, to the patient.

Helen: The patient, yeah.

Shada: So, yeah.

Helen: We're patient advocates. We don't work, we work with surgeons. We don't work for surgeons.

Shada: OK, yeah, absolutely.

Helen: The patients are our priority.

Shada: Yeah, absolutely.

Helen: And.

Shada: Do I keep this?

Helen: Probably not. It'll confuse me. Just go in a pile of other of other papers,... I'll get round to.

Shada: Yeah, too many things to deal with.

Helen: Yeah.

Shada: Thank you so much Helen. I really, really appreciate your help and time. That's mass of time, and I'm honoured, seriously!

Helen: I'm very happy to do it. I mean, I really think it's a great idea, and pleased if it helps, and I would love at some point.

Shada: Thank you.

Helen: To, to see what you do eventually.

Shada: I will, well this is what I presented. Hopefully if I do anything in the future, I will let you know.

Helen: Yeah.

Shada: Merry Christmas.

Helen: Well thank you so much. I really did need to hear that.

Appendix D

Interview with Breast Cancer Oncologist (Dr. Annabel Borley)

D.1 Interviewee's Role

Dr. Annabel Borley works for Velindre NHS Trust, which is a tertiary oncology service. Her job is mainly to look after the non-surgical treatment of breast cancer.

D.2 Interview Aim and Structure

The interview with Dr. Borley was held in Velindre Hospital for a total of 61 minutes. The interview aimed to evaluate the usefulness of the SHarE prototype system according to one of the users of the current breast cancer care support systems. In the first 31 minutes, the research was presented along with a demonstration of SHarE. In this presentation, the research problem was introduced through a breast cancer treatment scenario in which the interviewee plays a role, then its research aim and main requirements were represented. After this, SHarE was demonstrated live and through a number of screenshots. In addition, some detailed discussions about the research were carried out during this introductory stage of the interview. In the remaining 38 minutes, the reactions to the system were extensively evaluated through a set of open questions, as shown in Table D.1 below.

D.3 Questions List

The questions are categorised into a number of main categories as shown in Table D.1

Table D.1: Interview questions with clinical oncologist in breast care.

Category	Questions list
Interviewee role in healthcare organisation	What are the role(s) you play in the healthcare organisation(s)?
Information access needs	What types of information do you need/ use/manage as part of your job?
	Is it of a sensitive nature? [Give a number between 1-10]
Research problem	Do you sometimes find it hard to access or receive this information either from CaNISC or other systems? Or receive it late?
	What do you do in such cases?
	Do you agree on the research problem?
	Any additional problems you face when you do your job in terms of information availability?
SHarE	What do you think about the proposed system?
	Do you think it is useful? Easy to use?
	Do you think it will help in terms of information availability at the point of care?
	Do you think it has the potential to address the identified issue?
	Do you think SHarE has the potential to change your behaviour?
	Additional comments? Recommendations?
Controls and Requirements	For each of the functionalities: 1. Does current system provide it? 2. Is it important? 3. How it can be improved? 4. Challenges? Comments?
Future	Finally, if the patient is to have access to their information electronically, do you see this system suitable?

D.4 Interview Synthesis

Information access needs. The information Dr. Borley needs as a breast cancer oncologist, includes "everything," according to her. She elaborated by saying: "I need to know their demographics, their basic address, age. I need to know what has happened to them so far, so all the details about their examination, their presentation, their imaging, their pathology, and the MDT discussion, but I also need to know their personal medical history." When the interviewer asked Dr. Borley to rate how sensitive this information is on a scale of 1 - 10, her response was: "Well, it's personal medical records, so they should always be confidential, but I don't really know how to do that, because it's widely available to all healthcare professionals." However, she agreed with the interviewer that this information needs to be reviewed; it should be confidential whilst at the same time being available to those who need it.

Research problem. Dr. Borley confirmed that although she can get information from the Clinical Portal quite easily, she finds it hard to find information about the patient at times. She gave a common example of such cases by saying: "it's usually pathology results not being entered onto the Clinical Portal or transferred onto CaNISC," although they have been done already, but not yet made available to other CT members. When the interviewer sought a justification for such a recurring issue, Dr. Borley said: "No idea, I don't know, walls between them or something." Another example that came to the interviewee's mind which she described as her biggest irritation was: "the biggest problem we have is that some of the patients who get diagnosed through screening service have their initial biopsies in a different place than the breast centre. They get sent, the biopsies get sent to a different pathology department in Newport, and they don't release the, they don't put the receptor tests, which are the things that we really need, back onto the patients Clinical Portal. They keep it in their system, and they won't release it, so that's my biggest irritation." Although Dr. Borley claimed that this delay does not normally cause any delays to the treatment, she said: "but it causes a lot of hassle trying to find it out." This is because, in such cases, she would normally: "telephone them, and then they fax it over with the names blanked out on it." Furthermore, Dr. Borley agreed with the interviewer that there is more pressure as she commented: "yeah, it's frustrating that there are so many systems, which in isolation are quite good, but they don't talk to each other." This validates the research problem insofar as the systems today are isolated and the information does not always flow with the patient. She referred back to the example she discussed before to support this idea by saying: "I think we've discussed this before, referral letters, for me to have a patient referred that is still waiting for a letter to be sent or to be faxed over in the post."

SHarE. The interviewee appreciates that SHarE is trying to address the cross-organisational information-sharing issue when she commented about the system in general by saying: "I think it has got to happen, we've got to have joined up systems, and it's very frustrating that we don't. It's really important." Moreover, the interviewer asked if she believes that there is a potential for clinicians to adopt SHarE in the future, and she responded by saying: "Yeah I do," then added "for a simple, straightforward healthy breast care patient, that's fine. But they're not all like that." Therefore, she explained that there is a high degree of complexity in breast cancer care by saying: "a lot of patients aren't treated in isolation, there's a lot of other things feeding in as well, so with co-morbidities or they come in a different route to the breast care team. Or perhaps the surgeon would see somebody and think oh actually they're not that fit for an anaesthetic, they go for cardiology and anaesthetic opinions. So they." This means that SHarE will have to consider the level of complexity in this domain in order to meet these needs. Furthermore, Dr. Borley

agreed that, firstly, SHarE is a user-friendly system by commenting: "Yeah it looks easy yeah." Secondly, it could help in terms of information availability at the point of care: "Yeah as long as everything is entered yeah," she commented, and this would help address the problem. Thirdly, it enhances communication at the collaboration level, because Dr. Borley thought that SHarE "would help us be more joined up, certainly." Finally, she thought that that she would have to adapt to SHarE instead of it adapting to her practice, and the only difference in behaviour would be when it comes to automatic referrals. She commented by saying: "the information getting, I can do anyway on the Clinical Portal quite easily. The difference in this, is in the organisation, it's in the automatic referral I think, isn't it."

Controls and functional requirements.

- ***Information access is patient-centred based on the patient's condition and treatment stage and neither organisation or disease-centred.*** Initially, Dr. Borley agreed with the interviewer that this functionality is important, and confirmed that none of the current systems actually provides it as a functionality. She also appreciated that in SHarE each patient would have their own page, as well as the information presentation in SHarE.

- ***Information organisation in chronological order (in a timeline format) with a stamp showing date and time of care point, and who saw the patient.*** Initially, Dr. Borley agreed with the interviewer that this functionality is important, and mentioned that only the Clinical Portal provides it as a functionality when she said: "well the Clinical Portal results and letters are all in chronological order," and that she would want that to be the case for all the other systems. She also mentioned that this scenario shows a straightforward pathway, whereas most cases are more complicated than that. She said: "I think what you'll find is that some cases are like that, but quite a lot are a bit more difficult, like they may go round this loop a few times, diagnostic MDT biopsies, it's quite common for patients to have more than one biopsy." However, SHarE already implemented the loop as an option because these loops are already in the guidelines and the whole treatment pathway is mapped in the system with the option of repeating a treatment point. Besides this, SHarE shows the treatment pathway as a time-line, so even if a treatment is replicated (which should be an existing option in the guidelines) it will still be time stamped and all information will be provided. Finally, Dr. Borley appreciated that in SHarE, not all the information is shown to the CT member in the timeline, but if he/she needs it, all they have to do is hover over the treatment point and more information will show. She commented on this by saying: "I think it's quite good

to have the date hidden, I don't need to know what date they saw it," but agreed that if she needs to see it, it is available to her.

– ***Automated referral to a named CT member or a role that is picked up by the recipient with all information needed.*** Dr. Borley thought that automating the referrals would help make the communication better, especially in cases when she has a patient referred that is still waiting for a letter to be sent or faxed over in the post. However, she highlighted the duration of treatment being an issue in the system: "because my treatment goes on for a long time," and she continued "it can be up to a year." Therefore, she requires this functionality to be flexible enough to go back and forth between her and other CT member involved, namely the surgeon. She said: "it should carry on then, I should write my piece, what I propose and then I send a letter back. I could just enter it onto the system couldn't I," so the system automatically "tells the surgeon what I'm going to do, and then there is an ongoing update." She added: "but then, one the radiologist is going to be a follow up mammogram, so if they could be prompted in that, one that these people need mammograms." In the end, both interviewer and interviewee agreed that SHarE would help as allows everyone to know what is happening. Moreover, the interviewee highlighted the fact that the system should enable someone to book appointments as she explained by saying: "but I don't send out my appointments, I haven't got time to send out appointments, so that referral, push referral has got to go to an administrator here to organise it for me." Although she acknowledged that SHarE replaces the case notes by saying: "so it's really just, instead of looking in the case notes to see what I need to know and do, I'll find that on here." Finally, she commented by saying: "I think automatic referrals, not depending on secretaries and letters is good, but they're still going to have to, some secretaries are still going to have to put those into this aren't they? Or are they not? Because there's lots of nuances, that the patient, the surgeon might say, they don't do it very often actually, but they might say, please see this lady for chemotherapy but she's not very fit, and not very keen. So I get the referral, but that information might be lost if it's not put on there, so."

– ***Filter and gather needed information from the different systems at the point of care based on clinical guidelines.*** Dr. Borley agreed that this functionality is important: "I think as long as you know where to go if you want more, then I think filtering is fine to make it simple," she claimed. She then confirmed that current systems do not filter the information by saying: "No, I think you've got to wade through all the information yourself," and then have to read through it, so it can be time consuming. She added, "if you're seeing a new patient, what you really need

to know is the MDT summary, and what the MDT said the treatment plan should be, then I'd usually go back and check. Ok right that's fine, let me just check the pathology results," and based on the category, she will choose whatever is required, and thus she finds filtering the information to be helpful.

– ***Information can be amended after sharing by originator and this will automatically alert everyone involved.*** The interviewee agreed on the usefulness of such a functionality by justifying: "Yeah if it's wrong, because then there's, if you don't correct it there's a chance for ongoing errors isn't there when anyone goes back to look at it." However, she said: "But for instance, me, I would perhaps say this is what I want to give, this chemotherapy, but I have to do a test on your heart to see if it's safe to give it to you. If it's not safe to give it to you, then I might have to revisit that decision and give them different chemotherapy. So I wouldn't want to change originally what I said, because that would still be the original plan, but it changed on the basis of subsequent information." The interviewer explained to her that this features both cases; once the information is being amended or another piece of information is added to it. Dr. Borley asked about the alert by asking: "How are they alerted?" and she added: "do you have to go into every patient to look at that, to see if you get an alert? So if something has changed, a patient had a new problem or something, and everybody gets alerted, is there a sort of summary page that says: 'look up Susan, something has happened to her?' Because I've got about eight hundred patients, I can't open every case." Therefore, the interviewer explained that, technically, the system does not deal with amendments and adding additional information any differently. It will provide the opportunity to either simply change the text or add to it. Finally, Dr. Borley provided an example of when this functionality would be helpful by saying: "Yeah so pathologists often issue supplementary reports, if something new. So they say this is breast cancer, but then a bit later, they come back and say, we've done extra tests and it's a special kind of breast cancer." She then predicted that many challenges may be encountered in adopting these functionalities without elaborating.

– ***If extra information is needed at any point, trusted CT members could break-the-glass and access all information they need, then they have to justify it.*** The interviewee agreed this is an important functionality, and stated that current systems do not provide this functionality at all, and as a result of that, "if it's not there you can't get it," she commented. Moreover, Dr. Borley was asked about the two possibilities of using this feature; firstly to gather information that should be there from the guidelines but for some reason is not. Such cases could perhaps happen when CT members record information in their system, but do not do it through SHarE's

screen, so the breaking-glass will access the database, locate information about that patient and retrieve it. It is a concept of helping to gain access to information rapidly, because we believe that you need it and you cannot wait longer to contact the other person and say please provide that information. She said: "no, because from what you've shown me, everything is there anyway, so what more is there going to be? But if everything is done properly as it goes along, then it shouldn't really be needed should it?" The interviewer asked whether Dr. Borley agrees with the idea of justification when she said: "do you justify, or you don't justify? Is it time-consuming to justify?" and Dr. Borley responded by saying: "Yeah, because you would just say, I need to. I'm not sure you do, if you're a core member of the team, and it's information you should have anyway." She then continued, "Well if it's something you need to know that should be there anyway, and isn't there. I don't really understand, so if you wanted to see the mammogram result, that would be there anyway wouldn't it?" In the end, based on Dr. Morrey's opinion, both agreed that justification and breaking-glass may be best used by anyone who is not in the treatment care team, for example, out-of-hours, which will make more sense in that case. She emphasised that there must be an element of trust by saying: "Yeah, because we're all responsible for keeping data confidential, that's part of our role as, information governance and the Caldicott Guardian, it's his responsibility to make sure we all do it properly."

Later in the interview, when the interviewee explained her biggest irritation was when it comes to finding out relevant information, Dr Borley thought this feature would be practical in such cases to retrieve the information from other systems instead of her telephoning them, and then they fax it over with the names blanked out on it. In addition, the interviewer thought this feature would also be very helpful in some MDT reviews when the information is not available and there is not the organisation expected. She told the interviewer about an incident that happened in the previous week's MDT meeting by saying: "It wasn't very well organised, because the list that the MDT coordinator, it wasn't Mital, it was another lady did, and the list that the surgeons had and the list the pathologist had, were all different, totally different. So the results he had weren't expected and the results that we were expecting weren't there. So it was all a bit hopeless. So, if this would prompt the pathologist, help the MDT coordinator and the pathologist get the right results to the right MDT, that would be very helpful." Therefore, SHarE in such cases would allow the MDT coordinator to list all that information for the patients the CT knows the results are ready for. Finally, she added, "I think it's important you shouldn't have to do something like break-glass, it should be there." However, if it

was needed in some cases then: “it is better to break into only the information at the selected treatment point instead of all information recorded up until that particular point.”

– ***Labelling the sensitivity level of patient-identifiable information and communicating it to all healthcare professionals as a technique to raise their awareness.*** Dr. Borley asked the interviewer what she meant by raising awareness when it comes to sensitive information and she also wondered how sensitive would compare to normal? Therefore, the interviewer explained to her what the nurse had said about the Clinical Portal having a button there, saying break the glass, Dr Borley did not know about it. This explains why different CT members do not know all the systems very well. They are only familiar with the systems they use on an everyday basis. However, when she was asked if she thought labelling sensitive information is essential in this context, she said: “Would it be flagged up to make it obvious there is sensitive information?” The interviewer used an example illustrating its usage at a breaking-glass incident, and added that the labels can also be used to show the sensitivity level at the different steps, for example, when there is a referral to actually see how sensitive that information is. Dr. Borley’s response made it clear that the way she perceives the word “sensitive” as a clinician is totally different from how this research defines it. In this research, a piece of information is defined as sensitive if it contains information that would physically or emotionally harm the patient if disclosed and it falls into the wrong hands. However, Dr. Borley would label information as sensitive if the patient has a test result that shows this patient is a high risk one and his samples, for example, require extra care when processed to protect CT members from catching a contagious disease from these samples. She explained this by saying: “I’m not sure we’d ever use it that much to be honest. I think everything is, I don’t know what, I can’t imagine, what would not be relevant to be part of the core information. For instance, this week, they were referred a patient from the GP for an ultrasound of an arm pit lump, and so they saw the patient, did an ultrasound. They didn’t really know what was wrong with the patient, the patient didn’t tell them, but it turns out she had active TB on treatment and HIV. So extremely high risk patient, and there was no, they’d already done the biopsy, they sent the tissue to pathology, without any of these extra labels, because they didn’t know it was sensitive. So, but I was wondering if there was a danger you make it so sensitive that’s not obvious, that should be the first thing. I know it’s, because you’re talking about the protection of the people doing their jobs really. They would have taken extra care, they would have labelled the samples properly and none of that happened. That’s a downside of separating it out into different people,” and she

added: “I mean you still have to do it, but you would perhaps be more careful with your gloving and stuff like that.”

Consequently, the interviewer asked Dr. Borley whether she suggests that labelling should have certain information. For example, it would provide you the option as a care team to include information with a label, or, Dr. Borley was asked whether the information would be too sensitive and would only include the four classifications. She said: “Well is it, are you envisaging that the pathologist, no because this is replacing your forms isn’t it? So it’s got to go on there that this woman is high risk? There ought to be a flag saying high risk, because of something. I don’t know if that should be sensitive because that would put people off looking at it. It needs to be really obvious doesn’t it, that it is sensitive obviously, but it’s also important, it needs to be not hidden.” Therefore, Dr. Borley wanted to differentiate between information that is sensitive in the sense that it is important to look at, and labelling information as sensitive in a sense that it stops clinicians from accessing it to preserve a patient’s privacy. She actually suggested using it to label high risk patients at each stage of the treatment pathway when she explained: “At every stage, the GP needs to say this patient is high risk and then the surgeon when he refers her on says this patient is high risk, then the pathologist that is going to handle the specimen needs to know that. The only people who don’t need to know are the MDT coordinators and stuff, because they never see the patient.” This only happens in “very rare cases,” according to Dr. Borley. The interviewer wanted to know whether Dr. Borley approves of the selected classification scheme to be used for the same suggested purpose. It was therefore suggested that care team members use the ‘Highly Sensitive’ label to flag a high-risk patient reflecting the need for more caution, and Dr. Borley agreed by saying “you need to flag, you need to flag to say there is a problem, a sensitive problem, and it needs to be obvious.”

Suggestions Dr. Borley thought about another important idea by suggesting: “the other thing, it’s really important [SHarE] for audit, research, and governance, so we know. If I want to look back and see, perhaps the other thing I would want to know, everybody who was diagnosed with this particular cancer in that time, what’s happened to them.” However, the interviewer explained to Dr. Borley that this may be an essential requirement but it is out of the scope of this research, and Dr. Borley commented that CaNISC does that already but she would suggest it being linked to SHarE to help access more information by saying: “the current system can do that, yes, so it needs to talk to this system doesn’t it.”

Furthermore, another suggestion was to have another entry for nurses when Dr. Borley said: “Another person I would find it useful to have their entry is the breast care nurses.”

She actually emphasised the need for the system to have a dedicated entry box for nurses by explaining their role when she said: "well there's supposed to be a Key Worker to support the patient. They're supposed to be the patients advocate and to support them through treatment. But what they do in practice, is find out all the really important stuff. So they're the ones that will tell me, Mrs X won't cope with chemotherapy because she lives alone and her dog's sick and stuff. And the surgeons never tell me that. But that's really important." She continued: "Yeah because I did my new patient clinic today; Helen Grace sent me a list of all the patients and then she'd written little notes about them all, and that's more valuable than the surgeons' letters frankly." She also said: "I'm trying to help with a clinical project with breast cancer follow up, trying to make it more patient-centred and holistic, and what we're talking about doing is holistic needs assessments. So using some sort of framework and I haven't seen them yet, but to identify the patients' needs. So to say this patient is very anxious, and might need counselling, or this patient is struggling financially, and needs referral to welfare rights or benefits or. And so that is going to be recorded as part of it." Therefore, she highlight the need for a separate person: "I think it could be separate, it could almost be a separate person in the process. It could be like Helen, breast care nurse, needs assessment, or patient advocate needs." This would help gather more patient-centred information because according to Dr. Borley, "there certainly are these tools that you can record needs," which are not time related, and this is why the interviewee asked for it to be on the side of the system rather than a treatment point. Also, this page may not necessitate an alert of any type as, "Some people don't care, the pathologist doesn't care about anything other than the biopsy results." Therefore, it would help those who would need it. Dr. Borley emphasized that "it doesn't change the information to make the decision, but it influences the decision hugely." She added, "for instance, one lady was not an English speaker and so it was through them that we needed to know that we had to get a translator here before the clinic, before we arrange the patient, we arrange the translator." Therefore, the interviewer realised how important this is and actually suggested using a label for this which the interviewee agreed was important, saying: "So we can mark that, maybe it should be more like a label that says there is something important there that you need to take care of before you see the patient."

D.5 Full Interview Transcript with Breast Cancer Clinical Oncologist

Shada: Ok, the main purpose is to evaluate my system. So, I'll start with my treatment scenario, which we discussed a couple of months ago, the research problem

that I'm trying to address, and what we are trying to do. I identified a number or requirements that I believe will help address the problem. I will demonstrate SHarE through a couple of screenshots, and then I'll ask you a couple of questions if that's ok. So do you remember this paper, this exact paper you gave me with your lovely hand writing. So, this scenario is exactly the implemented scenario in SHarE. So, we're starting with the patient visiting the GP, if the GP is suspicious then he collects information about that patient and refers the patient to a specialist. In this case it's going to be a surgeon. The surgeon will refer the patient for a biopsy and an ultrasound. I think that these are wrong, it should be three there, four here.

Annabel: Yeah and the radiologist does the biopsy, but the pathologist reads it.

Shada: Oh ok, so you will let me know about the screens in terms of collecting the information. And the results from the three tests will be discussed in an initial MDT review. Most patients undergo surgery, and then after the operation there is another MDT and then chemotherapy, to be treated with chemotherapy or radiotherapy. I added this bit that years later if the patient relapses, then maybe they go to palliative care, for end of life care. Now the problem is what we found is the different colours indicate the different information systems used to collect that information.

Annabel: Ok.

Shada: So, we're dealing with different information systems that collects information and needs to share that information with each other. Now what we find is that these systems are isolated, they are not connected or integrated or linked in a very clear way. So sometimes information is being blocked from flowing with a patient. And from a research point of view I believe this is because there are inconsistency or no harmony between the security walls. Because security indicates how information should be available and stuff like that, and I'll explain that in another slide. So as a result the research problem, we believe sometimes information is not available at the point of care, because the information does not flow.

Annabel: Ok.

Shada: Now we know there is information from a disease-centred care to a patient-centred one, where there is more emphasis on integrated care, where healthcare professionals work as a care team. They share decisions and this needs cross-organisational information sharing. And this is what we are focusing on in my research. Now when we look at the different information systems, how we look at the information security, is that if you look at the single information system, in order to protect that system, you have to balance between information confidentiality, integrity, and availability. So, you need to make it available and confidential at the same time. And it's a trade

off, it's hard to get that balance in the first place. In order to attain that balance you need to create information security policy. And that consists of information security rules. The rules say who can access what information to get that balance, and in order to enforce it in a system in a machine, you need to select information security controls that will enforce that balance in the system. So it will reject people from accessing it, and we'll allow others to access it through user name and password and stuff like that. So this is by the use of information security controls, which create a point of control. Now this makes sure that all the elements of the system works in harmony.

Annabel: The point of control? yeah.

Shada: Yes. Ok, the problem is that we have different systems, different points of control, different security rules, so they're not in harmony. Different systems protects its information differently. So it's hard to share that information. So the aim is to create a Secure Healthcare collaborative Environment (SHarE). Ok, by enhancing secure cross-organisational information and sharing. By building, and that's what we're trying to do, we don't want to change what's happening today in the hospital, we want to keep the context of security of the local systems, and get a common information security context, at the collaboration level. So we will maintain what every single system already does. So we'll build a common security context, while maintaining security context of local systems. So, we'll evolve what kind of systems can do, by adding a couple of functionalities that will fully support cross-organisational information sharing. I'll show you what I mean by that right now, but I'll talk about the requirements. The extra things that will help share the information. First, we believe as the patient goes down a treatment pathway, this is part of breast cancer's Map of Medicine treatment pathway, so it says here clinical assessment, diagnostic imaging and this the biopsy, and then if the cancer is excluded. So we believe that information access should be patient-centred and not organisation-centred based on the treatment. So we should organise information in a chronological order as a treatment time-line. And that's based on the organisation collecting that information and we stamp each treatment point with a date, time of the treatment point and who actually saw that patient. So it helps, everybody to know where the patient is going, what's happening so far. Exactly like the Map of Medicine guidelines. Now the third requirements is that we automate referral, so we help information flow between the different users by automatically doing that. So, the person there can actually see the information coming from the other person. So when you click on referral then you refer the patient to the other doctor, then the information will go with that case, will be referred with that patient. And at

the other end the person will see all the information that we believe he/ she needs for the treatment. Fourth is to filter and gather information, so we don't actually pour everything, we just try to filter it in a way that helps the healthcare not to be overwhelmed with information. So we filter the information and gather it, but if the guidelines or the system does not provide the right information, there is missing information, when it's flowing between the different hospitals, we give the care team members an option to access extra information by breaking the glass.

Annabel: Ok what about adding new information as you go, that just gets added automatically as you go along?

Shada: If it's not part of the treatment point, then it's not what my system does. So we assume that, you at this point, you see the patient now, you record that information and then you click on a button. That button will automatically refer it to the second, the next person, the next treatment point, because the patient is going to see the other doctor. So these are the points that we care about. We'll come to that, because we can enhance the system in different ways, and this is why I'm meeting with you. So we give the option to break the glass to access extra information that wasn't referred to the doctor. And we give the option to amend the information after it was shared already. So this will automatically alert every one that is involved in the treatment. So if the surgeon, if there was an error in the record and he needs to change it, for example, say it's right breast, not the left for example. Then everyone who made a decision based on that, will make the changes, will be alerted so they can make decisions based on that updated piece of information. Finally, labelling sensitive information, labelling the sensitivity level of information for each identifiable information and communicating it to all healthcare professionals, is a technique to raise awareness. So we believe this is important but I'm here to get feedback about that.

Annabel: Ok.

Shada: So this is, these are the requirements, this is the scenario. Now this is my system, this is how this scenario is implemented. So we will start, these are the different people. So, Hessah is the GP, Carl is the surgeon, Kate is the oncologist. So as a general practitioners, Hessah logs in, she creates a new case. So it's web based, she logs in, she creates a new case, a new patient because she's the GP. She tries to find that patient in the system. Then once she finds that patient, she can record information about his medical history, and examination. So she puts that information in there as a GP. Now what we add in the system is she labels how sensitive the information she's recording. So we have different levels of sensitivity, 'Public' is just normal, 'Care Team' wide use, all people treating those people, this

is the default one, this is the green one, and we have 'Sensitive'. It's more sensitive for the care team. And this is 'Highly Sensitive' information. So she just labels it, and if she doesn't click anything it will be a 'Care Team' wide only as a default. But in this case for example, it's sensitive information.

Annabel: Is this a new record for this patient totally, or is this a presentation?

Shada: It's totally new.

Annabel: Because the patient will already have health records, because they've been to the GP over the last twenty years.

Shada: Oh, this is a new treatment pathway, but not a new record, because it's in the system already, it should be in the system. But this is, we look at treatment, because we organise information on a treatment time-line basis, then if the patient is having symptoms for a new condition, then we create a new treatment case, and this is a new case.

Annabel: Are you trying to develop a system, I think I might have misunderstood you, just for the management of the breast cancer? Or for the whole of the patient, for the whole general public health records?

Shada: This is only breast cancer, but it's supposed to be patient-centred, so we took only one treatment case, but this is when the information needs to flow between the different care team who are treating the patient for that condition. We did not consider another condition, this is something that we want to do in the future, but here we just took one example, to see how we can help every body involved with the treatment of patients, can access the information.

Annabel: So this is not on the same level as the patient, the sort of the NHS Spine in the patient held, you know there was this big IT project that every patient had a digital health record that can be accessed?

Shada: No it's not the record, it's the sharing of information, this is a bit different. But whatever is recorded here goes to the local system. So if this is a GP system it goes directly to the database of the GP system. So when he records this and then click on the button done, then it will be, this information that he records here, and that is needed for the next person who is a surgeon, this will go to the surgeon to see. But everything that he records here still goes to the regular system. So, after the GP collects that information then it will automatically, once she presses the button saying 'Done', it will be referred to a surgeon. Who is, in my case, Carl. So this is the surgeon, Carl logs in, she can see Susan's case here, this was done on the sixth of November. So she can actually just click on that button and pick up Susan's case to take it from there. She will see whatever is needed as information from the GP

and then she records the information because she is seeing the patient at that point. Once she clicks 'Completed' it will be referred to the next person, who is in my case, Kate. Kate is the pathologist. So Kate is the pathologist she logs in, she sees Susan is in her system, and takes it from there and completes whatever is needed. She does the biopsy and she records that. We'll come to how you can change the system as you suggested earlier. So the pathologist does not actually put the...

Annabel: No, so the surgeon would refer to the radiologist who would do another scan, and mammogram and take the biopsy, then the biopsy gets sent to the pathologist, the patient never sees the pathologist, the biopsy sees the pathologist.

Shada: Ok, ok, so in this case the pathologist will only see the result from the biopsy.

Annabel: The pathologist gets the choral tissue. That's it, and a form saying...

Shada: How is that stored in the system is it like an image, or like text? I don't know.

Annabel: No, the patient will go to the X-ray department and have a biopsy taken using an ultrasound, so they fire a gun and take a core, like an apple core. And then that gets put in a pot of formula, then that gets carried in a bag, with a paper form, to the pathology department. And the pathology department process it, which means chopping it up and putting it on slides, and look at it under the microscope. Then they decide whether it's cancer or not basically. Then they write a report which goes onto the Clinical Portal. and this is when you get the B, B...

Shada: Ok, so he still records that information in there, but it's after the.

Annabel: It's after they've analysed the biopsy, and they have nothing to do with the patient really, they just get the core of tissue.

Shada: Yeah, ok, but what about the ultrasound? Is there a report?

Annabel: Yeah.

Shada: So what about the biopsy? Two different reports or just the?

Annabel: It's often the same, it often says there is a mass in the left breast measuring three centimetres, and core biopsies have been taken through it.

Shada: Ok, excellent, thank you. So it's the other round here, after the biopsy we had the radiologist logging-in and picking up Susan's case. So I'll change that on the system.

Annabel: Yeah you need to change the order.

Shada: And then so, she decides whether depending on the age, whether it's ultrasound or mammogram. And then she will do it and then save the report write a report about it, and then store it in the system. So once the MDT who in my case,

is Claire. She's going to log in, and she will see Susan's information waiting for her there. Once she clicks on that, she will see the different information coming there. But she will click on the button she needs. So this is the image report, the biopsy report, there is from the surgeon and this is from the GP, once she clicks on them, she will see the information that was recorded at that point. And then there is the treatment plan there decided whether it's positive or abnormal, and then malignant or benign. This is a letter to the GP, because it says in the guidelines that the GP should be informed. So this is the system, it generates that letter, it's just to simulate how the communication happens. And then once the MDT is done, it's going to be, the patient will be referred to my surgeon who is Carl again. She logs in, does the operation you know, picks up Susan's case. And then she will record, she will write a report after the operation was done. And then after she saves there is another MDT which is the post operation one. Claire logs in, takes Susan's case, she accesses information and then records the treatment plan as well. After the MDT here comes the oncologist, who is Annabel, and she logs in, you will see Susan's case, you just click on it, and all other patients who are waiting for you. So you will see everything.

Annabel: God, bit depressing [laughter].

Shada: So you just click on it, and then you know, while you do the treatment you provide a report about it. And that's my system, just a simple way to represent how we can actually implement a treatment scenario. I'll show you how my system does the functionalities that I discussed, and then I'll ask you some questions if you don't mind. So we mentioned that the information should be organised in chronological order, like a treatment time-line, with a stamp. And information should be patient-centred. And this is how it is actually implemented. So you can see the hierarchy on the side of the screen, that says here that Hessah saw the patient and does examination and history and then Carl actually started the triple assessment, she checked the history and examination, and she referred it to Kate. Kate did the biopsy and then Amal did the mammogram. Claire did actually record the treatment plan, and she was diagnosed, so this was an alert, you know, this patient actually has cancer. Now she informed the GP by clicking on the patient, clicking on the button. And then it was referred to a surgeon so you can actually see what's happening based on the treatment. And if you hover over one of these you will see the date and time and everything and you will see the state, if it's outstanding, or it was done and all the details. So that is what the system can do to organise information in a different way. We automate referrals, so we've see how you can click on the button and then you can pick up the case. And you know, take it further. And we filter information like we see at the MDT, we can see how she filtered the information so she can access the

information that she needs at that point. And the "breaking-glass." The idea behind the breaking-glass, is to give all care team members the ability to break the glass to everyone. But not the author. For example, if you collected information about the patient, then you're the author of that information, you don't break-glass into your information, because it's yours. But we give the ability to others, who want to see that information and did not get that chance, to actually break into information, to actually break the glass and see the information that you collected. So in here, for example, this is Hessah's case, if you log-in as the oncologist, you can actually break the glass to Hessah's information. And you can see that I didn't implement it yet.

Annabel: So if I wanted to say, read the operation notes, I could get into the surgical information on the case?

Shada: So you just click that button, you will see that in every single treatment point. Because we trust that when you need it, then you need it. And you will only break the glass if you don't have it and you really need it, so there is an element of trust in here. So everybody breaks into every bodies, but as an oncologist, after you click on that, you justify why you need that information, and then we all show the information that Hessah recorded here, with the sensitivity level. So that's the idea mainly. But some people, my supervisor for example, said when you break into a piece of information you don't see only that persons information, for example, if you're here you see everything that has been recorded. But someone else said to me it's going to be overwhelming, so you only break the glass to that persons information, what do you think about that?

Annabel: So when you break, what do you get, you get the little box that they put in?

Shada: Yes. Yes you see the information that they've recorded. And whether there is an argument about the breaking-glass, because some of them say well if you say why do you need to break a glass, so maybe we can get the glass to break information that was not referred, based on the guidelines.

Annabel: No because from what you've shown me, everything is there anyway, so what more is there going to be?

Shada: Maybe they recorded information in their system, but didn't do it through SHarE's screen, so the breaking-glass will access the database, anything about that patient and grabs it. It's a concept of helping gaining access to information rapidly, because we believe that you need it and you can't wait longer to contact the other person and say please provide that information. So it could be.

Annabel: But if everything is done properly as it goes along, then it shouldn't really be needed should it?

Shada: Yes, so you will only need it if it's not done properly. So this is one way. For example, he may not recorded that information in here, and then clicked done. So the system will automatically refer the patient to the next person, but there is no information available. So maybe breaking the glass will access that in the database, so they will go grab anything from that system. But do you justify, or you don't justify? Is it time-consuming to justify?

Annabel: Yeah. Because you would just say, I need to. Well if it's something you need to know that should be there anyway, and isn't there. I don't really understand, so if you wanted to see the mammogram result that would be there anyway wouldn't it?

Shada: It should be.

Annabel: It should be.

Shada: But sometimes it's not there. So you need to literally let the system grab it from the database.

Annabel: Ok, well I suppose if you need a mammogram result, that would be fine, it wouldn't be difficult.

Shada: And you don't need to justify it right?

Annabel: I'm not sure you do, if you're a core member of the team, and it's information you should have anyway.

Shada: So maybe justification and breaking-glass to anyone who is not in the treatment care team. For example out of hours.

Annabel: Yeah maybe.

Shada: That makes more sense?

Annabel: That makes more sense.

Shada: Ok, so yes, after breaking the glass and the justification that we did in the system, at that point, when that was done, based on the time-line, you will see an alert, saying that Hessah's information is being actually broken into. And the justification was given. So this is to show, so when you log in you can see actually that this happened at that point, so everybody knows that this happened. This sixth, the requirement is the amendment of the information. So it's the opposite here, so only the author can amend their information. So this is Hessah's page, she can see, so you can, if you log in, you can see your breaking-glass, but if Hessah logs in, she will see dynamic control, because this is her information. So she can actually click on it and change the information. But it doesn't show on this screen. The very final functionality is labelling sensitivity, as a way to raise awareness. So when you record

the information, we believe that the only person who can decide how sensitive it is, is the person recording it, and because it's free text then they can click on the button and choose.

Annabel: What do you mean by raise awareness?

Shada: It's like you know, if there's super sensitive information then maybe it helps others to know, that in this content, there is very sensitive information, just to help you be aware about that.

Annabel: And what would be more sensitive than normal?

Shada: I don't know. Because I know that, I spoke to Helen, the nurse, before and she said the Clinical Portal, there is a button there saying break the glass.

Annabel: Is there?

Shada: Yes, and she never clicked on it, because she expects that super-sensitive information in there, is kept behind the glass, like HIV results or something. So maybe that kind of information. She said she never actually broke the glass into it, but there is this thing, that the concept of very super sensitive information being taken care of differently. Here I am giving information to everyone, because I trust they will need it. But maybe you need to know there is sensitive information in there. Just for you to take more care. Do you think that's essential or no?

Annabel: Would it be flagged up to make it obvious there is sensitive information?

Shada: Yeah for example when you break the glass, well we only have. We actually thought that maybe only when you break the glass we can show how sensitive that information is. For example Hessah when she recorded, the GP medical history details here, she labelled it as 'Sensitive' but when she put the examination, she left it as the default which is a 'Care Team' wide. So only breaking the glass will let you know how sensitive it is. But do you think we should also provide different steps, for example when there is a referral you can actually see how sensitive that information is?

Annabel: Yeah I'm not sure we'd ever use it that much to be honest, I think everything is, I don't know what, I can't imagine, what would not be relevant to be part of the core information. For instance this week, they were referred a patient from the GP for an ultrasound of an arm pit lump, and so they saw the patient, did an ultrasound. They didn't really know what was wrong with the patient, the patient didn't tell them, but it turns out she had active TB on treatment and HIV. So extremely high risk patient, and there was no, they'd already done the biopsy, they sent the tissue to pathology, without any of these extra labels, because they didn't know it was sensitive. So, but I was wondering if there

was a danger you make it so sensitive that's not obvious, that should be the first thing. I know it's, because you're talking about the protection of the people doing their jobs really. They would have taken extra care, they would have labelled the samples properly and none of that happened.

Shada: Do you think that's, so this can be.

Annabel: That's a downside of separating it out into different...

Shada: And taking more care when you actually deal with that, because it's HIV.

Annabel: Yeah, I mean you still have to do it, but you would perhaps be more careful with your gloving and stuff like that.

Shada: So do you suggest that labelling will have a certain label on it? For example it would give you the option as a care team to put an information with a label, or is it just super sensitive and only the four classification?

Annabel: Well is it, are you envisaging that the pathologist, no because this is replacing your forms isn't it? So your surgeon isn't going to fill in a form saying please do ultrasound and biopsy?

Shada: Yeah he's going to write it down and it will.

Annabel: So it's got to go on there that this woman is high risk?

Shada: Yes, so maybe when he types it in, in his box.

Annabel: There ought to be a flag saying high risk, because of something.

Shada: Yeah good.

Annabel: I don't know if that should be sensitive because that would put people off looking at it. It needs to be really obvious doesn't it, that it is sensitive obviously, but it's also important, it needs to be not hidden.

Shada: But, so you mean at the referral, when it happens, we put the label on it?

Annabel: At every stage, the GP needs to say this patient is high risk and then the surgeon when he refers her on says this patient is high risk, then the pathologist that is going to handle the specimen needs to know that. The only people who don't need to know are the MDT coordinators and stuff, because they never see the patient.

Shada: Yeah ok, so ok, interesting. It's only in cases that, that's rarely, that's not.

Annabel: Very rare.

Shada: So if they see the green, for example, if we're going to give them the option to label it as 'Highly Sensitive' that means you should give more attention to that patient and see the text, and you will see that it's high risk, because it's written

there, then that will help. But if you see a green button as a person receiving that information then you won't really take as much care.

Annabel: You would take care, but you need to flag, you need to flag to say there is a problem, a sensitive problem, and it needs to be obvious.

Shada: Ok, yeah, ok, thank you so much. So these are the main things in the questions. So that's excellent, I'll just take this. Here's the list of questions, starting from here. I know a bit of the role, but can you please tell me your role in the healthcare organisation?

Annabel: Ok so I work for Velindre NHS trust, which is a tertiary oncology service. And I look after the non-surgical treatment of breast cancer.

Shada: Ok, excellent. What type of information do you usually need to use your managers part of your job? when you seen the patien, the information that you collect, what type of information normally do you deal with?

Annabel: So basically a patient, I need to know their demographics, their basic address, age. I need to know what's happened to them so far, so all the details about their examination, their presentation, their imaging, their pathology and the MDT discussion, but I also need to know their personal medical history.

Shada: Ok so basically everything?

Annabel: Yeah everything.

Shada: Ok so if we say, if you will give me the sensitivity level of that information, is it super sensitive? Is it, if like if you're going to rank it from one to ten, normally how sensitive that information is?

Annabel: Well it's personal medical records, so they should always be confidential, but I don't really know how to do that, because it's widely available to all healthcare professionals.

Shada: At the care team level?

Annabel: Yeah.

Shada: Ok. So it still needs to be looked after, and not to be, it should be confidential and at the same time available to those who need it?

Annabel: Yeah.

Shada: Ok, do you sometimes find it hard to find information about the patient at some point?

Annabel: Yeah.

Shada: Can you give me an example please?

Annabel: It's usually pathology results not being entered onto the Clinical Portal or transferred onto CaNISC.

Shada: Ok so they've been done already, but not available? So what is the reason behind that?

Annabel: No idea, I don't know, walls between them or something.

Shada: So maybe the breaking glass might help you to access the information that's not on the system.

Annabel: Also the biggest problem we have is that some of the patients who get diagnosed through screening service have their initial biopsies in a different place than the breast centre. They get sent, the biopsies get sent to a different pathology department in Newport, and they don't release the, they don't put the receptor tests, which are the things that we really need, back onto the patients Clinical Portal. They keep it in their system, and they won't release it, so that's my biggest irritation.

Shada: Absolutely, and does it normally delay the treatment, because you don't have that information?

Annabel: No, but it causes a lot of hassle trying to find it out.

Shada: Ok, so what would you normally do in such cases?

Annabel: Telephone them, and then they fax it over with the names blanked out on it.

Shada: So do you think that breaking glass will help in that matter?

Annabel: Yes.

Shada: Ok do you agree that there is more pressure on the systems to share information? More and more by time, like it wasn't the case before, but nowadays there's more pressure on the systems that were developed at the disease-centred era?

Annabel: Yeah it's frustrating that there are so many systems, which in isolation are quite good, but they don't talk to each other.

Shada: Yeah ok, so you agree with the research problem that information, that the systems are isolated and the information sometimes is not flowing?

Annabel: Yeah.

Shada: Ok any additional problems you face in terms of information sharing and you know and information access?

Annabel: Well yeah I think we've discussed this before, referral letters, for me to have a patient referred that is still waiting for a letter to be sent or to be faxed over in the post.

Shada: So automated referral would help in that?

Annabel: It should be better, but it should carry on then, I should write my piece, what I propose and then I send a letter back. But I could just enter it onto the system couldn't I.

Shada: And the system does it automatically.

Annabel: The system tells the surgeon what I'm going to do, and then there is an ongoing updates. Because my treatment goes on for a long time. So that's perhaps phase two is it? It can be up to a year.

Shada: A year, ok? So everybody should know about the stage of your patient, or just the surgeon?

Annabel: The surgeon. But then, one the radiologist is going to be a follow up mammogram, so if they could be prompted in that, one that these people need mammograms.

Shada: Ok, ok. So it is important to get everyone to know what is happening?

Annabel: yeah, yeah.

Shada: Ok, excellent. What do you think in general about our proposed system? This is just a proof-of-concept, so it can mainly be enhanced, but this is the idea.

Annabel: I think it's got to happen, we've got to have joined up systems, and it's very frustrating that we don't. It's really important. The other thing it's really important for audit, research, and governance, so we know. If I want to look back and see, perhaps the other thing I would want to know, everybody who was diagnosed with this particular cancer in that time, what's happened to them, that's a different system isn't it.

Shada: That's a different system, we can actually implement that, if, through the search, but this is not it's main focus.

Annabel: So this is more a.

Shada: Managerial.

Annabel: Yeah, a sort of process driven thing.

Shada: Yes, but the current system cannot do that or?

Annabel: The current system can do that yes, so it needs to talk to this system doesn't it.

Shada: This system is actually linked to the current system. But you can open both together, so you can actually log into your system here, and to SHarE in here, and then you type in information that will go directly to your database, but when you click 'Done' it will automatically do the referral. But in your system you will see only the information that is stored there. So if that's the case, do you think there's a potential use for share? Like in cases for treatments of cancer? Do you think it's going to be useful for healthcare professionals?

Annabel: Yeah I do, but I think it's very, a lot of patients aren't treated in isolation, there's a lot of other things feeding in as well, so with co morbidities or they come in a different route to the breast care team. Or perhaps the surgeon would see somebody and think oh actually they're not that fit for an anaesthetic, they go for cardiology and anaesthetic opinions. So they.

Shada: So lots of complexities that happen, it's not as simple as that?

Annabel: Yeah but for a simple, straightforward healthy breast care patient, that's fine. But they're not all like that.

Shada: But definitely we can look at the complexities and let the system be flexible enough to consider other treatment pathways that interact with this one, and people who don't come from the very top of that route, they come from different places.

Annabel: The other thing is that with all these referrals that come in, how do you get notified of them? Do you get an email or?

Shada: No because once you see the patient, I see the patient, for example, I'm actually, at the MDT I click a button, then we do the treatment plan, and it goes to, for example the oncologist. Then the patient will get an appointment with the oncologist, then before you see the patient, you know that you're going to see the patient, then you click on the button and see that information before you see the patient.

Annabel: But I don't send out my appointments, I haven't got time to send out appointments, so that referral, push referral has got to go to an administrator here to organise it for me.

Shada: Yes absolutely, it's not your job. Because it's something, we need a time that suits the patient. So once the MDT does that, maybe automatically it will go to someone in Velindre, to take a right time, to get an appointment. But this is out of scope, the system, so once you know when you're going to see the patient, then you can actually just click on it, log in, you'll see Susan. If you're going to see Susan today you can click on that button. If you're going to see for example Shada, then you click on the other case. So you will see all the patients there waiting to see you.

Annabel: So it's really just, instead of looking in the case notes to see what I need to know and do, I'll find that on here.

Shada: You will find that on here. And you will see what we believe you need, but in case you don't you can click on the breaking-glass to see the extra information. Yeah so do you think it is useful?

Annabel: Yeah I think it could iron out some problems, were you in the MDT this week, were you there?

Shada: No.

Annabel: It wasn't' very well organised, because the pathologist, the list that the MDT coordinator, it wasn't Mital it was another lady did, and the list that the surgeons had and the list the pathologist had, were all different, totally different. So the results he had weren't expected and the results that we were expecting weren't there. So it was all a bit hopeless. So, if this would prompt the pathologist, help the MDT coordinator and the pathologist get the right results to the right MDT that would be very helpful.

Shada: So whoever logs in there as an MDT coordinator will see the list of patients, so.

Annabel: So she could list all the ones we know the results are ready for?

Shada: Yeah exactly. That will be automatically done because the tests were done already, so it's the stage at an MDT review, then it will go to the system waiting for anyone to read it, for the treatment plan to be, so that will help in that.

Annabel: That will help ok.

Shada: Is it easy to use? Do you find that?

Annabel: Yeah it looks easy yeah.

Shada: Ok do you think it will help in terms of information availability at the point of care?

Annabel: Yeah as long as everything is entered yeah.

Shada: Ok do you think it has the potential to add just the identified issue? Yeah we just mentioned that, so, about you know the information that is being blocked and if it gathers the information, or pulls the information from the database it will help to address that problem?

Annabel: Yeah.

Shada: Do you think that SHarE has the potential to change your behaviour? Or is going to adapt to your behaviour?

Annabel: Can I, would I be able to communicate backwards, could I communicate back to the GP through it?

Shada: Yeah we can provide links to the GP but like, for example, the guidelines here say you send a letter at that point, so we'll let the system do it. But we can actually have interviews with everyone involved and see what do you need? We can actually add it to the system. It can help to communicate through the system with

others. Because this helps with the collaboration level, it doesn't help with the point of local systems.

Annabel: It would help us be more joined up, certainly.

Shada: Yes, and you know who actually saw the patient, what time, what day, so you can keep up. That's the main thing. Ok, so you think that you will have to learn a lot to use it? Or does it actually do what you, does it adapt to your practice or you have to adapt to it? Because I believe systems should not change the behaviour of the peopl using it.

Annabel: The information getting, I can do anyway on the Clinical Portal quite easily. The difference in this, is in the organisation, it's in the automatic referral I think, isn't it.

Shada: Yeah, absolutely. Ok and any additional comments about the system?

Annabel: No I don't think so.

Shada: You mentioned a lot of useful things. So I'll very quickly, just the very last thing, should take us a couple of minutes. I'll take one of the several requirements of functionalities that we mentioned, and I'll ask you if you think it's important. If you think it is provided by current systems, and if it can be improved, the requirements itself and any comments. So we'll just take the first one, that information access is patient centred and not organisation centred based on the patient condition and treatment, do you think this functionality is important?

Annabel: Yes.

Shada: And do you think that the current systems can do it?

Annabel: No.

Shada: Ok I showed you in here how this can be, sorry, it's this one. So this is the way we organise it to make it look more patient-centred, do you think this can be improved? Do you need more information there? We've hidden the date and time, because we don't want a lot of information in there, but do you think this can be done, improved in a way or?

Annabel: I think what you'll find is that it's not, some cases are like that, but quite a lot are a bit more difficult, like they may go round this loop a few times, diagnostic MDT biopsies, it's quite common for patients to have more than one biopsy.

Shada: It will go down here, it will still be replicated here, with date and time, because it's treatment time line. But it's not, it's not based on the organisation, so whenever there's an MDT it will be listed based on the time and date, so it will always show.

Annabel: No I think it's quite good to have the date hidden, I don't need to know what date they saw it.

Shada: Ok but if you need to see it's available for you.

Annabel: Yes.

Shada: Ok. Any challenges about the use of this in general?

Annabel: So you'd have to go in, because this is each individual patient, so each patient would have their own page?

Shada: Yes exactly.

Annabel: No that's ok, I think that's fine.

Shada: Ok and information organisation is in chronological order, do you think that's important?

Annabel: Yes.

Shada: does the current system do it in chronological order? Like a treatment timeline?

Annabel: Well the clinical portal results and letters are all in chronological order, so.

Shada: Do you agree on that? You want that to be the case for all the other systems?

Annabel: Yeah.

Shada: Ok, what about automated referrals, we mentioned here the automated referrals, that you pick the case, because once you log in, this is your Intray, so you can see all the patients waiting for you, do you think that's important?

Annabel: I think automatic referrals, not depending on secretaries and letters is good, but they're still going to have to, some secretaries are still going to have to put those into this aren't they? Or are they not? Because there's lots of nuances, that the patient, the surgeon might say, they don't do it very often actually, but they might say, please see this lady for chemotherapy but she's not very fit, and not very keen. So I get the referral, but that information might be lost if it's not put on there, so.

Shada: So in my system's case, when he clicks on done, it's going to refer to you, then this information, he should put it in there.

Annabel: Yeah as long as he puts it in, or his secretary puts it in, it's alright.

Shada: It doesn't matter who puts it in, at that point, when the, at that treatment point, whether he's had someone in the room recording things for him for example, or he asks someone to do it for him. But we assume the healthcare professional actually logs in, and put that information in themselves.

Annabel: Another person I would find it useful to have their entry is the breast care nurses.

Shada: How do they work with the healthcare professionals, because in the guidelines it says the referral, the patient is being seen by a nurse specialist or an oncologist?

Annabel: Well there's supposed to be a Key Worker to support the patient. They're supposed to be the patients advocate and to support them through treatment. But what they do in practice, is find out all the really important stuff. So they're the ones that will tell me, Mrs X won't cope with chemotherapy because she lives alone and her dog's sick and stuff. And the surgeons never tell me that. But that's really important.

Shada: Yes its important. So do you suggest that we put like boxes along each treatment point, for nurses to put information in? Or how do you think that we can help the current system?

Annabel: I don't know, but the nurses, well, what we're looking at, I'm trying to help with a clinical project with breast cancer follow up, trying to make it more patient-centred and holistic, and what we're talking about doing is holistic needs assessments. So using some sort of framework and I haven't seen them yet, but to identify the patients needs. So to say this patient is very anxious, and might need counselling, or this patient is struggling with financially, and needs referral to welfare rights or benefits or. And so that is going to be recorded as part of it.

Shada: So like generic information about that patient that everyone should know about.

Annabel: Well everybody, I'm not sure everybody needs to know about it, it's more about signposting the patient and saying that yes, you need lymphoma or something, go off to there. But it would be, the people who, it would be helpful to have that on there as a record.

Shada: So let's say for example, there is a referral here and you click on that button, would you like to always see it on top of that page? This kind of information so if you log in, anyone logs in, or?

Annabel: No I don't think so, I think it could be separate, it could almost be a separate person in the process. Like where's your. Yeah it could be like Helen, breast care nurse, needs assessment, or patient advocate needs.

Shada: So it's like an additional point of care?

Annabel: Yeah possibly, I think you'd need to ask. But there certainly are these tools that you can record needs and that would be.

Shada: Specific patient needs?

Annabel: Yeah.

Shada: But you don't need to alert everyone in there?

Annabel: No. Some people don't care, the pathologist doesn't care about anything other than the biopsy results.

Shada: Ok yes, absolutely absolutely ok, sure that would be great. But that doesn't actually, it's not a sequence of time, she can do it any time?

Annabel: Exactly she could do it at any time, and we could do it here, we could do it when they get to here.

Shada: I'll think about how we can actually adjust the system to do that, because if we can, this is based on the treatment time line, so perhaps we could give her the chance to log in at any time and record that information. And whenever she records that information, it will be like, you can see here, like Helen added that information here, added there.

Annabel: Yeah because I did my new patient clinic today, Helen Grace sent me a list of all the patients and then she'd written little notes about them all, and that's more valuable than the surgeons letters frankly.

Shada: Ok, ok. And yeah, it needs to be there, to be seen.

Annabel: If you're not having any thing else then it needs to be there yeah. I mean they can still keep doing that obviously. And it doesn't change the information to make the decision, but it influences the decision hugely.

Shada: Ok, ok, absolutely, absolutely.

Annabel: For instance one lady was not an English speaker and so it was through them that we needed to know that we had to get a translator here.

Shada: Ok, so you prepare that before the treatment?

Annabel: Yeah before the clinic, before we arrange the patient, we arrange the translator.

Shada: So just trying to understand, ok, ok, so we don't deal with that as a breaking-glass.

Annabel: No because that's essential really, couldn't see her without the translator really.

Shada: So we can mark that, maybe it should be more like a label that says there is something important there that you need to take care of before you see the patient? Excellent, ok. Ok so automated referrals, what about filtering and gathering the information so you don't see everything, you see whatever we think, or the guidelines that is important for you. Do you think if you see everything it's fine? Or is it overwhelming? Or do you think it should be filtered? For example we give the MDT the option to click on the button she wants?

Annabel: I think as long as you know where to go if you want more, then I think filtering is fine to make it simple.

Shada: Ok, so you think it's important, but do you think the current systems do the filtering?

Annabel: No, I think you've got to wade through all the information yourself.

Shada: Ok, and then you have to read through it, so it's time consuming?

Annabel: Yeah.

Shada: Excellent. Ok, in each, any comments about that? The filtering? Do you, shall I hide it and then you click on a button to see it? Or shall I categorise it based on the person who actually recorded that information and then you just go to the surgeon's notes, and you see.

Annabel: Yeah if you're seeing a new patient what you really need to know is the MDT summary, and what the MDT said the treatment plan should be, then I'd usually go back and check. Ok right that's fine, let me just check the pathology results.

Shada: Ok and then based on the category you will choose whatever you want?

Annabel: Yeah.

Shada: Ok. So what about breaking the glass, as the main functionality, that if extra information is needed at any point, for example it s a bad referral, you didn't receive all the information for example, or anything. Do you think it is important that care team members should be able to access that information speedily?

Annabel: Yes.

Shada: Ok, do you think current systems provide that?

Annabel: No if it's not there you can't get it.

Shada: So you have to phone the person, you do it. Ok, so we mentioned the breaking-glass, you don't agree with the justification, so you always have to give them access and you would trust that they would do it for the, and you don't.

Annabel: Yeah because we're all responsible for keeping data confidential, and we're not, that's part of our role as, information governance and the Caldicott Guardian, it's his responsibility to make sure we all do it properly.

Shada: Exactly, exactly. So when we break the glass do you think we should access everything about the patient? Or only the care point that you're breaking into?

Annabel: what else is there though?

Shada: For example, here, you can see that this is Hessah's information, and here's Kate's information, it's Claire's, there's Carl's, so there's different people at each treatment point. Do you think when you break the glass you want to access everything recorded at that point? For example, if you actually want to break the glass here,then you see everything that is recorded up to that point? Or you just want that particular information?

Annabel: Yeah just that I think.

Shada: That information, ok. What about the super sensitive information? Does it have anything to do with the breaking-glass? Or you just label the information as high risk, and that's it?

Annabel: I don't think you should, I think it's important you shouldn't have to do something like break-glass, it should be there.

Shada: It should be there, ok. What about the information amendment, in case, for example that at that point there was an error there, and it's actually this page, here, for example, Hessah logs into the system and because the patient was referred to Carl, then Hessah can actually change the information, for example, you mentioned it was the left breast, and then it wasn't left, it was actually the right one. For example here, the surgeon actually sees the patient and the patient says no, I mentioned to the GP that it was the left, and it wasn't the right. So the surgeon contacts Hessah and says there was an error, can you change the system. And then Hessah logs in and can actually change that, do you think that's an important thing to do? To be able to change the information after it was shared?

Annabel: Yeah if it's wrong, because then there's, if you don't correct it there's a chance for ongoing errors isn't there when anyone goes back to look at it. But for instance, me, I would perhaps say this is what I want to give, this chemotherapy, but I have to do a test on your heart to see if it's safe to give it to you. If it's not safe to give it to you,then I might have to revisit that decision and give them different chemotherapy. So I.

Shada: You go back and add notes you mean?

Annabel: Yeah, I wouldn't' want to change originally what I said, because that would still be the original plan, but it changed on the basis of subsequent information.

Shada: Ok so adding more information, because what we're planning to do here, if Hessah logs in, she can change her information, she can add more information if she wants. And once she clicks on done for example, that she did the change, then everyone will be alerted about that change that she did.

Annabel: How are they alerted?

Shada: It's like the breaking-glass, like here for example.

Annabel: But do you have to go into every patient to look at that, to see if you get an alert?

Shada: No, only the patient that this is done on.

Annabel: But if there was an important change, like I don't know what, I can't really think. But if something has changed, a patient had a new problem or something, and everybody gets alerted, is there a sort of summary page that says.

Shada: Ok, ok.

Annabel: Like look up Susan, something has happened to her? Because I've got about eight hundred patients, I can't open every case.

Shada: If you open the referral here, it will say that, this will be an alert as well, it's a referral and an alert. For example here, I implemented the breaking-glass, so it will say here, that Susan's information has been broken at this point, at that time, and then it can be the same for amendments, you can say that Susan's information has been amended, and then when you click on that button you will see something like. Sorry I didn't implement that, I don't have screen shots for it, but something like this, it will say here that this information has been amended by a person, then you can break the glass and see it. So do you think that's important?

Annabel: yeah.

Shada: Ok, excellent. I never thought about adding more information but I think I should consider it, because it's the same concept. Changing it or adding something to it, is the same concept. But alerting everyone at the treatment point and the Intray, so you can see that this is happening to patients.

Annabel: Yeah so pathologists often issue supplementary reports, if something new. So they say this is breast cancer, but then a bit later, they come back and say, we've done extra tests and it's a special kind of breast cancer.

Shada: Ok you will have to, when you see that there has been an amendment, you go to that persons information and then you click on it and you will see the full report. But they have to record it into the system. Ok so do you think that current systems do that?

Annabel: No.

Shada: Ok and do you think it's important?

Annabel: Yeah.

Shada: And ok, excellent, any challenges you think if we implement that?

Annabel: Lots of challenges yeah.

Shada: Thank you so much.

Annabel: It's ok, love your graphics they look brilliant.

Shada: Well thank you so much, we are trying to proof that we can help with the communication. We want to help clinicians do their jobs, and there are ways of helping them. Because we don't want you to, you know to get to learn about this new system and everything, we want a very simple system to help you do your job and overcome all the issues we want to address in our research. Thank you so much for your time, I really appreciate that.

Appendix E

Interview with the Former Head of Clinical Information Unit (Dr. Dave Morrey)

E.1 Interviewee's Role

Dr. Dave Morrey is the former Head of Clinical Information Unit (CIU) at Velindre Hospital. From his past experience as the head of this unit, he explained its role by saying: "there are three main aims at the CIU. First, to use technology to help clinicians as they care for the patient in order to directly benefit both patients and those clinicians. Second, to measure the quality of care given in the Cancer Care Centre at Velindre Hospital and be able to benchmark that against other centres, and finally, to support clinical trials and research" [107]. Therefore, according to Dr. Morrey,"there was an element of developing systems for cancer care, as well as, using the clinical information to provide the management information for Velindre Hospital, as a trust. Because there was certain figures that needed to be derived. There was a data set for each admission of a patient to the hospital and each new referral to the hospital and things like that. And also it provided certain figures for performance of the hospital in terms of number of patients, whether the referrals to the hospital were changing with time and also the clinical information unit got involved in helping medical research, helping the clinicians with their research and also in audit. Checking the outcomes for patients and the quality care of them so" [107].

There have been 20 years of fruitful collaboration between CIU and the School of Computer Science Informatics at Cardiff University. According to Dr. Morrey, "the research contributed mainly to the development of CaNISC in a number of ways. The research and collaboration helped look at new areas come from ideas coming from clinicians, developers, university students and the university. Bringing information from the literature and testing things out in particular areas. Some of these were highly successful and we were able to adopt them straight away, others had to wait for the technology to catch up to

implement the ideas, and others went the wrong way which is pretty much the nature of research" [107]. Finally, the CIU's role mainly focused on the following three elements: helping clinicians and patients, clinical outcomes, and clinical trials and research [107].

E.2 Interview Aim and Structure

The meeting lasted 120 minutes and aimed to evaluate the SHarE system by discussing its potential adoption and integration with current systems, the challenges this integration may face, and any suggested improvements. It took over an hour to demonstrate the research problem through a breast cancer treatment scenario in which the interviewee plays a role, along with the research aim and the main requirements. This also included a demonstration of SHarE through a number of screenshots with an emphasis on how the seven functionalities are provided. This lengthy session provided the chance for a detailed discussion throughout this phase of the interview; it was useful to elaborate on relevant topics. The remaining time was spent asking open questions as listed below in Table E.1.

E.3 Questions List

The questions are categorised into a number of main categories as shown in Table E.1

E.4 Interview Synthesis

Interview synthesis is based on the categorisation criteria of the questions asked in the interview, as follows:

Current healthcare information systems. In this category, the interviewer was trying to paint a picture of the system's development at the CIU in particular, as well as the current movement in the development of healthcare supporting systems in the UK in general. Dr. Morrey started by stating that CaNISC was developed by the CIU in Velindre Hospital, and it is the main system used today to collect cancer-related information across Wales. CaNISC is also the only clinical information system used all over Wales in spite of the national programs. It is in a very good position and remains very important. It is used in cancer centres for care of patient, and it is used to generate management of information including performance statistics. It is used all over Wales for cancer national audit, as well as being used in screening; palliative care was also built on CaNISC. It is also linked

Table E.1: Interview questions with the former Head of Clinical Information Unit (CIU).

Category	Questions list
CIU's role in healthcare organisation	What is the role the CIU plays in the healthcare organisation?
Current healthcare information systems	Is CaNISC is the main system used to collect cancer related information across Wales? Was it developed in the CIU at Velindre?
	What are the other systems currently used today in cancer care? Are they built in-house or bought off-the-shelf?
	What is the recent movement in the development of healthcare systems in the UK in general and Wales in particular?
Information sharing needs and research problem	Are the other systems linked to CaNISC or information access has to be independent? Any problems?
	To which degree do you agree with the fact that there is more pressure on current systems to share information between hospitals?
	How are current systems coping with this pressure? What do they have on their agenda to address that issue?
	Do you agree on the research problem? Do you believe that the information sometimes does not flow with the patient/is not available sometimes?
	Is this because of the current systems? Or people's behaviour? (provide examples of conflicting opinions from previous interviews with Mital and Helen)
SHarE	What do you think about the proposed system?
	Do you think it has the potential to address the identified issue?
	Is there a potential for healthcare professionals to adopt/use SHarE?
	Is the integration of SHarE with CaNISC possible?
	Does SHarE add any value to CaNISC with the additional functionalities, if integrated?
	Any challenges, obstacles?
	Additional comments? Recommendations?
Controls and Functional Requirements	For each of the functionalities: 1. Does current system provide it? 2. Is it important? 3. How it can be improved? 4. Challenges? Comments?

with the Welsh Cancer Bank where patient consent is stored in CaNISC and the tissue and blood samples on another database [107].

Regarding other systems used alongside CaNISC, Dr. Morrey said: "there would be a radiotherapy system, connected to the treatment machines to manage and quality assure the radiotherapy treatments. There would be a chemotherapy system, which would be

used for prescribing and printing worksheets for production of chemotherapy, because quite often, the pharmacies make up their own doses rather than get something off the shelf. So those are the main ones; in a district general hospital there would probably be a surgery system for managing the surgeons' workload in theatre. And again in the district general hospitals, there will be a pathology system in Landough and the Royal Gwent; each of the district general hospitals there will be pathology departments and things, so you refer off to biopsies and things, they would report on those systems and yeah. Those, the reports would go into there. And obviously there is radiology systems for radiology results. And then there would probably be Patient Administration Systems but it's not really involved in the care, and obviously the GP system for there." When the interviewer asked which of those systems are actually linked to CaNISC, Dr. Morrey responded by saying: "it depends where about in Wales you are talking about," before he continued: "Certainly within Velindre, the radiology system at Velindre was linked in, as was chemotherapy and radiotherapy. So those were linked in, and so were relatively easy to get hold of. As you moved to other hospitals, the situation was much more patchy, in that probably radiologists and pathologies weren't linked in because of security aspects and volume of information and all the rest of it. So the further away you got from Velindre, the less links to some of the stuff in University Hospital Wales in Cardiff; certain results were there because we depended on the cancer centre being some small unit on its own."

Information sharing needs and research problem. According to Dr. Morrey, CaNISC started in about 1991, at a time when collaboration was not a major issue and "it was really 1997 that the idea of collaboration came in. He continued, "there was a Calman Hine* report saying the way forward for cancer care across England and Wales was actually this shared, and MDT's and all the rest of it."

Therefore, the interviewee was asked "to which degree do you agree with the fact that there is more pressure on healthcare systems to share information between hospitals because of that?" and Dr. Morrey answered without hesitation, "yes, I think that is true with this multidisciplinary care that we are talking about here." This confirms the need for cross-organisational information-sharing.

As a result of that pressure, "it was at that stage that CaNISC was completely redesigned to deal with that. And it had to be a pragmatic way of dealing with it, which leads you to certain problems and the rest of it."

Dr. Morrey explained, "it's always tricky with the legacy systems actually getting into them and gaining access to the information," Dr. Morrey continued. Then he explained in response to the question of whether CaNISC was designed as a disease, organisation, or patient-centred system by saying: "it was patient-centred by and large, but it got tricky in that if the patient obviously had other radiology results and other pathology results

which weren't related to cancer, and that made the linkage tricky. You can imagine your integration engine it has got to have some sort of rule to say, well what results do I bring across and move into CaNISC. Some of it was very raw in that they said, well we've got the referral for this patient, this is his patient numbers, tell me everything you know about them, and they'd bring it across, and then the clinician would have to decide what's important." The interviewer then asked about what happens when the patient has another condition, for example, and Dr. Morrey said: "Yes that, again, difficult things to know what to bring across and things, that's why it started breaking outside Velindre; it got difficult in integration on that." Eventually, he confirmed that CaNISC is mainly a cancer system.

Dr. Morrey said: "there was security concerns and the clinicians would be worried there is too much information being brought across that did not belong in the cancer domain if you like." Therefore, they wanted to restrict others accessing their information, and so Dr. Morrey commented "yes, the data protection people, and their system started putting up shutters, because they said why do you want to know all of that. But there was also data volume concerns as well. Because some of these databases were huge, the patients had been seen for years, before they maybe got their referral for cancer, or whatever. So when do you bring things across."

There is the pressure of sharing, then the pressure of security, so the people, the practitioners want more sharing and the people up there wanting more security, and that is really hard. But it is expected. First, how are current systems coping with that pressure? Dr. Morrey answered by saying: "with difficulty, the clinicians are switching between systems and screens and the projector has to flip between systems to do it. So all the things you've seen at the MDT's and, are exactly that, and how you've got a paper based case notes, you've flipped that up on there. And the information is not going to flow."

On the other hand, the interviewee mentioned data protection people adding shutters, and at the same time, agreed with the fact that there is more pressure to share, which shows evidence of conflicting beliefs: "they do, and, you probably saw in the MDT's the clunky way it works at the moment, in that you might have the MDT coordinator with one screen with CaNISC up, which is the shared information, might be with its limitations at the moment. But on another screen, another system, the radiologist is logged into their local radiology system, bringing up information on the screen about that patient in order to read it out to the meeting, which then has to be transcribed across there because there's not a direct linkage across it. Either because of security because of data protection but also difficulty of integration of systems on a technical level. And then the pathologist might be on another system bringing up their pathology reports which may just be a text report." The interviewer explained what she had observed at the MDTs in that the metastatic has

only two screens; for their normal breast cancer MDT, they have paper-based case notes, a radiologist form, a clinical form and they have CaNISC. And their oncologist came with a piece of paper, so it's so different and they needed that integration I think. And they recorded information after the MDT in the treatment plan, it goes back to CaNISC. It's the only way to get everything at that point for a decision. Dr. Morrey commented by saying: "yes, and you can see why the frustration of the clinicians in that it's clunky, it doesn't flow between systems on a system level, and the security, the clinicians are told it stands in their way of sharing. So it's at both levels, yes. So yes you've seen the."

The interviewer asked Dr. Morrey about whether he agrees with the research problem that sometimes the information does not flow, and whether he sees this based on his experience. He replied: "Oh yes, yes, all your experience from the MDT's is absolutely true, and I've also seen the difficulty from a national level of trying to get CaNISC to get information from other systems. And it's just beyond our resources to try and solve really."

Dr. Morrey mentioned that when it comes to adoption, clinicians' resistance is not an issue. He responded to a question regarding whether, based on his experience with CaNISC, it ever faced resistance from clinicians by saying: "I do not think the clinicians, no. I don't think in this particular case, it is the resistance of the clinicians. It's the resistance, is simply the resources and the will to do it. Also because they are trying desperately to catch up. If you like CaNISC and what we've done, and what you're able to do within this prototype here and way beyond what's available on the ground in most cases of the hospitals. And what the national people are trying to do is to get those people on the ground up to a common level before moving on and that's proving very difficult on that. So you have certain sympathy on that, but it is frustrating, I imagine, from Dr. Tom Crosby's point of view that he knows bread and butter stuff that he wants changed and he is struggling to get it to happen, and Anne Marie may well be the same that she wants things." Dr. Morrey continued commenting about Dr. Tom Crosby's struggle by saying: "Yes and also as clinical director, when the other consultants are getting problems, they will go to Tom and bend his ear." As a result, "he'll be able to tell you that years ago, we [CIU] just used to say well we think you ought to do it like this, and we'd have the meeting and decide to just go and do it, and it would be done, prototype fashion, fairly quickly so the prototype you're describing, the next stage, would be a prototype implementation in CaNISC and it would happen, and then you'd start seeing what the practical problems are, and evolve your prototype into the real system. It's not quite the same" [107]. Dr. Morrey explained later in the interview that "NWIS are withdrawn; most developers have gone on to try the first stage of the Welsh Clinical Portal. So CaNISC no longer has the development for sources devoted to it that they used to have. It's almost legacy tick over

to carry on. So that's the only proviso on that."

The current situation seems to be a difficult one to deal with, so the interviewer wanted to shed some light on the future plans of the CIU to tackle this issue, asking Dr. Morrey: "from your own experience throughout the years at Velindre Hospital, what do you think in these systems' agenda for the people to cope with that situation until everything is sorted out?" He answered by saying: "well, I suppose what eventually they hope will happen, I'm not quite sure what will happen in England now that they've abandoned their over-arching integration things. Yes, they were going to have this record which went across all the different organisations, all the different hospitals in England, of what they call a common spine. Yes, it was something called a common spine and all systems were meant to integrate with the common spine and send information into the common spine so you could, the clinicians would be able to see information from various places and things. I think they now lapse into more similar solutions to how the way Wales will go. I suspect it will go regional [Wales], and regional, what will happen, so you'd take off a geographical chunk that is reasonable where the patient flows, if you like. So you know that the patient is going to go round Wales, by and large, ok there are some referrals across the border, which are a bit more tricky. But from a Wales point of view, you can see the patient goes around there, so what you need to do is link those systems in some way, in that local region of Wales. Or it could be the local region of London, or whatever, and you know that in there, as you've identified on your slides there, you've got linking the GP's with the local hospital systems and etc. etc. and I would expect for something similar to how they foresee it working in Wales which is some sort of Welsh Clinical Portal where all clinicians use this portal. And the Welsh Clinical Portal implements some sort of security model, just the same as yours. And some sort of local integration engine behind there and it provides a common portal for implementing information and then they envisage, do not know whether it will happen, but they envisage that that clinical portal will link to CaNISC so that whether you say it's a cancer patient, suddenly you bring in CaNISC into the picture to gain information. And actually the information will be stored in CaNISC so that it will avoid needing to go into the local radiology system. Because the Welsh Clinical Portal, no matter where it is in Wales, will link in with the local radiology system. Or the local pathology system or the local patient and administration system. So there must be some sort of security model, and security system as you've indicated in order to cope with that. Don't know what it will be; I don't think they know themselves at the moment, it's quite a complex situation."

The interviewer asked Dr. Morrey about whether these future developments would keep those legacy systems, and he confirmed that: "yeah, I think at the moment, they may replace them bit by bit, because the pathology system for example, the local pathology

systems in Wales are being replaced with a national pathology system, which is one system for the whole of Wales with common codes. So at the moment, the pathology systems in the different hospitals use different coding systems for different diseases." Therefore, they want to standardise the different similar systems first, so they are doing it gradually. Dr. Morrey continued: "they are doing it gradually, and of course they run into problems, because there is a lack of money now to even implement the Welsh Clinical Portal and the roll out of this national pathology system to replace the local ones, it's a big implementation task, so it's taking time to do that. But yeah, that's how I guess it will go, and I expect that system of regional will be rolled out in England as well."

The interviewer explained two conflicting opinions regarding the research problem that were obtained from other interviewees in order to seek a justification for such a conflict from Dr. Morrey. She said: "the MDT coordinator said: 'Oh, the problem actually does not exist, because the information is always there but the clinicians do not really bother to look for it.' This is what she told me, while the nurse told me the exact opposite: 'no, there is a problem and the information is not there and it's really hard to get it out of the system.' So two different opinions about the same problem. Do you have a justification for that?" Dr. Morrey thought for a second before responding: "Well, I think probably both are right in that you got to understand the clinician for a lot of the MDT's round Wales won't have, won't know how to use the radiology system, or the pathology system. Now the MDT, yes he needs, and do they really want to get involved in all the intricacy that others have. As you see, you want to see, as you've shown in your security model, where you say, availability of the right information, not all the information. If you just access the raw radiology system, you're going to see everything, all the details a radiologist needs to know. Well you don't want to see, the clinician who is trying to treat the patient doesn't want to see that. They just want to see the filtered information as you've got it. So that's absolutely right, so both of them are right and the MDT coordinator has had to overcome those problems and knows just where to go, to individual systems to get it out. But it really is asking a bit much for the clinicians to actually do that, and most of them may know about CaNISC or their bits, or they may know about their local system or they may not. A lot of them don't use clinical systems on a day-to-day basis. So to ask them to suddenly flip between a pathology system or a radiology system or CaNISC, it's a bit much. So they're both right to a certain extent. And, also, they may well not have security credentials in all those systems. You tend to find that radiology systems are only made available to radiologists and not the other people, because they say, well, this system isn't really designed to be made available for everyone else, because you could just have clinicians going in and messing up systems. It's not protected; as a clinician you go in there, radiologists expected to make changes. Well, we don't have a separate

module for clinicians to log the information so it is, it becomes a real security risk to the local systems, to have lots of these people who don't know, not trained in the system, who don't think in the way those systems work, to access them."

There are different hospital numbers for hospitals used as patient identifiers. This means that, from a technical perspective, there is a problem in current systems as there is no unique unified identifier across the systems. Dr. Morrey explains, "It's for the same reason that there were different systems," before going on to say: "when they started out those legacy systems, there didn't use to be a universal identified, so you just issued a number for the patient identifier for that system. And you kept on using on that; it's only at a later date that the idea of a more universal identifier, the NHS number. It's an emerging scenario to try and overcome that. Otherwise you'd need multiple indexes for the searching. And again, some of the integration engines do have this, does take that facility, provided for you, which is another reason." Because of that issue, "it's always tricky with the legacy systems actually getting into them and gaining access to the information; it's always you've got integration engines to try and do these things." He continued, "it's always tricky, the integration, because that's part of the reason why we've had problems now. And the Welsh Clinical Portal and the other portals that have been round hospitals, they have the same issues basically. Because they need to grab information and you put one identifier in and hope you can get across." Dr. Morrey continued: "it could be the different hospital numbers, or the patient name and what number is there, because very simple example is that the surgery might have been done in Gwent and they will have maybe used a local patient number there. But you're in Brotaff or Velindre and you've got a different number for that patient. So you've got to link the two in some way. The way CaNISC does it, it will grab, it will store any number of hospital patient numbers against the patient's name and address." As a result, the patient has different numbers on different systems and "basically, you can use any of those numbers to search on those." Dr. Morrey commented, then he justified by saying "because, again, at a low level implementation, you'd have to know I'm going to that local system, what sort of identifier do I need to use for that patient to actually gain access to that. A lot of the local systems now do store the NHS number. You know, it's been mandated, it's not completely unique, but it's much better than what we used to have before with all of the local systems. So it's usually a lot of systems do have that number there."

Finally, Dr. Morrey was asked if he suggests that we use an identifier, and whether this should be the NHS number. He agreed by saying: "well, I do think NHS number is very useful; it's probably the best that we've got yeah. But just be aware that just like CaNISC, you might need a database behind it that says, well, yes the NHS has got that number, but

there are other local numbers for local systems." This is mainly because the movement towards a more unified record, the NHs number, is becoming mandated from April 2014 [115].

SHarE. In this section, the interviewer asked a set of questions that reflects the interviewee's opinion about the proposed ideas tackling the research idea, potential adoption by clinicians, possibility of integration from a technical point of view, and any challenges that could be faced. Dr. Morrey started by saying: "Yeah I can see the logical model following on that, and I like the way it builds on what we done before with the work flow and I think that will be helpful to demonstrate to the other clinicians on that. So I think yep, as you said there, it does have the potential to address the issues, yes it does." In addition, although Dr. Morrey could foresee a potential for healthcare professionals to adopt and use SHarE when he said: "I think there is," he predicted a possible barrier when it comes to changing the practice to fit the new system by saying, "the barriers as you say, and as we discussed a little, are the integration with those other systems. The clinicians will immediately say for my GP has I got to enter information separately into my SHarE system as well as into my GP system, what I'd really like to do is implement it in my GP system then SHarE to automatically extract it via my interface to present it within SHarE." Therefore, the clinicians would prefer to keep the day-to-day practice using SHarE without extra training. Therefore, the information is entered through the system SHarE, collected, presented in a screen, then a button is pressed for referral. Dave: "that's right, yes, and similarly, if someone is regular user of CaNISC like Dr. Tom Crosby, the information that he puts into CaNISC he would expect to be made available to others just as he'd expect to have the information from the radiology system or the pathology system to just be available to him. He's got to enter it into separate, two separate systems, then you're running up against the flow." He concluded by saying: "and it may well be that that's where it puts additional pressure on your integration engine and how your low level stuff gets in to the system. Is it just one way extracting information for presentation only or not."

"The Welsh Clinical Portal is supposed to be a viewing system only, I think, at the moment." Dr. Morrey clarified, then added that the Clinical Portal that Helen is using is not the Welsh Clinical Portal but Landough's UHW implementation of a clinical portal." He elaborated by saying: "well, each hospital or trust, as well as having its own radiology system and pathology system with separate implementations, also at the moment has its own portal for viewing stuff. They have a similar idea, but they're local implementation. Now what's happened is the national Wales people have said well yeah these are all very good little local models, but we want something which works across the whole lot of Wales, like CaNISC works across all of Wales, so we will produce a new Welsh Clinical

Portal, which is going to link in with local systems, but it's going to work the same as far as the clinicians looking at a system, he won't be able to tell if it's a clinical portal for Gwent, or Cardiff and Vale, and he just gets into it and sees the information there." This justifies the confusion because according to Dr. Morrey, "that's why, so they [the other implementations] work similar to what Helen showed, but it will look and feel slightly differently. And I think the first implementations, although they have the same look and feel across the different hospitals and trusts, or health boards as they are called now, only links with their local systems at the moment. So in other words, they haven't produced a unified system as you described there; it probably won't help in the first round. And even now they're still struggling to get these implementations, the local clinical portals replaced with this Welsh Clinical Portal. But that's where they're going, the second model later on will say well now we actually need to open up the barriers, then they start saying which security model are we going to use to do that. We start getting into that, but at the moment you can see it will be a fairly simple implementation to simply use the same rules at the moment, because the security, it's all been done." The discussion concluded that both the interviewer and interviewee agreed that the local security of these individual systems needs to be maintained, and there is a crucial need for a common security context to serve the sharing, when Dr. Morrey commented: "Yes that's right, so it's the second phase of the Welsh clinical portal implementation will then start saying, well now we've got to share things across the boundaries, and we've got all this business of things." Finally, Dr. Morrey commented that when it comes to the challenges faced for the development of the Welsh Clinical Portal and all that, "yeah, there are some real practical issues."

Dr. Morrey appreciated the fact that SHarE aims to build the common security complex to meet the sharing needs on top of the systems and maintain the security concept of local systems. Therefore, CaNISC, for example, and all other systems function as normal with no interruptions, while SHarE is built on top of it to create a new common security context just for the collaboration. As such, it has its own security concepts to help with sharing between them. He commented by saying: '"so it can help with the fact that the local systems or the existing systems do not know about multiple organisations or you have got issues with what you can share and what you cannot share because their systems rely on different data." He also added: "well, it's always tricky with the legacy systems actually getting into them and gaining access to the information; it's always you've got integration engines to try and do these things. And I suppose that's the way you'd have to do it. You'd program some integration engine to link the systems." Dr. Morrey concluded by saying: "I like the concept you are proposing; it's logical and it builds on what work we've done before and builds on Hessah's work flow and you can see how it's coming along and links to those things. But the practice of actually getting information out and

effectively being somebody to gain access to that information" is the tricky bit. However, Dr. Morrey agreed that SHarE will help with the integration regardless of the issues he predicts by saying: "Yes, I guess the answer is it's just at the moment integrating systems, wouldn't have to use integration engines, and it's a bit dirty how they actually link and get information across. You'd still have those issues, just the same as they are now, and you'd probably use an integration engine with its rules and things. It then sits behind the security framework on that."

Finally, Dr. Morrey agreed that healthcare is an extremely complex domain, and he commented about the fact that any solution that works in healthcare can work anywhere else by saying: "I wouldn't be at all surprised, you're talking about very long longitudinal records in terms of time history and complex organisations and different systems; it is probably one of the most complex systems, the integration engines are one of the most complex. And the security aspects of them are the most complex yeah."

Controls and Functional Requirements. The interviewer asked Dr. Morrey if the controls and functionalities identified in this research in general can assist in building the Welsh Clinical Portal as ideas without going into the details of their implementation. Dr Morrey responded: ""Yes, I think it's certainly ideas, I think that could be. He also added: "I don't know what security model, because in a sense, it may well be there's somebody behind the scenes is sketching this even out now, and I don't know who that is, or how far advanced it is. You'd need to contact someone within the Wales NHS informatics services, not quite sure how far advanced that is. I used to know someone who was doing that. I'm pretty certain that's still the state of play at the present time."

In regards to a possibility for SHarE being integrated with CaNISC with the previously mentioned concerns put in mind, Dr. Morrey promisingly asserted: "yeah, I think maybe with provisos of the integration engines etc, then it's a much better model to try these things out than others. Because in a sense, CaNISC is trying to do something similar, but it's a much more less sophisticated level. So yes, I think there is the real potential to try it out; the practical things are that NWIS are withdrawn, most developers have gone on to try the first stage of the Welsh Clinical Portal. So CaNISC no longer has the development for sources devoted to it that they used to have. It's almost legacy tick over to carry on. So that's the only proviso on that, but yes, SHarE is a much closer model to, because at least it understands that there is more than one organisation." Furthermore, when prompted about SHarE adding any value to CaNISC if it was to be integrated with it, he responded, "Yes I think it will" He then added, "yes I think it can add that extra functionality because it makes the sharing security model a bit more explicit and anything that helps with getting the information out, would be a help in that one."

– ***Information access is patient-centred based on the patient's condition and treatment stage and neither organisation nor disease-centred.*** The interviewee commented about this functionality by saying: "Yes, it is" an important functionality, and that current legacy systems provide it "to a limited extent," Dr. Morrey pressed. He continued saying: "because even as you've seen to a very limited extent only, CaNISC really understands the multi-organisational, crosses the boundaries and even then there's criticisms of CaNISC." He also explained, "well because you log in as a particular organisation and you see information presented about that organisation. Now you can click down the bottom to see information that has been entered somewhere else. You can see a summary of it and click into that information, so you can actually see it, but it's not all presented at the same time. So some of the clinicians, especially those that are not used to using CaNISC on a regular basis, say well I want to see it complete centric, I don't want to see this organisation, I want it to be organisation transparent as far as I'm concerned, so that's the criticism that they would make." He added: "it's partition based, that's right, the partitions are visible to the user. If you know the system very well then you can easily overcome it. So Tom Crosby says well it isn't really a problem, but Ian Moneypenny who doesn't use the system on a regular basis says, wow I just want to see it. Whereas SHarE would show it all there, he would say yeah that's much better for me, because you hide some of the barriers and partitions." Finally, regarding a question about ways the interviewee would suggest to improve this functionality, Dr. Morrey said: "No, I think that's good, I like that model because it's logical and follows a natural model at the moment. I think the only issue you might have is if you can't get information from the underlying systems to match in with your model there. That would be the only issue, but in terms of logical things, I think all the clinicians would sign up that, and understand that."

– ***Information organisation in chronological order (in a timeline format) with a stamp showing date and time of care point, and who saw the patient.*** Dr. Morrey also commented by saying: "Yes, I think that is important, yes." He then explained how information is presented at CaNISC by saying: "it's not the primary way of presenting the information you can get a summary in CaNISC. There is a summary that brings up all the things that have happened, similar to this but not in the logical treatment pathway that you've done it, ok? But it does show you the different organisations the patient has been to see and who's put stuff in there, but it is a bit clunky because it doesn't follow the pathway as yours, yours is a more logical pathway way of presenting it. And also that summary page is not the default one you get when you go into CaNISC; I log in as Velindre clinician or a UHW clinician,

so it's not the default one." In addition, Dr. Morrey mentioned that the Welsh Clinical Portal, in its first stage, is implemented as a linkage between the mini local Clinical Portal. This means that although this system will address the cross-referencing and gather most of the information about the patient from the different hospitals to help with the comorbidity, it still will not change the way it is organised. In other words, it will still organisae the information the same way as these local portals do, namely categorising information based on its type.

– ***Automated referral to a named CT member or a role that is picked up by the recipient with all information needed.*** "I think that is important," the interviewee answered, and confirmed that none of the current systems automate referrals by saying: "no, it's no, you've got to go and dig it out from that, there's nothing. That's one of the criticisms, not criticisms, limitations of CaNISC, in that it doesn't have anything active about it, you're always going to do things yourself." Moreover, it is crystal clear that referrals were never part of the security model in CaNISC this is because when the interviewer asked Dr. Morrey about whether referrals should be implemented to a named person or a role, he honestly said: "the honest truth is I don't know, I don't know enough about it. I don't honestly have enough practical knowledge of that; I think you need to pick that up from the people who are involved." However, he said: "sometimes people have different roles, it's all about, there's a little bit of research wasn't there, and was it Alysia, she did the role base, and I think we ran into problems, of sometimes people had different roles at different times within the team. So I defer on that one."

– ***Filter and gather needed information from the different systems at the point of care based on clinical guidelines.*** Although Dr. Morrey clarified that current systems do not provide such a functionality when he said: "No, I don't think there is an automatic way of doing that," he emphasised its importance by saying: "Yes I think that would be very helpful, yes."

– ***Information can be amended after sharing by originator and this will automatically alert everyone involved.*** Regarding this functionality, Dr. Morrey said: "I think it's certainly important to do that." He also added: "then you've got to make sure it's cascaded through. Yes it is important to know about those, because there could be some important changes." However, current systems "deal with it, poorly," Dr. Morrey commented, then elaborated by saying: "it has to be manual. You know they used to, currently the way they do it, because they're used to generating reports by paper to go through, they'd have to generate another report and send it through. Sending it through electronically to another system, they do it poorly at the moment

but it would have to be done. That's something that is a challenge for your low level integration engine, what are you going to do about that."

Furthermore, the interviewer elaborated and asked whether the amendment should be done by anyone in the care team or only the person who reported it, and Dr. Morrey's response was: "no, it's, in our experience on CaNISC, it has to be the person who recorded it, because they might have a different opinion of it, and for, should we say a nurse, or let's take the worse case scenario, medical secretary of Dr. Tom Crosby thinks oh that's wrong, and goes and changes something from a consultant on another system in another organisation, I think that's wrong, because they haven't got the knowledge to do it. I think you do need, I think it is a functionality that you need in your security system to recognise that someone is going to see; with this sharing you improve information accuracy and therefore the information security system or the workflow system needs some way of trying to make that as smooth as possible. Alerting the other people, the other end, hey there's an issue here, can you please attend to it, then they need to cascade the cascade through." Then the interviewer added: "and you can see the security system finding a way of bringing things together within the one context, you have got a better way to improve the accuracy of the system because it's easier to review. And also, if you then use your workflow to implement, you've got maybe a way of better alerting people at the other end that there's an issue, and also hopefully then cascading that result through. So again it works much better."

– ***If extra information is needed at any point, trusted CT members could break-the-glass and access all information they need, then they have to justify it.*** Initially, the interviewee agreed with the interviewer that this is an important functionality, especially to grab the information that is needed. However, the use of this feature suggested by the interviewer (as discussed in previous interviews) can be at a bad referral, meaning when CT members did not record the information through SHarE for example, so in this case, all information about the patient is broke into using SHarE. On the other hand, it can only be used to store information that is labelled with sensitive information to add the extra protection. Dr. Morrey made a choice of preference of application by saying: "yeah, I tend to go along with that, the break the glass just gives you access to whatever information is there, which brings me back to that initial question I asked, is that how do you know what, because the one scenario you talked about is this is standard information that you'll come across anyway, so you know it should be there. Assuming that the clinician at the earlier stage put it in. You know it should be there, but it has for some reason not been included with the referral." He continued: "so I think that one, yes you can see

it's a simple situation and you don't really need the break-the-glass for that one. But the break the glass is for something which is when something is broken down here, so we need to access the raw information to get that. I mean break glass is a great concept because it's easy to explain to patients and everything else, but I do worry slightly in that, how do you know whether someone has actually stored some information behind the break-the-glass, because there is no indication on the system at the moment that it's there. Have you got to search through each step to find out." He asked, "is there an issue that you do not know what you don't know?" The interviewer explained by saying: "because here it says that it's been through the GP, it's been through the surgeon, but you can't see that information. So you know that the patients were seen them, but why is it not there. You can tell that it's passed, why was the information not there." He added: "right, so in that case, you need to access the system at a raw level really, basically. Yeah, I think that's probably what you need to do, yeah that's." The interviewer explained a real-life case she experienced in one of her observations where this feature would be handy by saying: "twelve of the patients were not discussed at one of the MDT's I've been to because the information was not there at that point of time. And the patient has been referred but the information was not there. The MDT members' response was: 'we don't know why, so we're going to investigate why this is happening and come back next week.' But a week delay makes a huge difference to the patient's treatment," the interviewer concluded. Dr. Morrey commented on her statement by saying: "yes the clock is ticking and things, and the patients wouldn't understand that delay," and continued, "yes, and that's the scenario I said, that the poorly patient would see things quite differently to a general open question about access in the general public. Yes. So ok, I wonder if that helps or not on those."

Moreover, Dr. Morrey gave an example regarding taking patient consent to break into their information when he said "I'll throw in something whilst I remember it; one of the things that NWIS have done with the out of hours system, because what they've got is access to the GP systems, the scenario in Wales, is that the GP practices, is that they don't have the GP's on the out of hours service, so you've got somebody who doesn't know anything about that patient. And they've got the patient in front of them and they need information on that patient in order to treat them, because the patient is there and needs treating. And what they actually do which has working in unlocking the GP's system, is that they actually have the patient in front of them and say do you give me permission to access your system in order to treat you, and of course, that's a completely different question to asking the general public; do you think you should share that information or not,

and under that circumstance people say very sensitive. But if you ask the patient, the poorly patient, whether you can access their information, well of course, I'm feeling ill, I need that access." Then the interviewer's reaction was to ask him about what happens if the patient is not conscious and he responded by saying: "well that's then maybe when you need the break-the-glass, but ordinarily with the out of hours one, and probably with this cancer system here, you may well be going to discuss the patient in the MDT, discussing that patient, you need that information, you may well come along with something which helps you break-the-glass, because the patient has given their implicit consent. Because a lot of this is implied consent between there. You may have something which you need to put complicit consent in order to get over this issue. I don't know, it's not something that's been done in the cancer field, because they don't feel that they've seen so many patients in the cancer field to have to go to each one and say do you agree to share that information with the patient, by and large, thinks of course I need to share this information, how the hell, I've just been to see the surgeon down there, why on earth don't you know what's happened to me there, I don't want to, providing that information. But that might be another scenario into the break-the-glass. I know that complicates things for you a little. It is a case of balancing, I would have thought." The interviewer interrupted and made a comment by saying: "in that case, maybe the person is not normally supposed to see that information. He's taking this information because this is an emerging case, it's not the regular treatment, so now that this is happening." Dr. Morrey responded: "yes, because I suppose most of time we're presuming compliant consent."

Nevertheless, Dr. Morrey expressed a privacy concern raised by this functionality by saying: "one thing on security, one scenario, I don't know if anyone has raised it with you. But I don't know whether your security model deals with it, you know you're talking about roles and individuals; one of the issues we came across with CaNISC and its implementation is that if you limit access. I mean the logical way to limit access is to say, well consultant 'A' has not had a referral for that patient, therefore they can't see information about that patient. And we didn't do that, what we said was once there's been a referral into that particular organisation then anybody in that organisation can actually see information about that patient. And the reason we did that rather than, because I mean the logical thing is to say well that patient belongs to that role. Well, not that hospital, it belongs to that consultant firm, that individual consultant and everybody in his team. The problem we ran into was when you implement that then in terms of the security model, secretaries, medical secretaries for an example, or sometimes maybe a nurse, would actually

have wider access than the consultant." He continued: "well, the reason is that the consultant belongs to his firm, and he sees patients about his firm. The nurse or the medical secretary may need to cover for another medical secretary who works in another consultant firm. So, you end up with a situation where the medical secretary or maybe the nurse, in their role which spans consultant firms, needs to have wider access than individual consultants and it becomes quite a nightmare to actually implement that. Which is why we, the way that CaNISC operated it, was to say that once you got a referral into the organisation, then anybody in the organisation can actually see it, and the way we enforced that was there's a security log, so any time anybody reads anything or changes anything, it's recorded in the database. And everybody knows there is that full audit trail, so they have to be able to justify it for themselves, why they're looking at that patient. So, in other words, if a medical secretary worked for Dr. Tom Crosby, but was asked to cover for Peter Barrett Lee, then justifiably she's looking at Peter Barrett Lee's patients, information about those patients or reading it." Dr. Morrey added that although "she always logs in with her name, the CaNISC security model is quite wide. Anybody within Velindre can see the patients that have been referred to Velindre, and sometimes we have had the practical example where there's been perhaps a patient with a well known celebrity or some famous sports man, and then they want to see, and just out of curiosity, they've gone it to see what's happened. Or there could the example where they're a neighbour, just a clinician, they're a neighbour of that clinician, and what's happening, I haven't heard anything about the results. And that consultant may log in, or another clinician or a nurse on the ward may log into that patient to see what results are, before the proper clinician has had. And that's a situation." Eventually, the interviewer asked the interviewee if he would go back in time to do it properly, whether he would go for the first option that whenever it is referred to a role then only that role can see that information. Dr. Morrey's response was: "I don't know. I don't know whether our cracked with Alysia's researched on there. But I pointed out as a practical example of a security model, and I don't know to what extent." The interviewer concluded by explaining how such cases are tackled in SHarE when she said: "SHarE here only lets you see information for the patient referred to you. You don't see everyone, and because it's patient-centred, this is for Susan, when this case goes up and it's for Susan, and everything needed for Susan's case is gathered and reported in there. Nobody else's case." Dr. Morrey thought before commenting: "what you've then got is the situation where you'd have to authorise Dr. Tom Crosby's secretary to have that role. But there may well be a break-the-glass situation under that circumstance." The interviewer said the breaking-glass is

for everyone, before Dr. Morrey responded by saying: "right ok, then that might be legitimate use of break-the-glass, because that medical secretary doesn't normally provide any cover for Peter Barrett Lee, because he's up the end of the corridor and there's a different team providing cover. But under those circumstances, she may need to break-the-glass simply because nobody is available to authorise her on the system and she's got to provide some care, under those circumstances. And it may be that Alysia's research sorted that out, in which case you're building on Alysia's research for that. But it is, these are practical examples you get into, and it's your security model, it may well need to pick these up, and how are people going to be authorising these."

– ***Labelling the sensitivity level of patient-identifiable information and communicating it to all healthcare professionals as a technique to raise their awareness.*** Dr. Morrey thought this functionality should have a default and agreed with the interviewer that "Care Team" should be the default. He commented: "the reason I ask about the default is that by establishing a default which is 'Care Team,' which is a logical choice, it means that putting the information in doesn't involve lots of extra work, because you've got a default there, you haven't actually got to keep pressing that button."

Potential Challenges

– *Security access mechanisms at a low level.* Dr. Morrey generally commented about the research idea by saying: "I can see the logical consistency you are doing from that over-arching framework there, I know it links in with the pathways we've done, so that's nice and logical." However, one of the things that the interviewee wondered about relates to "the lower level interfaces with those legacy systems. Where they have their own security access mechanisms and the users, I mean, in a sense the, you could have Annabel as the oncologist trying to access or break-the-glass on a radiology report, when she's not a registered user on the radiology system. How does your system deal with it?" The answer the interviewer provided was that the main aim of this proposal's security model is to avoid interrupting the security contexts of the legacy systems linked with SHarE. Therefore, if Annabel can hack into the radiology system at the hospital, then will still be able to do it and this is not our job. What this research aims to do, is to make sure she does not access this information from SHarE without being a CT member who treats that patient, and she needs to access it to care for that patient. Therefore, she cannot log in and search for all the patients and see all of their operations; she only accesses the information for patients she sees or actually cares for. The bottom line is that

SHarE is not concerned with the security in terms of what is going on there,;if it can happen today then it will happen with the system, because it does not block people from doing it, but it is dealing with the common security mechanism at the collaboration level and not at the level of each individual system. The good feature about SHarE is the notifications that the system provides as part of improving the CT member's experience in a shared environment. Therefore, if the CT member amends information in legacy systems directly, then it is only there for themselves and no one will know about it unless he/she manually notified everyone they think is involved. While amending that information through SHarE, this notification will be made automatically through that system. However, theoretically, SHarE should also update the information at the legacy system's database, only if it was recorded through SHarE in the first place, otherwise there would be issues if SHarE was able to update legacy systems' information. Dr. Morrey commented about this by saying: "well, it's always tricky with the legacy systems actually getting into them and gaining access to the information, it's always you've got integration engines to try and do these things. And I suppose that's the way you'd have to do it. You'd program some integration engine to link the systems. I'm just thinking off the top of my head here, because the examiner might say I can see how your top level framework concept, the concept you are talking about, I like, it's logical and it builds on what work we've done before and builds on Hessah's work flow and you can see how it's coming along and links to those things. But the practice of actually getting information out and effectively being somebody to gain access to that information." He agreed with the interviewer that SHarE could actually become a burden as it will be another extra system that will need to be used along with the number of other systems.

– *Integration engines.* Dr. Morrey commented about integration engines when he said: "well, it's a case of parting identifiers into the information engine and passing that information to the identifier and saying I want to gain access to that record, and it's maybe an HL7, or an interface like that, that allows the transfer of information out when you request that information. There are commercial solutions and yeah, there are various integration engines on that". He added, "if you don't have an integration engine, you're tending to write bespoke interfaces, and bespoke interfaces tend to use standards like HL7 for interchange of information between systems." One question he asked is: "how would it work down at the bottom, as opposed to the interface between clinicians and the team members?"

  Furthermore, one of the clear challenges in the integration of SHarE with legacy systems, is the fact that patients have different identifiers for the various hospitals.

Although there is a unified NHS number, current systems have local identifiers, and it would be challenging in terms of how to map these identifiers to link the patient to the different records in the different systems to view it on SHarE. Dr. Morrey said: "it's always tricky, the integration, because that's part of the reason why we've had problems now. And the Welsh Clinical Portal and the other portals that have been round hospitals, they have the same issues basically. Because they need to grab information and you put one identifier in and hope you can get across". He commented by saying: "it could be the different hospital numbers, or the patient name and what number is there, because a very simple example is that the surgery might have been done in Gwent and they will have maybe used a local patient number there. But you're in Brotaff or Velindre and you've got a different number for that patient. So you've got to link the two in some way. The way CANIS does it, it will grab, it will store any number of hospital patient numbers against the patients name and address." In other words, the patient has different numbers on the different systems, and, according to Dr. Morrey, "basically you can use any of those numbers to search on those." He added: "because, again, at a low level implementation, you'd have to know I'm going to that local system, what sort of identifier do I need to use for that patient to actually gain access to that. A lot of the local systems now do store the NHS number. You know it's been mandated, it's not completely unique, but it's much better than what we used to have before with all of the local systems. So it's usually a lot of systems do have that number there," especially, according to Dr. Morrey, when the patient moves "from organisation to organization, which is something concerned with security, because the last thing you want to do is bring up information for the wrong patient, from a different system." He continued, "once you get into Welsh names, you've got all sorts of problems, and I'm sure there's lots of scare stories. You can have all sorts of scenarios where you've got, you can even have silly systems where parents may have named two twins a similar name, the first name is similar of same first letter, or even the initials are the same. And there they are, got the same date of birth, born in the same place, same parents. And they've got the same initials. It is tricky. So all these are security issues. And they're not unique to your system, but they are cases that can happen. And obviously these integration engines can help do that."

To conclude, the interviewer asked what Dr. Morrey thought about a possible unique identifier that can be used in SHarE, and he said: "well I do think NHS number is very useful; it's probably the best that we've got yeah. But just be aware that just like CaNISC, you might need a database behind it that says well yes the

NHS has got that number, but there are other local numbers for local systems." The interviewer asked for clarification about why there are different numbers for hospitals in the first place, and Dr. Morrey responded by saying: "it's for the same reason that there were different systems. When they started out those legacy systems, there didn't use to be a universal identified, so you just issued a number for the patient identifier for that system. And you kept on using on that; it's only at a later date that the idea of a more universal identifier, the NHS number. It's an emerging scenario to try and overcome that. Otherwise you'd need multiple indexes for the searching. And again, some of the integration engines do have this, does take that facility, provided for you, which is another reason." He then added: "well some of them will use the local PAS number, which is their identifier in that particular region, so that's the reason why. So that's why your low level interface might have that integration engine, which deals with searching all the different numbers and storing different numbers." Besides this, he commented later in the interview by saying: "there may well be interfaces to different things and ideally you'd use integration engine which means it's all in place. But worst case scenario is that you'd have to write a bespoke interface to get information on particular patients or extract it from particular systems."

At the end of the intensive interview, Dr. Morrey commented by saying: "I don't think you've missed anything. I like what you've done, I would love to be in post, and have sources within CaNISC to actually be in a good position to use it, because it's the issue we've run into a few, over recent years, in that the research has run ahead of our ability to implement it in there. Because we've been slowed down by the national people in their view of things."

E.5 Full Interview Transcript with the Former Head of CIU

Shada: So I just want to evaluate the system and you're the perfect person to do that because you've been involved a lot in the lovely CaNISC. Ok so SHarE is for my research and PhD's point of view, it's a patient-centred information access control. Implementation for a secure healthcare collaborative environment. So it's for me, I'm trying to provide a solution that can help with the adoption of patient-centred concept, in healthcare. So this is what I came up with. Ok so I'll start to talk about research background, a little bit of the background and then I'll introduce scenario

that I use as a basis for my implementation and the investigation. Then an identification of the main problem we are trying to address, the aim and what we're trying to do, and the requirements that we identified hoping that will address this problem. And then I'll demonstrate SHarE with a couple of screen shots and I'll ask you a couple of questions, it's so simple.

Dave: OK.

Shada: I'll give you this, it's a sheet with the questions, we can do that later. It has the agenda and the requirements. Thank you. So starting with the research background. Well, mainly when I started my PhD, I aimed to investigate an address security issues or information security issues in collaborative environments in general. I picked healthcare as my applicable domain and mainly because of the connections of my supervisor and it was the perfect decision to make. And in healthcare, we find that patient-centred care is an exemplar of such environment in the healthcare domain. This is where it comes from. I wanted to create a secure collaborative environment in healthcare, this is my main aim, that can enhance secure cross-organisational information sharing. Because when I met Dr. Tom Crosby this was one of the main things that they had trouble with, is information shared cross organisations. And the concept, the way I want to do it, is build a common security context, on top of the systems and maintain the security contexts of local systems. So like CaNISC is kept as it is, security with everything and all the other systems but build this on top of it. It has it's own security context to help with sharing between them. So this is what I want.

Dave: So it can help with the fact that the local systems or the existing systems don't know about multiple organisations or you've got issues with what you can share and what you can't share because their systems really on different data. Yeah, OK.

Shada: So this is the treatment scenario, this is what I implemented and this where I investigated the problem. So in breast cancer treatment, the patient sees the GP with the symptoms, and then the GP collects information about the patient, asks the questions, check the history and everything. Then they examine the patient, if he is suspicious then he would refer the patient to a specialist and he will share information with that specialist and this is in another hospital. The specialist will then start the triple assessment, the triple assessment starts with a further medical examination and history check. And then the specialist will refer the patient to a radiologist and pathologist for ultrasound and biopsy. So the results from these three tests will be discussed at an MDT. At an MDT review they collect that information, the test results and everything and they decide the treatment plan. And then most of the patients, follows the common "Happy Pathway," they call it so, without complexit-

ies, keep it simple straightforward pathway, is that most patients undergo surgery, operation as the first treatment option. After the surgery, or the operation there is a post-operation MDT and up to the MDT that involves both types, where the patient case is again discussed after the operation. After the MDT, they're happy with the pathway normally, by an oncology who treats the patient with chemotherapy or radiotherapy. And then maybe if the patient relapses years later they're referred to palliative care. So that's typical common scenario in treating breast cancer. Now, the problem we found in such a scenario, or maybe other any scenario regardless of it's complexity, that the secure cross-organisation sharing needs more focus. And what we found is that many of these systems are legacy. They were developed at a time when they were not in the habit of sharing information, so that's mainly the problem.

Dave: Yes, yes.

Shada: So there's nothing wrong with them, it's just that they were built before the concept of sharing, collaborating and everything. And it's so expensive to build a system, so it's not easy to just wipe everything and go further, so you use what you've got but you've got address the problems that you're facing. So they are discrete legacy systems, from Dr. Crosby's meeting, he said that sometimes it blocks information flow with a patient. So when a patient moves from one hospital to another this information sometimes does not flow. We believe the main reason, because information availability is very critical in security. So in security you balance the integrity, confidentiality, and availability of information. So for example if you make something highly confidential and you compromise on availability then that's not a secure system. So from our point of view information availability is a security concern, and we believe the main reason why the information is being blocked is because of security rules not being in harmony. So every system has it's own way of doing things and securing stuff, making information available. So this result and the information haven't been available at the point of care. And this is very important to make information available. This is the problem we are identified in our research. So we know that there is transformation or shift, from the disease-centred towards a more patient-centred one where all the systems come together and they share the information around the patient case. And this is emphasised more on integrated care, healthcare professionals working as a care team. They make sure decisions and this makes a huge, well they need cross-organisational information sharing, this is very important for this patient-centred care. And this is what we're focusing on, the cross-organisational information sharing. And if we look at, the different colours indicate the different information systems involved. So you see we have at least six

different systems involved. And we'll be looking at the problem again of information security, that's not in harmony. But I would just like to explain how I look at information security from my research's point of view. If you take one information system, say this is the oncologist for example. In order to secure the system there is a need to balance between information confidentiality, integrity, and availability and the three of them may actually conflict, so if you increase confidentiality, availability will be compromised, and vice versa. So this is the main security concept in any system, and in order to obtain that balance between these three you need to create an information security policy that consists of a set of information security rules. This is like a managerial thing, but in order to implement it and enforce it within the system, you need to use information security controls. Which is more technical translation of that main policy. And the controls ensure the systems elements work in harmony for this single information system. So this will make sure everything works properly and everything is working in harmony. But legacy systems, that system has it's own luck (i.e. the information security control), that keeps the harmony inside the system, but you will find that all the other systems have different controls that are not consistent. And it's compromising on information availability, so what we want to do, is evolve what kind of systems actually can do, with additional functionalities to fully support a secure cross-organisational information sharing. So by keeping the legacy systems or keeping their local context, security context and build this on top, to help with secure cross-organisational information sharing. So we identified six functional requirements for our investigation interviews and everything, we believe that these are important to reach our goal and address the problem.

Shada: One, is that when a patient goes down to treatment, this is just part of the breast cancer integrated care pathway from Map of Medicine, so the patient goes from a triple assessment up there, and then the patient goes down, for treatment. We believe that it is very important that the information organisation is different, in that collaborative context. So at the collaboration level as the patient goes down a treatment pathway information should be organised in chronological order, so you see which point first, based on history. And for each point of care, it must be very clear, with a stamp that the date and time of point of care is noted. And who saw the patient, to make clear where information is, who collected it and everything, and the involvement of different healthcare professionals.

Shada: Number two, that referrals between each doctor are automated, between each point care are automated to make referrals. So when the patient sees doctor A then after the patient sees the doctor, the doctor then types in the information that he needs to share with the others, and then once presses the button, the patient is auto-

matically referred to a named or a role. And this can be decided before the treatment point, so the system can be programmed to do the referral to certain people. So, this is number two. Automated referral to named team members or role, that is picked up by the recipient, so the other doctor will pick up the referral and then they can see the information that has been referred with the case.

Dave: I see, right ok.

Shada: And then the third functionality is that the information should be filtered from the other hospitals. So we don't just collect everything we filter what is needed at that point to, to overcome the overwhelming of information. But this is only based on the guidelines. However, some people make mistakes, they don't refer all the information, or something happens in the middle, so there's a need to access extra information that has not been referred, or that has not delivered or anything. We introduce the concept of "Breaking the Glass."

Dave: I see yes.

Shada: It's to access the information, the trusted care team member, is believed to need that information for treatment and for the care, but it's not there, so he needs to access it. So he breaks the glass, accesses the information and justifies why he accessed that information. Finally the system will log that and it will be clear that there had been a break event. And fifth, is we believe that these will help access patient, to make the information access based on the patient case. So it's more patient-centred and not organisation-centred. Because current systems are isolated and information access is based on the needs of the organisation. But if you make a common one you need to make it based on the treatment and patient and patient case and not the organisation. And finally there was an issue with integrity, sometimes information comes wrong, and Dr. Crosby mentioned sometimes it's hard to track who originated that information, and if there's a mistake it's hard to find that person and ask him to amend it. Because they don't have the right to change it. So we're giving that functionality here that you know, we give, because you know from the chronological order of treatment points who actually entered that information, so you can ask them to amend that information, and once it's amended everyone involved in the treatment is alerted. And they make decisions based on that.

Dave: So that means the integrity.

Shada: Yeah we're trying to help with the collaboration and everything. So this is my system, I call it SHarE, and I'll show you the scenario that I told you, how my system deals with it, when the information has been collected. So this is, well

this is my general practitioners, the very first system, and my general practitioner is actually named Hessah. So it's the same tool that Hessah used in her research.

Dave: Ah right, yes, yes.

Shada: And the things that we need for the security. So Hessah logs into the system, she's my GP, she creates hopefully, that's clear for you.

Dave: Yeah, yeah, I'm ok with that.

Shada: So she creates a new case, if she has a new patient coming in. She tries to find that patient, so she puts the NHS number for example, and once she finds the right patient, because the patient needs to be registered in the system. So once the patient is found, medical history is entered. The GP examines, the patient asks questions, enters and records that information in that box here. If you scroll down you will see four items here, for my security I think it is important to label the sensitivity of that information. So it's for all the pages but I've only done it on this page. So for me it's just a proposal that I have, that information is Not Sensitive is the white, and green is for Care Team Wide sharing, and the amber is for Sensitive information and the red is Highly Sensitive information.

Dave: Is there a default on that setting?

Shada: Care Team Wide is the default, will be the default, I put it there in my example. Because the people in the system are all care team members.

Dave: I see yeah.

Shada: So its made for everyone, but it's.

Dave: Unless it's.

Shada: Exactly. Unless it's a little bit sensitive, or very sensitive. We believe this sensitivity labelling will help to protect more severe information. So there's the breaking glass, and we see there is sensitive information being broken into, the procedures will be different in that case. So it's just for the system to learn how to deal with different situations.

Dave: The reason I ask about the default is that by establishing a default which is care team, which is a logical choice, it means that putting the information in, doesn't involve lots of extra work, because you've got a default there, you haven't actually got to keep pressing that button.

Shada: Yes, because it's time consuming, I can understand that. If you agree that care team should be default.

Dave: Yeah makes sense in this one then.

Shada: And you believe that the right person to decide how sensitive it is, is actually the person recording it, and it's free text so it's the owner of the information there, and he can tell how sensitive it is because he's recording it. And there, after the medical history it's the examination so he records about the examination, it's all in the guidelines. This is care team wide sharing. And then when this is done, when she clicks the bottom this will automatically be referred to a surgeon. Who is a specialist in this case, and in my scenario, Carl is actually my surgeon. Let me give you the list of CT member roles. So these are the people in my system. So Carl is my surgeon, so it's automatically referred. Now when Carl logs in because she's seeing the patient next time, then when she logs into the system, she's my surgeon. When she logs into the system she will see the patient's case with needed information in there. So my patient's name is Susan, and it says here that it's outstanding and this is the time and date that this has been referred, so it's very clear to her. So she only clicks on that button, and she picks up the case, after, read more about the information she received from Hessah, the GP, then she can actually examine the patient and enter more information. But the information is there and it's automatically referred. So when she clicks on it she can start with further examination and history check and also to label the information. And then when she clicks on that it will be referred to a pathologist automatically and if you hover the mouse over the treatment point, because these points show the treatment points, the hierarchy, you can see the details of the treatment time and date, so there is more information there.

Dave: Ah I see, right.

Shada: So it's referred to the pathologist, the pathologist performs a biopsy, as part of the triple assessment and I think it's Kate in my case. So Kate logs in, picks up the case, she sees all the information she needs then she performs the biopsy and enters information about it there. And then she presses the Done button. When she presses done it will automatically be referred to a radiologist, the radiologist performs the ultrasound or a mammogram based on the patient's age. And then it's Amal in my case, she logs in, picks up the case, she performs, she has to do this test to check her age, so she's older than thirty five. It's going to be a mammogram, if she's younger then it's going to be an ultrasound so it's different. So she does this and then she writes a report about it, presses done. When it's done it goes to an MDT, so my MDT coordinator will log in to collect the information for the MDT discussion, her name is Claire, she picks up the case. She can click on the button where the information is being recorded and it's ready for her to see it. So the first one is primary care, if she needs to see any notes from the GP for example. There's a secondary care from the surgeon. There's the biopsy and there's the imaging. So she clicks on the

right button then she sees the information that she wants. A treatment plan should be written down and then a decision whether it's malignant or not. And then an automated letter will be sent to the GP to inform them. After that it's going to be Carl again the surgeon to perform an operation, in this case the next treatment is an operation. She logs in, picks up the case, does the operation, writes a report, and then closes it, then it goes for a post operation MDT. Claire logs in again at the time of the MDT, she picks up the information and, I haven't put anything in that page, but it's just the same thing. Then it's referred to the oncologist after the MDT if it's decided that it's chemotherapy. Then Annabel, my oncologist, she logs into the system, picks up the case and then starts with the treatment and records information about the patient's case. So this is how I designed my system. The system can do any sort of scenario and it adapts to the choices. So we put choices like ultrasound instead of mammogram, but it follows whatever the choices are for that case, it's very flexible in terms of the treatment pathway.

Dave: So as soon as the work flow system is in place really.

Shada: Well I've produced it from the guidelines for my system. We've got guidelines that were not very detailed, so I went to meet the people and they told me how it works. And they were very confident what is needed, they know exactly, they're not like maybe it goes to, no they know what happens. And we can actually have chemotherapy first then the operation. All kind of sorts of potential routs that the patient can follow. Ok I've showed you my system and how my system works, but I haven't shown you the main functionalities of the security bit, this is all we have, the information has been organisation So I'll talk again about SHarE's functionalities, and I'll show you some screen shots of what my system does for these main functionalities. If you're tired, we can take a break?

Dave: No I'm fine.

Shada: Ok so we mentioned that information should organise in a different way, in a chronological order, showing the date and time, and who actually saw the patient. We also mentioned that information access should be patient-centred, and not organisation-centred in this system. And this is how we believe the system does it. So you can see the different points of care, who actually saw the patient and at what time. And this is based on the treatment and condition of the patient and is not to do with the organisation where the information is being kept. Ok, and if you look you can see more details, we don't want to overwhelm them with more information so, whether we need to know, the basics are there if you want to see more information, and the items to give alert and everything. The automated referral to a named care team member or a care team member's role, that is picked up by the recipient with

all the information that we believe is needed based on the guidelines. And this is there, this is the list of patients awaiting that person's action. Filtering and gathering the right information from the different systems at the point of care, this is the MDT case here where she clicks on the button to take the information she needs for the MDT review. So this is an example of how we filter information. And yeah the breaking glass feature, if extra information is needed at any point, then we believe that trusted care team members can break the glass and access all information they need after justifying it. So in my system at each point of care in this case, after Hessah recorded the information and referred it to a surgeon, any person but Hessah can break the glass and break into Hessah's information. So this should be in every single point, but I only implemented one as a concept. So breaking glass, anyone down the pathway that did not record that information can break into it, when they click on it, they have to justify it and submit a justification for the access. Only accesses Hessah's information.

Dave: I see, so each point has it's own break the glass?

Shada: So if it's the surgeon's information, breaking glass there, after the MDT for the treatment plan, breaking glass there. In case the information was not the right information was not retrieved.

Dave: Is there an issue that you don't know what you don't know.

Shada: I'll come to this, it's very important. After she justify for it, for example, Annabel has this one, and then she sees the information that Hessah recorded along with the sensitivity level of that information, just to make you aware you're accessing sensitive information of care team wide sensitivity. Just to help them understand how to look after Hessah's information. And this is the breaking glass, now there are two things with breaking glass, because I met with Helen and Mital and with my supervisors. Breaking glass for me is to access information that is not provided at a point.

Dave: Right yeah yeah.

Shada: Helen said that the glass shouldn't be broken unless it's a bad referral, meaning if they refer the case and forgot to send information with it. For example the GP did not write anything down with the referral but they recorded it in their system. So I enforce the system to give me that information because I'm supposed to have it. This is one thing. The other thing is that, because we were marking what the guidelines says, maybe it's not very detailed and they missed something. So you can't see it until they fix it so you have to access that information because it's critical, the continuity of patient care is more important than anything else, so you just

access whatever the system actually missed, to provide you. Helen said you don't need to break the information I'm supposed to, because I'm supposed to have that broken into for me.

Dave: Right ok, according to the guidelines and things?

Shada: Yes, so it's not that, if you filter and believe this information should be there, it should be broken into anyway, but it will only be the care team members logging in to this. So all care team members should be trusted to see everything. So it's not, for example, a clerk going in and seeing information, it's actually only the care team that can only look into it, the care team members only. So if she says there is no need for breaking glass because the information should be there, but like the Clinical Portal they have this breaking glass for only super sensitive information, only HIV positive result and stuff like that that is very very sensitive is kept behind the glass. And only, anyone can break it, but it's very sensitive that you don't break it unless you really need it. This is the other kind of breaking glass option that Helen said is important. And she said you don't have to justify it because it's time consuming. You don't need justification from a care team member to say, I need that information. So it's time consuming it should be there. What do you think about that?

Dave: Yeah.

Shada: What we're trying to do makes more sense. The break glass concept for information that is not there, not referred, missing at that point, or only information that is super sensitive and labelled with sensitive information.

Dave: Hmm, it's an interesting concept isn't it, I'll throw in something whilst I remember it, one of the things that NWIS have done with the out of hours system, have you come across the out of hours?

Shada: Yes, but nothing about the system.

Dave: Well what they're, the way they've got. Because what they've got is access to the GP systems, the scenario in Wales, is that the GP practices is that they don't have the GP's on the out of hours service, so you've got somebody who doesn't know anything about that patient. And they've got the patient in front of them and they need information on that patient in order to treat them, because the patient is there and needs treating. And they, what they actually do which has working in unlocking the GP's system, is that they actually have the patient in front of them and say do you, give me permission to access your system in order to treat you, and of course, that's a completely different question to asking the general public, do you think you should share that information or not, and under that circumstance people say very sensitive. But if you ask the patient, the poorly

patient, whether you can access their information, well of course I'm feeling ill, I need that access.

Shada: What if they're not conscious?

Dave: Well that's then maybe when you need the break the glass, but ordinarily with the out of hours one, and probably with this cancer system here you may well be going to discuss the patient in the MDT, discussing that patient, you need that information, you may well come along with something which helps you break the glass, because the patient has given their implicit consent. Because a lot of this is implied consent between there. You may have something which you need to put complicit consent in order to get over this issue. I don't know, it's not something that's been done in the cancer field, because they don't feel that, they've seen so many patients in the cancer field, to have to go to each one and say do you agree to share that information with the patient, by and large, thinks of course I need to share this information, how the hell, I've just been to see the surgeon down there, why on earth don't you know what's happened to me there, I don't want to providing that information. But that might be another scenario into the break the glass. I know that complicates things for you a little.

Shada: Actually we have yeah, it's just how we can balance.

Dave: Yeah it is a case of balancing. I would have thought.

Shada: In that case, maybe the person is not normally supposed to see that information. He's taking this information because this is an emerging case, it's not the regular treatment, so now that this is happening.

Dave: Yes because I suppose most of time we're presuming compliant consent.

Shada: There's a basis here that it's a very organised, planned treatment pathway, what can wrong? Well the hospital told me that information does not always flow, so you need to find a way to get that information. So we said breaking glass will go directly into the database and extract that information. Even if the interface is not implemented to actually show that. So you just go there, grab information about that patient, search that system.

Dave: Yeah I tend to go along with that, the break the glass just gives you access to whatever information is there. Which brings me back to that initial question I asked, is that how do you know what, because the one scenario you talked about is this is standard information that you'll come across anyway, so you know it should be there. Assuming that the clinician at the earlier stage put it in. You know it should be there, but it has for some reason not be included with the referral.

Shada: When we're talking about latest systems they're not very connected.

Dave: That's right, so I think that one, yes you can see it's a simple situation and you don't really need the break the glass for that one. But the break the glass is for something which is, when something is broken down here so we need to access the raw information to get that. I mean break glass is a great concept because it's easy to explain to patients and everything else, but I do worry slightly in that, how do you know whether someone has actually stored some information behind the break the glass, because there is no indication on the system at the moment that it's there. Have you got to search through each step to find out.

Shada: Because here it says that it's been through the GP, it's been through the surgeon, but you can't see that information. So you know that the patient were seen them, but why is it not there. You can tell that it's passed, why was the information not there.

Dave: Right so in that case you need to access the system at a raw level really basically. Yeah I think that's probably what you need to do, yeah that's.

Shada: If they've gone to an MDT and you know like twelve of the patients were not discussed at the MDT because the information is not there.

Dave: Right ok.

Shada: And they're like the patient has been there but the information is not there, we don't know why, so we're going to invistigate why this is happening and come back next week. But a week delay makes a huge difference to the patient's treatment.

Dave: Yes the clock is ticking and things, and the patients wouldn't understand that delay.

Shada: And the patient is suffering, you need to submit that as quick as possible.

Dave: yes and that's the scenario I said, that the poorly patient would see things quite differently to a general open question about access in the general public. Yes. So ok, I wonder if that helps or not on those.

Shada: This is the one we discussed, and it is an important thing?

Dave: yes, yes.

Shada: Once you've seen that there's been an event of breaking glass, then because the chronological order of the treatment points and everything is based on the time stamps, then once the breaking glass happens, it will add to the hierarchy that this event has been done. And this person, the named person who broke the glass is logged into the system, it tells you who it is, that actually broke the glass at this time. And broke which information. So the person owning the information like Hessah in that case, will actually know that Annabel accessed the information. They can speak to see what's going on.

Shada: Ok. So after the scenario here, we talk about the first one and the automated referrals and then filtering information, breaking the glass with justification. if Annabel broke the glass and justified it. You can see here at this point that information was broken. And you can see the time and everything for it. And finally the amendment of information. And alerting everyone involved. It's the same concept as the breaking glass, but the only difference is that everyone can break into my information but I'm the only one who can change my information. So Hessah when she logs in, she sees Dynamic Control/ Amendment option and the other's when they log in, they don't see that. They see their own information, so when Hessah, when she clicks on that, she will access her information, change it, and then press the button, and when she does that, like the breaking-glass, everybody will be alerted at that point, that the information has been changed. So they can make a decision based on that information, they can go on and see. Ok, questions. Hopefully that wasn't too much.

Dave: No, no, the one question I'm sure externals might ask, is how easy do you think because I can see the logical consistency you are doing from that over arching framework there, I know it links in with Hessah and the pathways we've done, so that's nice and logical. Where it gets dirty is the lower level interfaces with those legacy systems. Where they have their own security access mechanisms and the users, I mean, in a sense the, you could have Annabel as the oncologist trying to access or break the glass on a radiology report, when she's not a registered user on the radiology system. That's the dirty level, how does your system deal with it?

Shada: Annabel for example finding ways to access. From the legacy system or from these systems?

Dave: Yeah from the legacy systems.

Shada: Totally she can still do that, because we're not trying to block people, because they will, this is the problem of the legacy systems, this is there own security complex and access. So they deal with it the way they used to deal with it regardless.

Dave: I see ok.

Shada: Our security context in here, Annabel, she can't log in and see Susan's case. And if she doesn't log in and search for all the patients and see all of their operations, she only picks up or accesses the information for patients, she is going to see or actually care for.

Dave: So your framework deals with this.

Shada: So I don't care about the security, yes, like in terms of what's going on there, if it can happen today then it will happen with the system, because it doesn't block

people from doing it, but it's dealing with the common security mechanism at the collaboration level and not at the level of each individual system.

Dave: Yes I can see, at the lower lever, the dirty level, it's quite tricky because certain systems like.

Shada: What are your concerns?

Dave: Well I'm thinking of a GP system, within the content of a GP system, you know there might be, change in data item, and you get certain things happening within the context of that GP system. But actually how you implement the interface between the top level security framework and the GP system, in order the change something at the GP level to actually break out if you like through the low level interface and get into the top level system, that could be tricky to implement.

Shada: It's true, it's true. Because if the GP does any amendments in his local system, without dong it through SHarE, then it will not say that the treatment has been done, so it's still outstanding at the GP's side, waiting for them to write that report, then if he does that, if he sees the patient and clicks done and refers the case, automatically, through SHarE system, and he still does change things in his system, but if you break the glass you can access the information he entered there, without notifying others, because it's something that he entered in his database, so you can access anything else he entered there, and we believe it it important that it doesn't interfere with the GP system it's all in the database, so that's the kind of thing, do you think that can be?

Dave: Well, it's always tricky with the legacy systems actually getting into them and gaining access to the information, it's always you've got integration engines to try and do these things. And I suppose that's the way you'd have to do it. You'd program some integration engine to link the systems. I'm just thinking off the top of my head here, because the examiner might say I can see how your top level framework concept. The concept you are talking about, I like, it's logical and it builds on what work we've done before and builds on Hessah's work flow and you can see how it's coming along and links to those things. But the practice of actually getting information out and effectively being somebody to gain access to that information.

Shada: Yeah this may be adds an extra burden if it's extra system they have to use with the legacy.

Dave: Yes, this is it, yes.

Shada: But if they need to access information this is the best way to get it from the other hospital, apart from their own hospital, is just trying to drag and pull that information. This will be automatically done, so this is one of the things. We

believe this solution is not the perfect solution, we have that in mind, and it's not a permanent thing. It's a temporary thing until the systems are fully integrated, fully connected and everything works perfectly so you will not need this. And maybe the new systems will come along, this is just a temporary solution, we believe will help with addressing some problems, information flow with legacy systems

Dave: Yes I guess the answer is it's just at the moment integrating systems, wouldn't have to use integration engines, and it's a bit dirty how they actually link and get information across. You'd still have those issues, just the same as they are now, and you'd probably use an integration engine with it's rules and things. It then sits behind the security framework on that.

Shada: Yeah, how do the integration engines work? Is there a simple way for me to understand?

Dave: Well, they're almost like black boxes really, they'll use some sort of interface, that system talks that particular language...

Shada: Like with CaNISC for example?

Dave: Yes.

Shada: So it does the referral or just submit information through it?

Dave: Well it's a case of parting identifiers into the information engine and passing that information the identifier and saying I want to gain access to that record, and it's maybe a HL7 or an interface like that, that allows the transfer of information out when you request that information. There are commercial solutions and yeah there are various integration engines on that.

Shada: Do they have security mechanisms that, certain ones?

Dave: I'm not sure.

Shada: Do you have a name I can go and look at?

Dave: That's a damn good question. I don't to be honest with you, if you don't have an integration engine you're tending to write bespoke interfaces, and bespoke interfaces tend to use standards like HL7 for interchange of information between systems.

Shada: Ok.

Dave: You probably don't need to know a lot about it, but it may be something the examiner will ask, because you're, he may well ask, because you can see the top concept, how's it going to work at the bottom level.

Shada: That's one thing I wanted to ask, how will it work with the current systems. Because SHarE is a web-based solution, the other one, you can get online or through

the network to that system, and you still have your own system working. It's just you know can do whatever you want without the restraints and things, but when it comes to a patient case that has been referred you enter that information in here in SHarE, you say done and then transfer that. Once you record the information into your database it's stored in your systems. It's just the ways that it's linked to, when you click done you can actually, have an automated referral that is going to the other hospital, you don't have to worry about faxes, emails, letters, that physical thing sent to them, so it's through the system they pick it up, then they can put it into their own systems and things.

Dave: What I do suggest is do a google search first of all on integration engines, or integration engines in healthcare and look at something like the HL7 standard, just so that you're prepared for any questions that might come along. And Alex would know what I'm intending now. It's just in case the examiner asks about those low level things, well how would it work down at the bottom, as opposed to the interface between clinicians and the team members etc. etc. Just so you have some sort of preparation there. It's always tricky the integration, because that's part of the reason why we've had problems now. And the Welsh Clinical Portal and the other portals that have been round hospitals they have the same issues basically. Because they need to grab information and you put one identifier in and hope you can get across.

Shada: With the identifier, do you mean the person and the...

Dave: It could be the different hospital numbers, or the patient name and what number is there, because very simple example is that, the surgery might have been done in Gwent and they will have maybe used a local patient number there. But you're in Brotaff or Velindre and you've got a different number for that patient. So you've got to link the two in some way. The way CaNISC does it, it will grab, it will store any number of hospital patient numbers against the patients name and address.

Shada: So the patient has different numbers on different systems?

Dave: Yes that's right and basically you can use any of those numbers to search on those.

Shada: So you can find the patient and link it to the patient?

Dave: Yes, because again at a low level implementation you'd have to know I'm going to that local system, what sort of identifier do I need to use for that patient to actually gain access to that. A lot of the local systems now do store the NHS number. You know it's been mandated, it's not completely unique, but it's much better than what we used to have before with all of the local systems. So it's usually a lot of systems do have that number there.

Shada: So in here if you suggest that we use an identifier, do you think NHS number?

Dave: Well I do think NHS number is very useful, it's probably the best that we've got yeah. But just be aware that just like CaNISC, you might need a database behind it, that says well yes the NHS has got that number, but there are other local numbers for local systems.

Shada: Why were there different numbers for hospitals?

Dave: It's for the same reason that there were different systems. When they started out those legacy systems, there didn't use to be a universal identified so you just issued a number for the patient identifier for that system. And you kept on using on that, it's only at a later date that the idea of a more universal identifier the NHS number. It's an emerging scenario to try and over come that. Otherwise you'd need multiple indexes for the searching. And again some of the integration engines, do have this, does take that facility, provided for you. Which is another reason for.

Shada: I notice in MDT we have different numbers, and some have a letter at the very beginning.

Dave: Yes that's it, well some of them will use the local PAS number, which is their identifier in that particular region, so that's the reason why. So that's why your low level interface might have that integration engine, which deals with searching all the different numbers and storing different numbers.

Shada: If a patient goes from one hospital to another, then you need to...

Dave: Yeah from organisation to organisation. Which is something concerned with security, because the last thing you want to do is bring up information for the wrong patient, from a different system.

Shada: And it can have several Dave Morrey's in there..

Dave: Exactly. Once you get into Welsh names you've got all sorts of problems, and I'm sure there's lots of scare stories. You can have all sorts of scenarios where you've got, you can even have silly systems where parents may have named two twins a similar name, the first name is similar of same first letter, or even the initials are the same. And there they are, got the same date of birth, born in the same place, same parents. And they've got the same initials.

Shada: That's very tricky.

Dave: It is tricky. So all these are security issues. And they're not unique to your system, but they are cases that can happen. And obviously these integration engines can help do that. Sorry bit of digression, but it is important, especially if the examiner starts asking those and you haven't got answers. So I'd do a little google search on integration engines.

Shada: You can use these commercial search engines, so I can link to it and be prepared for that.

Dave: Yes there may well be interfaces to different things and ideally you'd use integration engine which means it's all in place. But worst case scenario is that you'd have to write a bespoke interface to get information on particular patients or extract it from particular systems.

Shada: That's good, I'll put it in my. You have a list of questions can you please go through them. I was just thinking shall I go from the top or just go for the main ones. Depends how much time you have?

Dave: Wherever you think it' going to be helpful.

Shada: Ok we'll go through the first one quickly. So the first one, number one, what was the role of the Clinical Information Unit (CIU) in general?

Dave: It helps organisation.

Shada: Do you want me to shout the number?

Dave: Yes please. Are you ok if we?

Shada: Absolutely.

Dave: Yeah seeing who plays the healthcare organisation. Well, the CIU is the clinical information unit, so we, what's the best way of saying that, the role. It, there was an element of developing systems for cancer care. There was also using the clinical information to provide the management information for Velindre NHS trust, as a trust. Because there was certain figures that needed to be derived. There was a data set for each admission of a patient to the hospital and each new referral to the hospital and things like that. And also it provided certain figures for performance of the hospital in terms of number of patients, whether the referrals to the hospital were changing with time and also the clinical information unit got involved in helping medical research, helping the clinicians with their research and also in audit. Checking the outcomes for patients and the quality care of them so.

Shada: Is CaNISC the main system you use to collect cancer related information across Wales?

Dave: Yes it is. Yes.

Shada: And it was developed by the Clinical Information Unit right?

Dave: Yes, yes it was, yes.

Shada: Great, what are other systems currently used today in cancer care in general?

Dave: Right we're talking about Wales wide here are we? Or? I think yeah, if you're talking about.

Shada: We're talking about the UK but you know cancer care where CaNISC is working or other systems are.

Dave: Right ok, well, the other systems are typically there would be a radiotherapy system, connected to the treatment machines to manage and quality assure the radiotherapy treatments. There would be a chemotherapy system, which would be used for prescribing and printing worksheets for production of chemotherapy, because quite often the pharmacies make up their own doses rather than get something off the shelf. So those are the main ones, in a district general hospital there would probably be a surgery system for managing the surgeons workload in theatre. And again in the district general hospitals there will be a pathology system for recording.

Shada: This is Landough?

Dave: Yes in Landough and the Royal Gwent, each of the district general hospitals there will be pathology departments and things, so you refer off to biopsies and things, they would report on those systems and yeah. Those, the reports would go into there. And obviously as you mentioned in your scenario here there is radiology systems for radiology results. And then there would probably be patient administration systems for. But it's not really involved in the care. So and obviously the GP system for there.

Shada: For the different areas. But which one of these are actually linked to the CaNISC?

Dave: Right good question, it depends where about in Wales you are talking about. The...

Shada: Sorry if these questions are too much, I just can't get this information just from reading from papers and the Internet.

Dave: No you can't. Certainly within Velindre, the radiology system at Velindre was linked in. as was chemotherapy and radiotherapy so those were linked in. So those were relatively easy to get hold of. As you moved to other hospitals the situation was much more patchy. In that probably radiologists and pathologies weren't linked in because of security aspects and volume of information and all the rest of it. So the further away you got from Velindre, the less links to some of the stuff in University Hospital Wales in Cardiff, certain results were there because we depended on the cancer centre being some small unit on it's own.

Shada: And it's specialised in cancer mainly but with other disease?

Dave: Yes, it is a cancer system and there is other diseases yes.

Shada: So mainly now would you agree with that or not. CaNISC is not a patient-centred system, it's actually organisation-based, or disease-based?

Dave: It was patient-centred by and large, but it got tricky in that if the patient obviously had other radiology results and other pathology results which weren't related to cancer, and that made it, the linkage tricky. You can imagine your integration engine it's got to have some sort of rule to say, well what results do I bring across and move into CaNISC. Some of it, it was very raw in that they said, well we've got the referral for this patient, this is his patient numbers, tell me everything you know about them, and they'd bring it across, and then the clinician would have to decide what's important.

Shada: What about if the patient has another condition for example?

Dave: Yes that, again difficult things to know what to bring across and things, that's why it started breaking outside Velindre it got difficult in integration on that.

Shada: Excellent for me to know that. It's not good in general.

Dave: No it is an issue yes. So there was security concerns and the clinicians would be worried there is too much information being brought across that didn't belong in the cancer domain if you like.

Shada: So they wanted to restrict that?

Dave: Yes the clinicians started putting, or the data protection people, and their system started putting up shutters, because they said why do you want to know all of that. But there was also data volume concerns as well. Because some of these databases were huge, the patients had been seen for years, before they maybe got their referral for cancer, or whatever. So when do you bring things across.

Shada: In healthcare it is an extremely complex domain. And do you think any solution that works in healthcare can work any where else?

Dave: I wouldn't be at all surprised, you're talking about very long longitudinal records in terms of time history and complex organisations and different systems, it is probably one of the most complex systems, the integration engines are one of the most complex. And the security aspects of them are the most complex yeah.

Shada: Ok so to which degree, question number six, to which degree do you agree with the fact that there is more pressure on healthcare systems to share information between hospitals?

Dave: Yes, I think that's true, with this multidisciplinary care that we're talking about here.

Shada: Ok but you just mentioned the data protection and everything to put shutters down. It seems a conflict really to me.

Dave: They do, and, you probably saw in the MDT's the clunky way it works at the moment, in that you might have the MDT coordinator with one screen with CaNISC up, which is the shared information, might be with it's limitations at the moment. But on another screen, another system, the radiologist is logged into their local radiology system, bringing up information on the screen about that patient in order to read it out to the meeting, which then has to be transcribed across there because there's not a direct linkage across it. Either because of security because of data protection but also difficulty of integration of systems on a technical level. And then the pathologist might be on another system bringing up their pathology reports which may just be a text report.

Shada: The metastatic have only just two screens, for their normal breast cancer MDT, they have case notes, paper based, and they have a radiologist form, a clinical form, they have CaNISC. And their oncologist came with a piece of paper, so it's so different and they needed that integration I think. And they recorded information after the MDT in the treatment plan, it goes back to CaNISC. It's the only way to get everything at that point for a decision.

Dave: Yes and you can see why the frustration of the clinicians in that it's clunky, it doesn't flow between systems on a system level, and the security, the clinicians are told it stands in their way of sharing. So it's at both levels yes. So yes you've seen the.

Shada: There's the pressure of sharing, then the pressure of security, so the people, the practitioners want more sharing and the people up there wanting more security, and that's really hard. But it's expected. Ok, how are current systems coping with that pressure.

Dave: With difficulty, the clinicians are switching between systems and screens and the projector has to flip between systems to do it. So all the things you've seen at the MDT's and, are exactly that, and how you've got a paper based case notes, you've flipped that up on there. And the information isn't going to flow.

Shada: How do you think, this maybe like a prediction or something, but from your own experience throughout the years at Velindre Hospital. What do you think in these systems' agenda for the people to cope with that situation. For example, I'm suggesting an idea here that can cope with that situation until everything is sorted out?

Dave: Well I suppose what eventually they hope will happen, I'm not quite sure what will happen in England now that they've abandoned their over arching integration things. Yes they were going to have this record which went across all the different organisations, all the different hospitals in England, of what they call a common spine.

Shada: A common spine?

Dave: yes it was something called a common spine and all systems were meant to integrate with the common spine and send information into the common spine so you could, the clinicians would be able to see information from various places and things. I think they now lapse into more similar solutions to how the way Wales will go. I suspect it will go regional, and regional what will happen.

Shada: When you say regional you mean Wales?

Dave: Well Wales would be a region yep, so you'd take off a geographical chunk that is reasonable where the patient flows, if you like. So you know that the patient is going to go round Wales, by and large, ok there are some referrals across the border, which are a bit more tricky. But from a Wales point of view you can see the patient goes around there, so what you need to do is link those systems in some way, in that local region of Wales. Or it could be the local region of London, or whatever, and you know that in there, as you've identified on your slides there, you've got linking the GP's with the local hospital systems and etc. etc. and I would expect for something similar to how they foresee it working in Wales which is some sort of Welsh Clinical Portal where all clinicians use this portal. And the Welsh Clinical Portal implements some sort of security model, just the same as yours. And some sort of local integration engine behind there and it provides a common portal for implementing information and then they envisage, don't know whether it will happen, but they envisage that that clinical portal will link to CaNISC so that whether you say it's a cancer patient, suddenly you bring in CaNISC into the picture to gain information. And actually the information will be stored in CaNISC so that it will avoid needing to go into the local radiology system. Because the Welsh Clinical Portal, no matter where it is in Wales, will link in with the local radiology system. Or the local pathology system or the local patient and administration system. So there must be some sort of security model, and security system as you've indicated in order to cope with that. Don't know what it will be, I don't think they know themselves at the moment, it's quite a complex situation.

Shada: But you will always keep it in those systems?

Dave: yeah I think at the moment they may replace them bit by bit, because the pathology system for example, the local pathology systems in Wales are being replaced with a national pathology system, which is one system for the whole of Wales with common codes. So at the moment the pathology systems in the different hospitals use different coding systems for different diseases.

Shada: So they want to standardise the different similar systems first, so they're doing it gradually.

Dave: They are doing it gradually, and of course they run into problems, because there is a lack of money now to even implement the Welsh clinical portal and the roll out of this

national pathology system to replace the local ones, it's a big implementation task, so it's taking time to do that. But yeah that's how I guess it will go, and I expect that system of regional will be rolled out in England as well.

Shada: Excellent, very good information, you give me the background. Do you agree with the research problem that sometimes the information does not flow, do you see that from your experience?

Dave: Oh yes, yes, all your experience from the MDT's is absolutely true, and I've also seen the difficulty from a national level of trying to get CaNISC to get information from other systems. And it's just beyond our resources to try and solve really.

Shada: Ok so is this a combination of the reason why this is a problem maybe, because of the structure of the systems and peoples behaviour or both? Or just the systems? Because the MDT coordinator said:"oh, the problem actually does not exist, because the information is always there but the clinicians don't really bother to look for it." This is what she told me, but the nurse told me the exact opposite: "no, there is a problem and the information is not there and it's really hard to get it out of the system." So two different opinions about the same problem.

Dave: Well, I think probably both are right in that you got to understand the clinician for a lot of the MDT's round Wales won't have, won't know how to use the radiology system, or the pathology system. Now the MDT, yes he needs, and do they really want to get involved in all the intricacy that others have. As you see, you want to see, as you've shown in your security model, where you say, availability of the right information, not all the information. If you just access the raw radiology system you're going to see everything, all the details a radiologist needs to know. Well you don't want to see, the clinician who it trying to treat the patient doesn't want to see that. They just want to see the filtered information as you've got it. So that's absolutely right, so both of them are right and the MDT coordinator has had to overcome those problems and knows just where to go, to individual systems to get it out. But it really is asking a bit much for the clinicians to actually do that, and most of them may know about CaNISC or their bits, or they may know about their local system or they may not. A lot of them don't use systems, clinical systems on a day to day basis. So to ask them to suddenly flip between a pathology system or a radiology system or CaNISC, it's a bit much. So they're both right to a certain extent. And also they may well not have security credentials in all those systems. You tend to find that radiology systems are only made available to radiologists.

Shada: And not the others?

Dave: And not the other people, because they say well this system isn't really designed to be made available for everyone else, because you could just have clinicians going in

and messing up systems. It's not protected, as a clinician you go in there, radiologists expected to make changes. Well we don't have a separate module for clinicians to log the information so it is, it becomes a real security risk to the local systems, to have lots of these people who don't know, not trained in the system, who don't think in the way those systems work, to access them.

Shada: Ok that's very, very good, excellent. We'll go onto my prototype itself, and then I promise we'll be done. So in general what do you think about this proposed system?

Dave: Yeah I can see the logical model following on that, and I like the way that it builds on what we done before with the workflow and I think that will be helpful to demonstrate to the other clinicians on that. So I think yep, as you said there it does have the potential to address the issues, yes it does.

Shada: Excellent, is there potential for healthcare professionals do you think to adopt and use SHarE?

Dave: I think there is. The barriers as you say, and as we discussed a little are the integration with those other systems. The clinicians will immediately say for my GP has I got to enter information separately into my SHarE system as well as into my GP system, what I'd really like to do is implement it in my GP system then SHarE to automatically extract it via my interface to present it within SHarE. Similarly if I'm...

Shada: To keep the practice up to day, doesn't need any extra training. So the information is entered through the system SHarE, collects that information present it in a screen, then press a button for referral.

Dave: That's right yes. And similarly if someone is regular user of CaNISC like Dr. Tom Crosby, the information that he puts into CaNISC he would expect to be made available to others just as he'd expect to have the information from the radiology system or the pathology system to just be available to him. He's got to enter it into separate, two separate systems, then you're running up against the flow.

Shada: That's a very important thing to consider when I talk about the systems, that when it comes to real life in practice, this is why I'm having this interview to know what you think about it, it's very valuable.

Dave: Yes and it may well be that that's where it puts additional pressure on your integration engine and how your low level stuff gets in to the system. Is it just one way extracting information for presentation or is it, the Welsh Clinical Portal is supposed to be a viewing system only, I think, at the moment. So that you.

Shada: CaNISC?

Dave: No the design for the Welsh clinical portal, the system that the clinicians use.

Shada: Helen showed it to me, they only see and view, letters, tests and stuff like that.

Dave: Is she actually using it? The Welsh clinical?

Shada: Yes she said it's been there for about ten years, so it's not very recent.

Dave: Ok where does Helen come from?

Shada: Helen, I met her in Llandough.

Dave: Llandough? Ok. I tell you what it is, it's probably not the Welsh clinical portal, it's their UHW implementation of a clinical portal.

Shada: So how different are they?

Dave: Well, each hospital or trust, as well as having it's own radiology system and pathology system with separate implementations, also at the moment has it's own portal for viewing stuff, ok. They have a similar idea, but they're local implementation. Now what's happened is the national Wales people have said well yeah these are all very good little local models, but we want something which works across the whole lot of Wales, like CaNISC works across all of Wales, so we will produce a new Welsh Clinical Portal, which is going to link in with local systems, but it's going to work the same, as far as the clinicians looking at a system he won't be able to tell if it's a clinical portal for Gwent, or Cardiff and Vale, and he just gets into it and sees the information there. Ok?

Shada: Now that makes sense, because it's a recent thing.

Dave: yes so that's why, so they work similar to what Helen showed, but it will look and feel slightly differently. And I think the first implementations, although they have the same look and feel across the different hospitals and trusts, or health boards as they are called now, only links with their local systems at the moment. So in other words, they haven't produced a unified system as you described there, it probably won't help in the first round. And even now they're still struggling to get these implementations, the local clinical portals replaced with this Welsh clinical portal. But that's where they're going, the second model later on will say well now we actually need to open up the barriers, then they start saying which security model are we going to use to do that. We start getting into that. But at the moment you can see it'll be a fairly simple implementation to simply use the same rules at the moment, because the security it's all been done.

Shada: Because it's like in here in the slides, these are the local security of these individual systems, and we need the common security context to serve the sharing.

Dave: Yes that's right, so it's the second phase of the Welsh clinical portal implementation

will then start saying, well now we've got to share things across the boundaries, and we've got all this business of things.

Shada: If we take the functionalities identified in this research without implementation, do you think these functionalities can be helpful to build the Welsh Clinical Portal in that sense as ideas without going into the details of their implementation?

Dave: Yes. I think it's certainly ideas.

Shada: So before the implementation stage, if we go back to the main concept and ideas that we have, this can be implemented in the Welsh Clinical Portal right way?

Dave: Yes, I think that that could be. I don't know what security model, because in a sense it may well be there's somebody behind the scenes is sketching this even out now, and I don't know who that is, or how far advanced it is. You'd need to contact someone within the Wales NHS informatics services, not quite sure how far advanced that is. I used to know someone who was doing that.

Shada: Can Hazel tell me about it?

Dave: She might be able to yes, she might be able to put you in touch with somebody who is looking at that. I'm pretty certain that's still the state of play at the present time. If I see Hazel I'll ask her, but if you see her before me obviously ask her.

Shada: Ok.

Dave: Sorry I'd digressed a little bit.

Shada: It's ok, so we answered twelve. Thirteen, does it have a potential to be integrated with CaNISC? With your concerns put in mind?

Dave: Yeah I think maybe with provisos of the integration engines etc, then it's a much better model to try these things out than others. Because in a sense CaNISC is trying to do something similar, but it's a much more less sophisticated level. So yes I think there is the real potential to try it out, the practical things are that NWIS are withdrawn, most developers have gone on to try the first stage of the Welsh Clinical Portal. So CaNISC no longer has the development for sources devoted to it, that they used to have. It's almost legacy tick over to carry on. So that's the only proviso on that, but yes, SHarE is a much closer model to, because at least it understands that there is more than one organisation.

Shada: Do you think, if SHarE work with CaNISC, that it would add any value to CaNISC? Do you think that it will add value with these functionalities that we mentioned?

Dave: Yes I think it will.

Shada: Because CaNISC already does a great job, it's just the bit in-between.

Dave: Yes I think it can add that extra functionality because it makes the sharing security model a bit more explicit and anything that helps with getting the information out, would be a help in that one.

Shada: I think you mentioned the challenges and.

Dave: Yeah it's all on the ground there, it's organisational and resources and etc. etc. on that. I felt like we've touched on those.

Shada: Very important stuff you've mentioned, you've told me frankly and that way it shows.

Dave: Yeah there are some real practical issues.

Shada: You have this wonderful idea in the PhD, but when it comes to practice you need to consider reality and everything. it's really great. In the last page, I just listed the requirements and I'm going to ask for each one of them if it's important, do you think that the current system provides it and if there is any challenges there you think. So starting with the first one which is information accessed is patient-centred, and not organisation-centred based on the patient's condition, do you think that this requirement of functionality is important?

Dave: Yes it is.

Shada: Do the current stems provide that?

Dave: To a limited extent, because even as you've seen, to a very limited extent only CaNISC really understands the multi organisational, crosses the boundaries and even then there's criticisms of CaNISC.

Shada: Why?

Dave: Well because you log in as a particular organisation and you see information presented about that organisation. Now you can click down the bottom to see information that has been entered somewhere else. You can see a summary of it and click into that information, so you can actually see it, but it's not all presented at the same time. So some of the clinicians especially those that are not used to using CaNISC on a regular basis say well I want to see it complete centric, I don't want to see this organisation, I want it to be organisation transparent as far as I'm concerned, so that's the criticism that they would make.

Shada: But this is because it's partition-based, right?

Dave: Yes it's partition based, that's right the partitions are visible to the user. If you know the system very well then you can easily overcome it. So Tom Crosby says well it isn't really a problem, but Ian Moneypenny who doesn't use the system on a regular basis

says, wow I just want to see it. Whereas SHarE would show it all there, he would say yeah that's much better for me, because you hide some of the barriers and partitions.

Shada: Excellent. Do you think the organisation information based on a patient-centred view could be approved?

Dave: Oh yes, yes, yes.

Shada: I mean in SHarE, do you think it can be improved in a different way, not CaNISC?

Dave: No I think that's good, I like that model because it's logical and follows a natural model at the moment. I think the only issue you might have is if you can't get information from the underlying systems to match in with your model there. That would be the only issue, but in terms of logical things, I think all the clinicians would sign up that, and understand that.

Shada: Good, second is the information organised in chronological order, do you think this is important as well, means the information of the patient is shown in recent history?

Dave: yes I think that's, that is important.

Shada: Because with CaNISC as we just said it's organisation-based, and so partition, this is a different way to present it, it is important but I want to know from your experience.

Dave: Yes I think that is important yes. It's not the primary way of presenting the information you can get a summary in CaNISC. There is a summary that brings up all the things that have happened, similar to this but not in the logical treatment pathway that you've done it, ok? But it does show you the different organisations the patient has been to see and whose put stuff in there, but it is a bit clunky because it doesn't follow the pathway as yours, yours is a more logical pathway way of presenting it. And also that summary page is not the default one you get when you go into CaNISC, I log in as Velindre clinician or a UHW clinician, so it's not the default one.

Shada: Ok so number three, automated referrals to a named member or role, that can be picked up with the right information or the filtered information, so when you pick up the referral it's automated and then when you pick it up you can see the information that is needed?

Dave: yes I think that is important.

Shada: Do any of the systems do automated referrals?

Dave: No, it's no, you've got to go and dig it out from that, there's nothing. That's one

of the criticisms, not criticisms, limitations of CaNISC, in that it doesn't have anything active about it, you're always going to do things yourself.

Shada: It's a very good foundation CaNISC has, but you can't do everything. I mean the system is still limited to functionalities, main ones that can help you do your job, but there's so much other stuff going on. Do you think it needs to be referred to a named person or a role?

Dave: Ah!

Shada: Helen told me that today, it is referred and in practice referred to a named person, because we are a very small community, so we know who to refer to. But maybe in a bigger community it should be a role instead. So what do you think?

Dave: Yeah, that's, the honest truth is I don't know, I don't know enough about it.

Shada: It's because you come from the technical side of things.

Dave: I don't honestly have enough practical knowledge of that, I think you need to pick that up from the people who are involved.

Shada: I can ask Dr. Tom Crosby about that, because he's from the security Caldicott Guardian.

Dave: Sure.

Shada: He will tell me maybe, I don't know. I ask different people that question and I get different perspectives.

Dave: Yes and sometimes people have different roles, it's all about, there's a little bit of research wasn't there, and was it Alysia, she did the role base, and I think we ran into problems, of sometimes people had different roles at different times within the team. So I defer on that one.

Shada: Ok no worries. Filtering, and gathering information from different systems?

Dave: Yes I think that would be very helpful, yes.

Shada: Does the system do it? The current system?

Dave: No, I don't think there is an automatic way of doing that.

Shada: Ok and we mentioned that you can break the glass, if we need to extract some missing information we can break the glass, I think we talked extensively about that, what is needed with breaking glass, and how to improve it. But in general, do you think the current systems do that?

Dave: No, there's nothing on that.

Shada: Do you think it's important to grab the information that's needed?

Dave: Yes, it is. It is yes.

Shada: Final final one, and then I'll.

Dave: One thing on security, one scenario, I don't know if anyone has raised it with you. But I don't know whether you security model deals with it, you know you're talking about roles and individuals, one of the issues we came across with CaNISC and it's implementation is that if you limit access. I mean the logical way to limit access is to say, well consultantA hasn't had a referral for that patient, therefore they can't see information about that patient. And we didn't do that, what we said was once there's been a referral into that particular organisation then anybody in that organisation can actually see information about that patient. And the reason we did that rather than, because I mean the logical thing is, to say well that patient belongs to that role.

Shada: Hospital.

Dave: Well not that hospital, it belongs to that consultant firm, that individual consultant and everybody in his team. The problem we ran into was when you implement that then in terms of the security model, secretaries, medical secretaries for an example, or sometimes maybe a nurse, would actually have wider access than the consultant.

Shada: Why is that?

Dave: Well the reason is that the consultant belongs to his firm, and he sees patients about his firm. The nurse or the medical secretary may need to cover for another medical secretary, who works in another consultant firm. So you end up with a situation where the medical secretary or maybe the nurse in their role which spans consultant firms, needs to have wider access than individual consultants and it becomes quite a nightmare to actually implement that. Which is why we, the way that CaNISC operated it, was to say that once you got a referral into the organisation, then anybody in the organisation can actually see it, and the way we enforced that was there's a security log, so any time anybody reads anything or changes anything, it's recorded in the database. And everybody knows there is that full audit trail, so they have to be able to justify it for themselves, why they're looking at that patient. So in other words if a medical secretary worked for Tom Crosby, but was asked to cover for Peter Barrett Lee, then justifiably she's looking at Peter Barrett Lee's patients, information about those patients or reading it.

Shada: But she always logs in with her name?

Dave: She always logs in with her name, and the CaNISC security model is quite wide. Anybody within Velindre can see the patients that have been referred to Velindre, and sometimes we have had the practical example where there's been perhaps a patient with a well known, celebrity or some famous sports man, and then they want to see, and just out of curiosity they've gone it to see what's happened. Or there could the example where

they're a neighbour, just a clinician, they're a neighbour of that clinician, and what's happening, I haven't heard anything about the results. And that consultant may log in, or another clinician or a nurse on the ward may log into that patient to see what results are, before the proper clinician has had. And that's a situation.

Shada: Ok so if you want to do it properly, and go back, to do that again in a proper way, would you go the first way that you mentioned, that whenever it's referred to a role then that role only can see that information?

Dave: I don't know. [laughter] I don't know whether our cracked with Alysia's researched on there. But I pointed out as a practical example of a security model, and I don't know to what extent.

Shada: Share here, only let's you see information for the patient referred to you. You don't see everyone, and because it's patient-centred, this is for Susan, when this case goes up and it's for Susan, and everything needed for Susan's case is gathered and reported in there. No body else's case.

Dave: What you've then got is the situation where you'd have to authorise Dr. Tom Crosby's secretary to have that role. But there may well be a break the glass situation under that circumstance.

Shada: The breaking glass is for everyone.

Dave: Right ok, then that might be legitimate use of break the glass, because that medical secretary doesn't normally provide any cover for Peter Barrett Lee, because he's up the end of the corridor and there's a different team providing cover. But under those circumstances she may need to break the glass simply because nobody is available to authorise her on the system and she's got to provide some care, under those circumstances. And it may be that Alysia's research sorted that out, in which case you're building on Alysia's research for that. But it is, these are practical examples you get into, and it's your security model, it may well need to pick these up, and how are people going to be authorising these.

Shada: And the only way to do it is to speak to people that have been involved in such scenarios, and you can't pick them from reading and stuff, it has to be from people involved. Just the last question, with regards to information, do you think it is important to be able to change the information electronically and then alert everyone involved?

Dave: I think it's certainly important to do that.

Shada: Ok what about the current systems? Can they do it? Because the example, when you think about it as a main functionality, is when I spoke to Tom Crosby,

he said sometimes we type in the wrong code for the cancer type. So we can't do anything about it, there was an error there, but we can't go back, so we have to speak to the hospital and say please change that.

Dave: And then you've got to make sure it's cascaded through. Yes it is important to know about those, because there could be some important changes.

Shada: Ok do you know how the current systems deal with it?

Dave: They deal with it, poorly, it has to be manual. You know they used to, currently the way they do it, because they're used to generating reports by paper to go through, they'd have to generate another report and send it through. Sending it through electronically to another system, they do it poorly at the moment but it would have to be done. That's something that is a challenge for your low level integration engine, what are you going to do about that.

Shada: That's why we said we have to alert everyone, because if this happens, we need to change what happened, we need to make sure that. So we can go to the local systems, do any changes they have to do about that, but they still need to be alerted by that. But do you think the amendment should be done by anyone in the care team? Or the person who reported it?

Dave: No, it's, in our experience on CaNISC, ,it has the be the person who recorded it, because they might have a different opinion of it, and for, should we say a nurse, or lets take the worse case scenario, medical secretary of Dr. Tom Crosby thinks oh that's wrong, and goes and changes something from a consultant on another system in another organisation I think that's wrong, because they haven't got the knowledge to do it. I think you do need, I think it is a functionality that you need in your security system to recognise that someone is going to see, with this sharing you improve information accuracy and therefore the information security system or the workflow system needs some way of trying to make that as smooth as possible. Alerting the other people, the other end, hey there's an issue here, can you please attend to it, then they need to cascade the cascade through.

Shada: Because I was in one of the MDT's it was very funny when I was there, that this case happened. Everyone was talking the right breast, and it just result in everything and then the consultant said "wait a minute, in my report it says left breast and not the right one. So what shall we do, is it an error that it's the left not the right, or shall we do tests for the left and see if there is something else in the left breast." So that's another thing when you need to go and see if there's an error, or if there's something else we need to.

Dave: And you can see the security system finding a way of bringing things together

within the one context, you've got a better way to improve the accuracy of the system because it's easier to review. And also if you then use your workflow to implement you've got maybe a way of better alerting people at the other end that there's an issue, and also hopefully then cascading that result through. So again it works much better.

Shada: Wow, I'm so thrilled, we've done all the requirements, asked all the questions I had in my mind. Anything to conclude?

Dave: No not really, Shada, I just wish you all the best really, I don't think you've missed anything. I like what you've done, I would love to be in post, and have sources within CaNISC to actually be in a good position to use it, because it's, the issue we've run into a few, over recent years, in that the research has run ahead of our ability to implement it in there. Because we've been slowed down by the national people in their view of things.

Shada: It's amazing the impact it has, it's a very big deal, it's very important, and as I told you it can't do everything. I've asked because you've done things that are very important as well, it's just because this is recent.

Dave: In the past we'd always be able to build in it might not have looked exactly the same, but we could build in the ideas and the results and research into the next phase implementation, the clinicians would start asking us for that. We're running, certainly the development has been slowed.

Shada: Have you had resistance with clinicians?

Dave: I don't think so, no I don't the clinicians, no I don't think in this particular case it is the resistance of the clinicians. It's the resistance, is simply the resources and the will to do it. And also because they are trying desperately to catch up. If you like CaNISC and what we've done, and what you're able to do within this prototype here and way beyond what's available on the ground in most cases of the hospitals. And what the national people are trying to do is to get those people on the ground up to a common level before moving on and that's proving very difficult on that. So you have certain sympathy on that, but it is frustrating I imagine from Dr. Tom Crosby's point of view that, he knows bread and butter stuff that he wants changed and he's struggling to get it to happen, and Anne Marie may well be thee same that she wants things.

Shada: I haven't met with her yet, I'll think about. I'll speak to Tom about it as well

Dave: Yes and also as clinical director, when the other consultants are getting problems, they'll go to Tom and bend his ear.

Shada: So the kind of questions I asked you do you think he will be able to answer that kind of thing?

Dave: I think certainly he'll give you a clinical view, much better than I can on that.

Shada: So his views on using SHarE and CaNISC, more than the involvement.

Dave: Yes I think so yeah. He, yes that's right, he'll be able to tell you that years ago, we just used to say well we think you ought to do it like this, and we'd have the meeting and decide to just go and do it, and it would be done, prototype fashion fairly quickly so the prototype you're describing, the next stage would be a prototype implementation in CaNISC and it would happen, and then you'd start seeing what the practical problems are, and evolve your prototype into the real system. It's not quite the same.

Shada: Absolutely, when was CaNISC made?

Dave: It started about ninety one.

Shada: No way in collaboration was a major thing at that time?

Dave: No, it was really ninety seven that the idea of collaboration came in, there was a Calman Hine* report saying the way forward for cancer care across England and Wales was actually this shared, and MDT's and all the rest of it, and it was at that stage that CaNISC was completely redesigned to deal with that. And it had to be a pragmatic way of dealing with it, which leads you to certain problems and the rest of it.

Shada: Thank you so much, for the time, effort, ideas and for coming, and I'm sorry about the headache. Thank you so much

Appendix F

Joint Interview with Caldicott Guardian (Dr. Tom Crosby) and Information Technology Lead (Ms. Ann Marie Stockdale)

F.1 Interviewees' Roles

The assessment session aimed to interview two roles at the same time, Dr. Tom Crosby and Ms. Ann Marie. Initially, Dr. Crosby plays two main roles: a Consultant Oncologist treating UGI cancer, and Caldicott Guardian for the Cancer Centre. This is in addition to several other leading roles including: Clinical Director of the Velindre Cancer Centre, and Chair of the Cancer Service Management Board and being an oncologist who accesses patient information for patient care continuity, and at the same time, a Caldicott Guardian who is concerned about patient privacy and information governance. These contradicting roles make Dr. Crosby the perfect person to set the right balance between information availability and confidentiality in the context of healthcare.

Ms. Ann Marie Stockdale, on the other hand, is an IT Lead at Velindre Hospital; she also sits on the CaNISC Service Management Board and the Change Advisory Board and I Head the IM&T Department at Velindre the Cancer Centre.

F.2 Interview Aim and Structure

The interview with Dr. Crosby and Ann Marie was held in Velindre hospital for a total of 61 minutes. It was attended by Prof. Alex Gray, the research's lead supervisor, who made a couple of comments throughout the interview. The interview aimed to evaluate SHarE system from someone who can see the research problem and assess the proposal

from both clinical and managerial perspectives. In addition, the interview was aimed at exploring the following areas: if it addresses the problem in hand, there is a potential for adoption, use, and integration of SHarE with current systems, the challenges this adoption may face, how it can be improved and if it complies with the six Caldicott Guardian Principles and national standards. In the first 20 minutes, the research was presented along with a demonstration of SHarE. In this presentation, the research problem was introduced through a breast cancer treatment scenario in which the interviewee plays a role, then its research aim, and its main requirements were represented. Afterwards, SHarE was demonstrated live as well as through a number of screenshots. In the remaining 41 minutes, the reactions to the system were evaluated through a set of open questions, as shown in Table F.1 below.

F.3 Questions List

The questions are categorised into a number of main categories as shown in Table F.1

F.4 Interview Synthesis

Information sharing needs. When both interviewees were asked the extent to which they agree that there is more pressure on the current systems used, Ann Marie commented "it's certainly an increased requirement isn't it, to share the information or to have access to the information related to a patient," and Dr. Crosby supported her idea by saying: "Yeah, yeah I agree and that it is a really important issue and it's become more so since I think we do record this information electronically now in lots of different systems, so that has raised the level of frustration that we cannot see it all and it's not joined up around the patient." He also added the patients' perspectives of this pressure, by saying: "I think also something important is that we've had a - there's been a patient survey recently about what they want from healthcare. I don't know if I've got it somewhere, but there's been an exercise from Welsh Government out to patients to - I'm sure I'd find it. But one of the things that the patients have frequently complained at is that they go to different providers and have to repeat their story and to see providers who don't know the information about them as an individual. So I think that would just add weight to it, you know, sort of coming from patients that they find it frustrating."

Moreover, the interviewer asked about how the current systems are coping with that pressure, and Dr. Crosby explained a number of ongoing projects by saying: "Well, there's a CaNISC roadmap. There's all sorts of things so that GPs are moving to two systems I

Table F.1: Interview questions with Caldicott Guardian, UGI Oncologist, and IT Lead.

Category	Questions list
Interviewees' roles in healthcare organisation(s)	What are the role(s) you play in the healthcare organisation(s)?
Information sharing needs	To which degree do you agree with the fact that there is more pressure on current systems used in cancer care to share information between hospitals?
	How are current systems coping with this pressure? What do they have on their agenda to address that issue?
	To which degree do you agree that there is a need to carefully balance between information availability (for clinical decisions) and confidentiality (to avoid the information from falling into the wrong hands) in this context?
Research problem	Do you agree on the research problem I'm addressing?
	Is this because of the current systems? Or people's behaviour?
SHarE	What do you think about the proposed system?
	Do you think it has the potential to address the identified issue?
	Is there a potential for healthcare professionals to adopt/ use SHarE?
	Is the integration of SHarE with CaNISC and other systems possible?
	Does SHarE add any value to CaNISC and other systems with the additional functionalities it has, if integrated?
	Any challenges, obstacles?
	Additional comments? Recommendations?
Controls and Requirements	For each of the functionalities: 1. Does current system provide it? 2. Is it important? 3. How it can be improved? 4. Challenges? Comments?

think in the whole of Wales, electronic sort of systems, so standardisation of the GP electronic systems. There's an electronic referral project that's going on, taking information ultimately from GP systems and putting it into secondary care systems across the clinical gateway,"and Ann Marie added: "They're on Phase Two now, so the secondary can send information back to the GP." Then Dr. Crosby continued by saying: "And the cancer community is trying to design the referral pro formas," and Ann Marie interrupted by saying: "and it's being used in the Health Board. It's called the Welsh Clinical Care Gateway." Dr. Crosby elaborated by saying: "then that comes into secondary care. There is a component of the CaNISC roadmap that would then allow referrals between secondary care, I think, using the gateway as well, isn't it, the idea, the thought around it. There's then

another proposal around an MDM module being redesigned. You might have seen what we have already, but around an MDT module. Then, lastly, there is an ongoing project particularly focusing on breast cancer, looking at sending care plans and well care plans from secondary and tertiary care back to primary care." He tried to explain the latter project to the interviewer by saying: "at any stage or whatever, we're saying around a patient, but particularly focusing at the end of treatment, making a holistic needs assessment of that patient and then referring that, sending that patient back to primary care, encouraging self-management but also signposting back to primary care, who to contact in the future if there's a future problem, so that sort of thing. So there is a number of pieces of work, but at the moment it is all not...done yet, rolled out". Finally, Ann Marie added a final major ongoing project by saying: "There's also the Clinical Portal, the Welsh Clinical Portal that will allow us to see results." The interviewer asked Ann Marie to elaborate on that project explaining what it mainly focuses on, and she did by saying: "It's literally an area that you can go into and you can see information relating to that patient from the results perspective, so blood sciences, from other Health Boards." Dr. Crosby added: "And assuming it's on any national system, so be it LIMS, which is the pathology system, we have a single pathology system being rolled out in Wales." Ann Marie continued: "And it will allow electronic test requesting as well." Furthermore, she commented about the different portals used today in cancer care by saying: "they use a couple of portals. They use one from an Aneurin Bevan and one from Cardiff and Vale at the minute," and Dr. Crosby explained "But Cardiff have called theirs their portal, but it's not Welsh Clinical Portal."

Eventually, Dr. Crosby responded to a question about the degree to which they agree there is any need to carefully balance between information availability for clinical decisions and confidentiality to avoid the information from falling into the wrong hands by saying: "Yeah, I think that is obviously important."

Research problem. Initially, Dr. Crosby stressed the fact that the main problem he is facing as a Caldicott Guardian is the mis-interpretation of security by saying: "I think it's sometimes the interpretation of the security rules are not in harmony as opposed to the actual security rules. But it's the same principle, we know the problem you're talking about." the other interviewer tried to understand what that actually meant in reality and so he questioned "Its interpretation into the machine readable form presumably?" and Dr. Crosby's response was: "that's right, I mean it's local interpretation of standard advice as it were and leads to barriers." He seemed to agree on the technical explanation for that misinterpretation in that the different systems employ different security controls that makes the systems not inharmonious and this brings the concept of misinterpretation of security as well, so different security context and different interpretations". Moreover,

he commented about the research problem of information not flowing sometimes and not being available at the point of care by saying: “frustratingly slowly, but there is always a lot of that work going on,” and Ann Marie continued “There are dependencies, especially for CaNISC, that we have to do Nadex authentication to enable us to get WCCGM portal, so it’s not as straightforward.” This makes it not as simple as it sounds.

Furthermore, Dr. Crosby added “And I think then there is also, I suppose, co-dependent in that there was a risk of developing a system that would work for cancer, following a cancer patient through the journey, but then diabetes, stroke and everything else. So we want it all a part of the same system and then, as you say, that then necessitates infrastructural support from the Welsh demographics and lists the patients so we’re all talking about the same patient, everything carefully.” This highlights the fact that it is harder when there are multiple integrated care pathways or different conditions. In addition, the interviewees were asked about the main reason they believe is behind the problem, whether it is to do with the systems or people’s behaviour. Also, the interviewer even supported her question with two conflicting opinions she received from previous interviews with the MDT coordinator and nurse, in which the former responded to this question by saying ‘Well the information’s always there but people can’t find it.’ They find it hard to use the system to find it, whereas the latter said: ‘No, the information is not there where we want it.’ Ann Marie responded immediately by saying: “probably a bit of both.” Then Dr. Crosby agreed by saying: “Yeah. The design of CaNISC is not intuitive; it’s on a provider level and not a patient level. So you have to find your way around it and then - so if Cardiff and Vale, the Surgeon put in information, even if they put it into CaNISC, they’d put it under their provider episode. And you have to have a fairly good knowledge to navigate around the case note to find that if you were, say, a Velindre person.” He also added “Sometimes yeah, the information is not there at all; it’s just on their PAS system or Merlin or somewhere else, so I suspect it’s true, that both are somewhat true.”

He finally summarised a couple of current requirements and needs by saying: “but there’s a couple of things, first there’s information that flows and there’s a balance also between whether it is pushed to somebody or whether it’s available to be pulled at the time of need. And I think there is benefits to both ways. So a referral acts not only to give somebody the information, but also to trigger the arrangement of an out-patient appointment. So that needs to be a push system. At the same time, there’s the issue of burdening people with information that they don’t need either at all or at that time. But also, as I say, a letter has two forms, functions. It gives you information but it also acts as a prompt to make an appointment and things, so you need to have both of those.”

SHarE. Generally commenting about SHarE, Dr. Crosby said: “well, I think it’s great, if it’s set at - there were sort of tweaks to how we’d want it to look and run as we’ve sort of

talked about, I think is just what we're trying to achieve," and he also agreed on the fact that it has the potential to address the identified problem. Ann Marie said: "It looked like it had an element of workflow in it, which is something that would be useful for us. Well, that you can move things around the system, that you can then see." Dr. Crosby elaborated by appreciating how SHarE operates differently by saying: "yeah and we haven't really talked around that, the way you build on an information source rather than we start again at every time. So I don't to a certain degree, because when it's allowed to people cut and paste and put information into my referral and I just put, 'further to above', you know she has a sort of fit on everything about cutting and pasting which is bad practice, but because the system doesn't work in other way, it's electronic, somewhere we can put it where we want it. And so for a new patient, I just have to say, 'further to above', put my oncology additional information in and it takes me about two minutes to type myself. Whereas other people are writing, 'this patient has present...' rehearsing all the information that's been given to them in paper format, starting again; our Secretaries having to type it de novo and it leads to risks of errors. You forget something because you've got four attempts to take somebody's history as it were." Ann Marie added to that, "I think what we don't have is a common grounding, do we, in terms of how we capture information and where in fact it is captured in CaNISC" and Dr. Crosby totally agreed with her statement.

The interviewer moved to another question regarding the potential for healthcare professionals to use such a system with the current ones or whether is would add more pressure and become an additional burden. Dr. Crosby responded by saying: "we're always having to learn new systems and it's really irritating and hard but we accept it. And I think on both sides it depends on what side of the bed you got up on." Therefore, the interviewer asked him: "do you think that's going to be an extra burden?" and he said: "I think the prize is pretty good and so I think people would be undergoing some training, make it as intuitive as possible and not additional burden as much as possible. And yeah, they'll always be prepared to learn a different system. Well yeah, well they will - we're either going - we're not going to stay using paper; we're not going to stay with lots of different systems in Wales; we will have to move and merge and see things in different views and yeah, I wouldn't say it's a huge problem." The interviewer built on the positive feedback and asked if they believe there is a potential for integration with CaNISC and other systems, but before answering, Ann Marie questioned: "so it's just viewing?" and the interviewer explained that it is a viewing system and you can still record on it, but it will go to the database that is shared between the legacy systems and this. Therefore, there is no replication, so it is the same information, but it is just where you view it. Then Dr. Crosby said: "so that is more like a clinical portal then, that that hopes to be the sort of Google of all information about that individual that you look up and orders it and structures it." Ann

Marie added: “so you go to a single point as opposed to multiple.” Eventually, they both approved it. Moreover, they both agreed with the interviewer that SHarE could add value to legacy systems with its functionalities.

The interviewer then asked about any potential challenges they could think of, and Dr. Corsby responded with laughter by saying: “well yeah, huge.” He added: “that organisation’s any worse than anybody else to change.” Then he explained: “but no, they’re just sort of getting signup across organisations, across services. So, you wouldn’t do all of this for cancer without other people having it, for rheumatology or other sort of situations; trying to integrate in with existing developments in Wales. I think those would be the big ones. And governance, we’re still not quite sure, well we probably are really, but really sure about how to use emails and information. I know there’s various guidance that comes out of the things.” He then continued: “and so NWIS have really struggled to be that central governance body that says, right this is perfectly safe to everybody if you do it this way.” Ann Marie added: “yeah, what it kind of says is tells you what you can’t do but doesn’t give you an alternative solution.” Then Dr. Crosby elaborated by saying: “yeah and if you’re going to do this, you’d better do it this way than any other. Rather than be very clear, it’s absolutely fine to do that. And then as soon as you get that ambiguity, different organisations, different Caldicott Guardians, some very relaxed like me, other people interpret that they feel that patient safety is in their hands and they’re holding it and they mustn’t let it go to anybody else in case there’s an error. I come to it from a tertiary point of view where we are constantly challenged by not having information available at the point of need to manage the patient that’s in front of you. And the reports that we’ll hear are where information went to the wrong person, which is very rare, very rarely leads to any harm, unless it’s population information, large quantities of it. And it seems to influence more the governance agenda of some.” However, the interviewer commented by saying “OK, but I remember you mentioned at the last meeting that there’s more harm done to the patient if the information is not available,” and Dr. Crosby’s responded: “absolutely, yeah, yeah.” Finally, the interviewer asked a very important question to Dr Crosby about whether he considers that the requirements meet the Six Principles of the Caldicott Guardian, and he responded by saying: “I think they’re fine and they are, in principle. So, the tone is all restrictive isn’t it? Rather than ensure that everybody in the system who’s going to manage an individual patient has access to it, that should be one of the principles shouldn’t it, really?” Ann Marie added “it’s in the patient’s best interests then as long as you can evidence that,” which Dr. Crosby agreed with and then commented by saying: “yeah and nine times out of ten it is, or you can audit it and have to justify it if called too. So, with electronic systems, it’s much easier to have audit trails than with paper records.”

Controls and functional requirements.

- ***Information access is patient-centred based on the patient's condition and treatment stage and neither organisation nor disease-centred.*** Both interviewees agreed that this is a "very important" functionality and current systems do not provide it "yet" which indicates the fact that this research is foreseeing the future need in the current developments which are moving towards the route this research is taking.

- ***Information organisation in chronological order (in a timeline format) with a stamp showing date and time of care point, and who saw the patient.*** This functionality was approved with some concerns. Initially, Ann Marie commended the importance of this functionality by saying: "I think it's very useful." However, although Dr. Crosby agreed, he highlighted a concern by saying: "yeah, but potentially there should be the ability to re-order it for different needs. So that you may just want a list of all the radiology investigations on their own, so you should be able to have different views." Ann Marie justified by saying: "because it could become very, very, very busy," and Dr. Crosby agreed with her. Prof. Gray sought a clarification from Dr. Crosby by asking: "so what you're really saying is select subsets that would still be in chronological order within the sub-set?" and Dr. Crosby responded by saying: "yes, that's right, absolutely, yeah and obviously should be able to do that with various categorisation. I mean there is that we are at a level where we still would prefer to be overburdened with information. I have to be, you know, because there is the risk of it. But I'd still prefer to look through and have to trawl through and find the relevant parts than what we have at the moment where it's not available. But it definitely is a risk as more and more healthcare professionals add into the record."

  The interviewer then mentioned that although SHarE did not yet add a different disease or condition to show how information can come from different treatment pathways, this is something that is planned in the future and he was asked for his opinion on how he sees information being presented in such a case. For example, is it important to consider all conditions on one page or have different pages for different conditions? Dr. Crosby said: "I think, again, it's probably you need both, because I think increasingly, cancer is becoming a disease of old age, well it always has been, but where patients have other co-morbidities and it's important to see those. And I don't think we've begun to really address the issues of co-morbidity, they're complicated. And so if you're coming down the cancer pathway, you're going to need to look into their diabetic history or their other things, so..." At this point, Ann Marie interrupted, "And we do need that information." Then Dr. Crosby

continued by saying: "yeah, so again it's an ability to be able to order it in a cancer only but then have views of others as well." Finally, Prof. Gray summarised by saying: "and that comes into the other systems that we were talking about at the start, needing to know about the other systems but not wanting - you need a button that almost says I don't want overburdened at the moment but I want something that alerts me to the fact that there are others."

Finally, Dr. Crosby commented by saying: "I think the other thing we're just having to sort of mention is how they're populated, because some of things around having free text and fields. Because the other purpose to it is there's data, there's communication, then there's coding and particularly increasingly giving it financial value, our transactions. And I think it's really important that we try to use an access friendly system. Whenever I've seen summaries built on clinical codes that are pulled off systems, you end up with C4.6X NOS nearly all the time and just write it. So it is a balance I think of getting that free text, which is much more descriptive and meaningful." The interviewer interrupted by asking: "so, free text is more valuable to the Clinicians?" and he responded: "yeah and I can understand why IT people are designing it. The first thing they say is well it sits in an information somewhere, let's pull that off from there and let's pull it off from there, but you know." Then Ann Marie added: "they look at the secondary element as opposed to the clinical element. So, for the reporting requirements, whereas you can't do that with free text. So it's doing the both." Dr. Crosby totally agreed with her. Prof. Gray said in that regard, "but, yeah it's things like records where we're constraining you in one stage, because you needed it for systems to work efficiently, but we're changing with the clouds and all these other things, the world is changing rapidly around us." Dr. Crosby commented by saying: "yes, yeah, yeah. I think also the other way around is that if you put good clinical textual information in, the coders would find that easier to be able to code anyway so that in their own systems they, anyway," and Ann Marie supported him by saying: "absolutely!"

– ***Automated referral to a named CT member or a role that is picked up by the recipient with all information needed.*** Initially, Ann Marie explained how referrals happen today by saying: "from the referral perspective only, we have it in paper format anyway. So by the time it reaches us, you've got that time delay, by the time you process, so if it's electronic, it will save time and we can audit it, we can manage it electronically. Whereas if you lose a bit of paper." Dr. Crosby agreed, then added: "yeah, yeah. Well we sit in a meeting and if we decide that it needs to be referred, then frequently that'll mean going back, the Surgeon remembering to dictate a letter; dictate a letter; the Secretary types it; sent; so our post was received

in our mailbox, gets to us. And realistically, that's always going to be a week and that could've been instant, or nearly instant, yeah, yeah." Then Ann Marie concluded by saying: "yeah and this is what WCCG does." Additionally, as Dr. Crosby explained, the future agenda for systems' development was to help cope with the increasing pressure for cross-organisational information sharing, and he mentioned that: "the cancer community is trying to design the referral pro formas." This indicated a need for automated referrals, so the interviewer pressed: "so there is a need for electronic referrals in the system?" and Dr. Crosby's answered by saying "yeah."

Furthermore, Dr. Crosby thought about the whether current systems provide this functionality by saying: "I think we've had that sort of functionality that's never been switched on in CaNISC and I think we've had it in part of the MDTs or something, I'm sure. With sort of - I think it might exist, but I don't think it's ever been switched on. You can email letters, but, anyway, it doesn't work anyway; we don't use it so in effect it's not there." However, he commented regarding how important he thinks this functionality is by saying: "but it is - yeah, it would be really good. With qualifications." He then suggested: "but I think you added the ability to add information to it. When you're in an MDT, you're deciding on a management plan individually for that patient. When you do a referral, you add in other information around that patient in context and things. So it's about having the right information. So I think a lot of people wouldn't accept a referral from an MDT at the moment for that, because there's not enough information. We still get more in the letters. So at the moment, many of us do - some do accept the referral because it's just better to get the patient in quickly. Other people sort of say: 'yeah, we accept the referral but send us a letter as well while the patient is getting...' So people are using it in different ways. So I guess it's taking information from one form and purpose, it's not always the same as the need for the information in the referral. Having said that, if we had access to all the other information, you know, the GP's, that would give you more information." Eventually, they all agreed that this functionality is, in a sense, shifting a burden across because it allows the person who the information is referred to, to have access to all of that information that is in the MDT and the extra letters, and he/she can extract what might be relevant. However, in current practice, they're doing a relevant thing that you know already in the referral letter. Therefore, SHarE is balancing this constantly at any referral.

– ***Filter and gather needed information from the different systems at the point of care based on clinical guidelines.*** Initially, Ann Marie and Dr. Crosby mentioned that, in current systems, clinicians can actually select what information they want

to access. Then, when they were asked about how they would prefer the filtering to be, Dr. Crosby said: "well, I think this will evolve under the system and I think, at first, I'd love to be in a system where I have too much information, and then after a bit, they go hang on a sec, it would be helpful if we only had this information. At the moment, we don't have enough" and he agreed with the interviewer that this involves the organisation of the information as well. Therefore, the idea in SHarE is to filter the information for clinicians based on a number of conditions: the clinician's role, patient's condition, and treatment point. However, clinicians can still access the extra information that they want. This was explained to the interviewees and "yes, absolutely, yeah," was Dr. Crosby's comment. Ann Marie then provided her opinion by saying: "I think what would be useful from what Tom mentioned earlier, is where information is copied and pasted into one section so the Oncologist has all the information in one place as opposed to having to look," which Dr. Crosby agreed with, before she added: "and if there was some functionality that could do that, that could be bring information into a summary page for the Oncologist, I think that would be really useful." Prof. Gray asked: "so, what you're needing is a sort of filter, but also a filter that can coalesce things or amalgamate them in some way?" Dr. Crosby answered immediately, "yes, yeah, yeah." Ann Marie then added: "absolutely, because in clinic, it's busy, they don't have time to go clicking through records and other systems and if there was a mechanism to summarise information into one place." Prof. Gray asked straight away: "and they normally know what it is that won't take some of the other systems in some general way." "Yes, definitely, yeah," was Dr. Crosby's answer. Shortly afterwards, Prof. Gray commented by saying: "it's because you're saying well I'm needing to get that from there because I wonder if they have this. And so it's a sort of filtered and then merge type thing." Then Ann Marie concluded by saying: "or maybe the opportunity to, I don't know, just select the information that can be configured for oncologists and tailor it." Ultimately, SHarE provides a summary from other treatment points based on what the other clinician decided to share with others.

– ***Information can be amended after sharing by originator and this will automatically alert everyone involved.*** "I think a mechanism to alert is quite useful and then it's up to the individuals if they want to go and look at that information," Ann Marie commented about this functionality. However, Dr. Crosby thought deferentially about this functionality and he expressed it by saying: "I wouldn't routinely let everybody know that information has been amended, but you just need to be able to see the trail if you want to look for it, who it was amended by and when. And we do that with ERMA forms quite a bit, don't we. You can, I never look at it, but

you can find that trail." The interviewer questioned whether this is because he does not want the alert or because he wants the amendment to happen but does not want alerts too much. He responded by saying: "well, alerts are always helpful if they're there somewhere and they're functioned to Warning or sort of, yeah." Then Ann Marie added: "I don't know if it's alert in its true fashion, I just think some visual," and the interviewer suggested using icons similar to the ones used in SHarE's classification scheme, and they both agreed that alerts would be something that when they want it, they will need it, but they would not want it most of the time, and Dr. Crosby agreed by saying: "absolutely, yeah." Ann Marie justified that need by saying: "because if you send alerts constantly, we'll lose what the true alert is," and Dr. Crosby added: "yeah, you lose the value of them anyway."

– ***If extra information is needed at any point, trusted CT members could break-the-glass and access all information they need, then they have to justify it.*** The interview intensively discussed this functionality from several perspectives: the best way to use this functionality, the need and means to justify it and how often it should be to become reasonably practical, and finally whom to alert after the incident and how often.

  Firstly, as this functionality has an immediate effect on the balance of information availability and confidentiality to trusted CT members, Dr. Crosby had another thought about the usage of this functionality by saying: "yeah, I mean, just on your presentation, I thought you set that balance sort of - the break-glass was too common event. So I would've thought that the surgeon would routinely be able to see all of the primary care information around that event. If they wanted to look into the primary care system around their ante-natal or psychiatric history, that may take a break glass, but if it was related to the actual event, all people in the whole [treatment]." He then said: "so the principle should be, I think, that the information follows the patient at their point of need. And the expectation I think from patients would be that the clinician, of course, you should be able to see the information around that event. There could be things like psychiatric histories, genetics histories; there may be things that require a break-glass. I'd just set that threshold a bit higher to be that more security, more confidential information that requires a break-glass to look at it." Therefore, the interviewer asked him immediately about what he thinks would be the best use for this feature as different healthcare professionals had various views about this functionality, and she asked: "what about emergency cases or more sensitive information? Because we're coming to breaking-glass and I want to talk specifically about what do you think is needed there? Because I spoke to nurses, oncologists in breast cancer and they had different views about how to

use the breaking glass. Some of them said, like you said, there is no need because it is supposed to be there. But maybe if it's not there, then it enforces the system to or maybe others said just for super-sensitive information and it's not all information, so you keep super-sensitive information in the box and then you break it when you need it. So what do you think about it?" Both interviewees responded without hesitation, as if they had a thought about it before. Dr. Crosby said: "sort of set up a super-sensitive level," and Ann Marie immediately followed, "that's the common approach that's been adopted, because we do have break glass functionality and it's fully audited."

In regards to justifying the use of this functionality, the interviewer initially asked the interviewees whether they think there is any need for justification for accessing sensitive information: "yes, and there is, it does exist and we do have break-glass in national systems, the portal being one of them," Ann Marie responded. She went on to explain how current systems do it by saying: "the highly sensitive information you have to select and you have to put your password in again and notification is sent to appropriate colleagues so they know that that has been activated, to make sure that it is right and proper." This means current systems do not justify it apart from confirming it through a second password check. Therefore, the interviewer said: "but they don't justify it but do you think there is a need for justification in text?" Dr. Crosby answered by saying: "It depends at what level it's set. If it is really, truly break-glass (i.e. for exceptional reasons), yes you'd want to sort of provide it." Furthermore, the interviewer wondered what the interviewees thought about the justification, whether it be before or after the incident; she explained maybe in emergency cases, such as Out-of-Hours for example, that people may need to access really all relevant information or everything about the patient, especially if he/she is not conscious. Ann Marie first responded by saying: "I'm not sure it asks for justification; just asks you to re-enter your password so that it's a deliberate act and I think there's a clear definition of what is held behind break glass." This led the discussion towards another idea, when Prof. Gray said: "I think what you said though, that you've got these audit trails, that would come back afterwards so there's a post-justification if it's needed is what you're saying," and Dr. Crosby said: "yes, if needed then yes," before Prof. Gray added: "but you're saying you wouldn't ask them because that's getting in the road of the immediate access. Somebody would come back and say, 'Oy you did this, why?"' Ann Marie responded by saying: "I think so, yes." However, Dr. Crosby was more concerned about how often the justification should happen than the justification itself by saying: "so, I would still say that issue is around how often you need to do it and as

soon as you start needing to do it, frequently asking people to justify it is silly, they don't do it and they'll write whatever, write rubbish in. So if it's exceptional then it's OK to justify it, but as you say I think probably then it's done on an audit basis rather than an all time justification." Finally, everyone agreed that it should not be too extensive, the amount of information that is being put in this super-sensitive and that it has got to be done very carefully.

Finally, the discussion led to the use of alerts in this functionality after a breaking-glass incident. Therefore, the interviewer explained the concept in SHarE and compared it with how current systems do it by saying: "and this is where I have alerting everyone after the incident of breaking glass. So, maybe in the case of current use, it's only alerting through the audit." Dr. Crosby commented by saying: "I would say it doesn't need to be brought, yeah," whereas Ann Marie thought "I don't think it - yes, it doesn't need to alert everybody." Dr. Crosby supported her by adding: "well, for everybody getting an email ten times a day, that somebody's glass has been broken is a big issue," then continued, "so it would be things like a Primary Care Manager or whoever their governance people are," and Ann Marie interrupted by saying: "it normally goes to the Medical Records Manager" who can then take action if there is a breach of trust and both interviewees agreed.

– ***Labelling the sensitivity level of patient-identifiable information and communicating it to all healthcare professionals as a technique to raise their awareness.*** Initially, the interviewer explained the concept behind this functionality through examples of usage. First, a mechanism is required to label the sensitivity of information which may be useful to a Caldicott Guardian from a managerial point of view, or second, to mark high risk patients as a mechanism that the person recording information flags it somehow. She asked the interviewees how important it is, and Dr. Crosby commented by saying: "yeah, set up at the right level of sensitivity," and the interviewer suggested putting labelled super-sensitive information behind the glass and then when there's a referral from the GP, then you can see the label, only a label and then the breaking-glass, for example, you can still see the label. She was asked, "Do you think that's important to raise awareness, do the current systems do it?" Ann Marie responded: "I think it's restricted who the information goes to initially, so by definition, it's managed as sensitive. It's not available to all." However, Ann Marie thought "I'm not quite sure what that's going to add to you as an Oncologist that there's sensitive data in there." Then another question was raised whether the consultant or the people who are possibly going to break-glass need to know that that information might be available behind, because there would be no point in breaking-the-glass if it was not going to be there. Ann Marie responded by

saying: “well you just break it just to see what it is and it might - yeah.” However, when the interviewer explained that when she spoke to the nurse, she said: ‘I never broke the glass. It’s there but I never dared clicking on it, because I don’t think there’s anything that I need extra that is not available on the system.’ Therefore, the interviewer how they could know what is inside the box to make the decision as to whether or not they need to break and Dr. Crosby responded by saying: “no, but there will be a time, there’s the genetic stuff and things and...”, then Ann Marie added, “And mental health also comes under that category.” Dr. Crosby continued: “we’re doing psychology, which I think they’re wanting to keep separate to some degree, which I’m not sure that they should. But there will be information that some people will have given in confidence.” Ann Marie also said: “It’s under the Act isn’t it, the mental health, paediatrics and gynaecology is all treated differently.”

Eventually Dr. Crosby said: “I think the default should be to all care providers and then have - and I think what you’re talking about a little bit with the break-glass is bordering onto alerts as well, you know, around HIV risk or something else that is routinely available and that you just want somebody to know it and factor that in as opposed to having to break-glass to find out the information. I think they’re slightly different things.” However, he commented by saying: “so when we talked just now about super-sensitive data being hidden but possibly making the person aware that there is, do they need to know the sort of area that it’s in? In other words, super-sensitive data can probably be classified into different areas; should there be something that says there is super-sensitive data of this type or will that encourage people to look at it?” Dr. Crosby answered: “yeah, I don’t know,” but Prof. Gray laughed and commented by saying: “this is your danger, isn’t it? Curiosity?” Dr. Crosby agreed by saying: “yeah, it is. I think you’d have to say there is super-sensitive information but probably not start describing what it’s around. I think that’ll probably lose the value.” Eventually, he agreed only to say there is super-sensitive but would not say any more than that.

At the end of the interview, Dr. Crosby summed up by saying: “It’s great. I mean you’ve sort of caught the essence of a lot of the problems that we have.” ?

F.5 Full Interview Transcript with Caldicott Guardian and UGI Oncologist, and Information Technology Lead

Key:

Shada = Lead interviewer, PhD Student

Alex = Second interviewer, Prof. Alex Gray, research supervisor
Tom = Lead interviewee, Dr. Tom Crosby
Ann Marie = Second interviewee, Ms. Ann Marie

Shada: ***OK, thank you for seeing me today. I'll just give a brief presentation. It's got the list of questions. So I'll just start the presentation talking about the reason for our meeting here today, which is to evaluate SHarE, which is the system that I use, and implemented as part of my research. Is that clear, yeah?***

Tom: Yeah.

Shada: ***So, also we're talking about the treatment scenario that I picked as a basis for my implementation and my investigation, the research problem that we identified in the research, what we aim to do, and the identified requirements that we're presenting here to address that problem. Then I'll give a couple of screenshots to demonstrate the system and then ask a couple of questions which is in the piece of paper there.***

OK, I'll start with a scenario. This is a scenario I took from one of the Oncologists, Annabel, Dr Annabel Borley.

Tom: Borley, yeah.

Shada: ***Yeah and Helen as well, the Nurse. So they helped me get sorted with the scenario. So the breast cancer scenario starts with a patient visiting a GP, the GP's surgery. If he is the specialist then he will refer a patient to a specialist and share information about that patient. Now the specialist starts a triple assessment and refers a patient to a radiologist for an ultrasound or mammogram and a biopsy, to be read by a pathologist. So the results from these three tests are discussed at an initial MDT review. Most patients in breast cancer, following the 'Happy Pathway' undergo operation as a first treatment operation, so surgery.***

After the surgeries there is another MDT, post-operation MDT review and then the second option for most of the patients is chemotherapy as a second treatment option. If the patient relapses years later then he/ she may be referred to end of life care. So that's a typical scenario; no complexity, simple, straightforward one.

And from here I'm going to talk about the problem, the aim and my system. So the problem we see here is that these systems, the different colours indicate the different information systems involved. So we see different information systems in the treatment. They are discrete legacy systems. Sometimes they block information flow between them, with a patient, when the patient needs to be referred from one hospital to another. From a research point of view we see that this is mainly because the security rules, information security rules for the systems are not in harmony and that sometimes may

result in the information not being available at the point of care when it is mostly needed. So this is the research problem we're investigating and that was from the meeting we had before with you.

Tom: I mean I would sort of say, just going back to that side, I think it's sometimes the interpretation of the security rules are not in harmony as opposed to the actual security rules.

Shada: ***OK, yes, OK.***

Tom: But it's the same principle, we know the problem you're talking about.

Shada: ***Absolutely, thank you.***

Alex: **It's interpretation into the machine readable form presumably?**

Tom: That's right, I mean it's local interpretation of standard advice as it were and leads to barriers.

Alex: **Yeah.**

Shada: ***Yeah. So we know there is a transformation from a disease-centric to patient-centric treatment approach, where these systems, legacy systems come together and share the information and get a holistic view of the patient's condition.***

Tom: I'd like to take that slide. Could do that for anything; it's not just information [laughter], it's any other systems turning it into sort of multiple discrete to patient-centred.

Shada: ***I'll give it to you if you want.***

Alex: **You want the two, do you?**

Tom: [Laughter] I could put one to eight on any number of systems that just don't talk to each other and you know.

Shada: ***So the new approach treatment, delivery approach, emphasises on integrated care and healthcare professionals come together and work as a care team, they share decisions and this needs cross-organisational information sharing, which is what I'm focusing on in my research. So if we look at the security in general, how in our research we see security, information security in a single system. So if we take the Oncology system, which is number eight for example. The way we see security, if we want to secure information then the first thing is to balance between information confidentiality, integrity, and availability. And we attain that balance in that single system through the creation of information security policy that consists of information security rules. These indicate who can access what to get that balance or to attain that balance. So in order to enforce it in the system, a selected information security controls are implemented or deployed in order to enforce that balance in the system and this creates a single***

point of control. This ensures the harmony of all the system elements. So they make sure that the information available, confidential and at the same time the integrity is preserved.

Now we see that because system number eight has the security controls, the different systems have different security controls in place, that makes the systems not in harmony and that comes to the concept of interpretation of security as well, so different security context and different interpretation.

Now the aim is to create a more secure healthcare collaborative environment by enhancing secure cross-organisational information sharing. So we care about the cross-organisational sharing mainly and not how the local systems work, it's just the sharing bit between the hospitals. We aim to do that by building a common security context or security model, while maintaining the security model or context of the local systems. So we want to do that by evolving what current systems can actually do with additional functionalities to fully support secure cross-organisational information sharing. So you want to keep what the systems are doing, it's just to help with a bit of cross-organisational information sharing. This is the aim of the research.

Now we identified seven requirements, based on the meetings, based on the literature, based on everything. And I'm listing them here and this is what I want to mainly evaluate. So in order to achieve what I just said, we believe that these are important. So first, as the patient goes down a treatment pathway, so this is just part of the breast cancer Integrated Care Pathway from Map of Medicine. And you see that there are different people, different systems, different information being collected. Now as the patient goes down the treatment pathway we believe that information access should be patient centred and not organisation centred and based on the patient's condition and treatment stage. So this is the first functionality that we believe is important. Second, so because that is important we believe that information organisation should be in chronological order, like a treatment timeline with a stamp, so you know the date and time of treatment, you know who saw the patient, the care team member for each treatment point. And this is how the information should be organised in the system.

Now we want to automate referral. We want to help with the information availability between hospitals, so we want to automate referrals. So when the patient is seen at Point A and is referred to Point B, then Point B can see the information that is needed at that point and it's automatically done by the system.

Fourth, we filter and gather information. So we don't push all the information; we filter what is needed for the other healthcare professional to do his job. But sometimes this does not- you know, some missing information is not there, not everything is there. It

may be a bad referral or the information was not put into the system. So maybe we give the care team members the ability to break the glass, which is a concept just to access extra information that's not available with a referral. And this will automatically alert everyone involved. I'll show you screenshots of how the system does that to make it more clear.

Six is to amend information or update the information after it was shared. So for example, the Surgeon writes a report, sends the patient to another healthcare professional. Maybe he wants to add more information after the sharing has been done, so he can actually change that information and everyone involved can be alerted that there is more information available about that patient.

And finally, labelling the sensitivity level of patient identifiable information. And we hope that this is one way to raise awareness between healthcare professionals and I'll show you how this is done.

So this is my system; I showed you a scenario and the functionalities and I'll show you what the system can do. So starting with the General Practitioner as the first system; Hessah is my healthcare professional. So this is the list of people in my system. So Hessah logs in, she's the GP. Once she logs in she can create a new case. This is a new treatment, so the patient just saw the GP for that, for breast cancer. The patient wasn't treated previously, for any cancer or breast cancer before, so it's a new treatment process. So the GP creates a new case. She puts the number; she finds the patient in the system, so she puts in the NHS number or something and then clicks 'Found'. Once she clicks 'Found' she can actually start recording information and see the patient.

So based on the guidelines, the GP collects medical history and examination, so there are boxes for each, so the GP can actually record that information. We added bits here about the sensitivity level of information, so the GP can actually express how sensitive that information. As an experiment we just put four different levels. The white one shows a general, not sensitive information at all, which is 'Public', can be publicly available. The green one is 'Care Team' wide only, so only those treating the patient can see that information. There is the amber, which is more 'Sensitive' and the red which is 'Super Sensitive' information. And I believe the best person to decide that is the person recording that information.

So we put these four different options. I know it's time consuming to click on that so we had a 'Care Team' wide as a default in case the healthcare professional doesn't click anything. So that's for all information but this is only implementing the first page. Once the healthcare professional or the GP Hessah, clicks on 'checked' then the case will be referred to Carl who is the surgeon to start with the triple assessment. Now Carl,

the surgeon, she logs in and she can see actually Susan's case; Susan is my patient. So Susan Smith is my patient; she sees that at that time the referral happened. And she just clicks on that button, this is the automated referral. And she will see what the GP has done; she will access the GP's information and with the sensitivity level, so the first box is the first piece of information and the second is the other piece. And then she can start collecting more information about the patient. So in the guidelines says the surgeon collects more medical history and examination information. So Carl collects that information and then once she clicks on 'Done' it will be referred to the Radiologist and it's the same thing.

Amal logs in; she picks up Susan's case, so decides the age, ultrasound; performs the ultrasound; takes the biopsy and this will refer to the pathologist. Pathologist Kate logs in, picks up the case and she examines the biopsy and decides things. And then it's referred to the MDT because the MDT is the second stage, well the fourth stage. So Claire logs in, she collects the information. Now at the MDT there are boxes for all the information that had been collected before. So the MDT coordinator can click on the button and access that information that had been recorded before. And then the treatment plan is decided and then sends a letter to the GP and then refers it to the surgeon for operation. The surgeon logs in, clicks on Susan's case and then does the operation and writes a report about it. Then a referral to a post-operation MDT, still the same thing. So Susan's case is there, automatic referral; decides a treatment plan; collects the information and everything; reads the information and then chemotherapy is the second treatment option. Then it's a referral to Annabel, the oncologist.

Annabel logs in, sees Susan's case, starts the treatment and records information for every session. So that's very straightforward; this is the scenario. And if the patient is treated then you can see up there that the patient hass recovered after the surgery and this information was recorded by Hessah, the GP. So this is a scenario. Just to emphasise on the functionalities, I'll show you how the system does them.

So we mentioned that we need organisation of information to be different, in chronological order and access is patient centred. So this is how the system does it. So this is the hierarchy, the treatment timeline. You can see how access - what treatment point is and the healthcare professional who did see the patient. If you hover over it you will see date and time, but we don't want to overwhelm the healthcare professionals with more information, so just the basics there and more information if you hover over it. And this is based on time, so regardless of the location of the treatment.

Now we mentioned automated referrals that can send the information automatically to the other healthcare professional and this is how it's done. So every single time a healthcare professional logs into the system to see the patient, for example there's an

appointment, then he can click on the button; read the information that is needed before he sees the patient; he sees the patient and records information; clicks 'OK'. We filter and gather information, this was an example at an MDT where the MDT coordinator can actually click on the right button to decide which information she wants to see and relevant to the case.

Fifth is the breaking-glass mechanism, which is the mechanism we want to help with the information availability. So in case that at a treatment point information is not being available then we give care team members, trusted care team members the ability to access that information, to enforce the system to actually pull that information out of the other systems. And for example, when you see the different stages, we saw the GP; the GP actually can't break glass because she's the only one recorded information. So at the second page when the surgeon logs in he can break into Hessah's information at the circle there. So this is Hessah's information there and there is a plus here; if the surgeon clicks on it she can break the glass into that information. And it's the same for all the other healthcare professionals. So the radiologist can break into the GP and the surgeon's information and for the pathologist or the others. So this is the idea behind breaking the glass is to be able to see the information at that stage that's not been actually available when needed.

So if an incident of breaking-glass, if someone breaks the glass then a justification window appears or pops in, so the care team member can justify it, justify why the information is being - you know, why this incident is happening; why he needs to access extra information and then the information can be shown with the sensitivity level. And once that happens, at the right time there is - everyone is alerted, so you can see that there has been a breaking glass event happening at the end there. So everybody knows what information has been accessed and at what time.

And sixth is the amendment of information or updating information. So it's the same page; you can see that the rule here is every person recording information can actually amend that information, but not amending other people's information. So in the GP's page you see that there is a green circle showing amendments or updates. So she can click on that button which is her information and she can actually update that information. And it's the same for the surgeon. The surgeon can break information into Hessah's, the GP's information, but Hessah can amend only her information and it's the same for the others. So the radiologist can break into others' information but amend only her information. Now for the surgeon there are two different stages that the surgeon logs into the system, so he can amend information that has been recorded previously.

Finally is the labelling of sensitive information to raise awareness. So we mentioned

that at the beginning when information has been recorded a sensitive level can be selected. And for example, if there is a referral then you can see that - a referral from the GP - shows the information and how sensitive it is. And also at a breaking-glass event you can see the labelling of the information and the sensitivity little button.

So that's my presentation and I would like to ask a couple of question if that's OK.

Alex: **Do you want to ask them if they have any questions just now about what we've seen? Is anything needing clarification?**

Shada: ***Yes, do you have any questions about the presentation, sorry?***

Tom: Well sort of lots of discussion things really rather than questions. I don't know, do you want to ask us ours first and then...?

Shada: ***Yes, OK.***

Tom: Probably easier.

Shada: ***So you can comment at any time if you feel that you wanted to make. OK, just to start with, I know Tom, Dr Crosby, you have a number of roles in the healthcare organisation and I listed them at the very first page. I know you're a Caldicott Guardian for the Cancer Centre and a Clinical Director of Velindre Cancer Centre...***

Tom: Yeah.

Shada: ***... a Chair of the Cancer Service Management Board and a leading role, you have a leading role in the Upper Gastro Intestinal (UGI).***

Tom: Yeah, I wouldn't say I have a leading role in the GI, well I do help the GI cancer. That was a CaNISC Service Management Board which I'm not anymore; I'm a member of it.

Shada: ***OK, so I'm mainly interested in being an Oncologist and a Caldicott Guardian. And when I see the balance, you're a medical and someone who's concerned about information security, so how you see things from both perspectives. What about you Ann, do you confirm these? And what about you, can I call you Ann?***

Ann Marie: *Yeah.*

Shada: ***Yeah, what about you, what about your role in the healthcare organisation?***

Ann Marie: *I also sit on the CaNISC Service Management Board and the Change Advisory Board and I Head the IM&T Department here at the Cancer Centre.*

Shada: ***OK, so my...***

Alex: **So what you're saying is you sit on the CaNISC Board now?**

Tom: Yeah and the CAB, again the sort of Change Advisory Board. I have Chaired it in the past and it's now Chaired by Steve Ham, who is the Finance Director.

Shada: ***OK. So the main question, I want to talk about the problem mainly. To which degree do you agree with the fact that there is more pressure on current systems used in cancer care mainly, because this is where I investigated mainly, to share information between hospitals? So do you agree on that aspect, that there is more pressure on information sharing?***

Ann Marie: *It's certainly an increased requirement isn't it, to share the information or to have access to the information related to a patient?*

Tom: Yeah, yeah I agree and that it is a really important issue and it's become more so since I think we do record this information electronically now in lots of different systems, so that has raised the level of frustration that we cannot see it all and it's not joined up around the patient. I

Shada: ***OK.***

Tom: I think also something important is that we've had a - there's been a patient survey recently about what they want from healthcare. I don't know if I've got it somewhere, but there's been an exercise from Welsh Government out to patients to - I'm sure I'd find it. But one of the things that the patients have frequently complained at is that they go to different providers and have to repeat their story...

Ann Marie: *Over and over.*

Tom: ...and to see - providers who don't know the information about them as an individual. So I think that would just add weight to it.

Shada: ***Yes, absolutely.***

Tom: ... you know, sort of coming from patients that they find it frustrating.

Shada: ***From a managerial point of view, what do you think how the current systems are coping with that pressure? What do they have in their agenda in order to address that in the future, if there is any clear vision about it?***

Tom: Well there's a CaNISC roadmap. There's all sorts of things so that GPs are moving to two systems I think in the whole of Wales, electronic sort of systems, so standardisation of the GP electronic systems. There's an electronic referral project that's going on, taking information ultimately from GP systems and putting it into secondary care systems across the clinical gateway.

Shada: ***So it's a referral from the GP to the specialist?***

Tom: Yeah, to secondary care.

Ann Marie: *They're on Phase Two now, so the secondary can send information back to the GP.*

Shada: ***OK, does it have any...?***

Tom: And the cancer community is trying to design the referral pro formas.

Shada: ***That's excellent; so there is a need for electronic referrals in the system?***

Tom: Yeah.

Ann Marie: *And it's being used in the Health Board. It's called the Welsh Clinical Care Gateway.*

Shada: ***OK, thank you. So to wh...***

Tom: So...

Shada: ***Yeah, sorry.***

Tom: Sorry, then that comes into secondary care. There is a component of the CaN-ISC roadmap that would then allow referrals between secondary care, I think using the gateway as well, isn't it, the idea, the thought around it. There's then another proposal around an MDM module being redesigned. You might have seen what we have already, but around an MDT module.

Shada: ***So how to improve the current one?***

Ann Marie: *Yeah.*

Tom: Yeah and then lastly there is ongoing project particularly focusing on breast cancer, looking at sending care plans from secondary and tertiary care back to primary care. So that...

Shada: ***Is it like the Integrated Care Pathway?***

Tom: So it's a sort of more - at any stage or whatever we're saying around a patient, but particularly focusing at the end of treatment, making a holistic needs assessment of that patient and then referring that, sending that patient back to primary care, encouraging self-management but also signposting back to primary care, who to contact in the future if there's a future problem, so that sort of thing. So there is a number of pieces of work, but at the moment it is all not...

Ann Marie: *There's also the Clinical Portal, the Welsh Clinical Portal that will allow us to see results.*

Shada: ***So what does it focus on, the Welsh Clinical Portal, mainly?***

Ann Marie: *It's literally an area that you can go into and you can see information relating to that patient from the results perspective, so blood sciences, from other Health Boards.*

Tom: And assuming it's on any national system, so be it LIMS, which is the pathology system; we have a single pathology system being rolled out in Wales.

Ann Marie: *And it will allow electronic test requesting as well.*

Tom: Yeah.

Shada: ***About the portal, is it the same one used in the MDT? Because I've seen them using a portal, but is it the same as the...?***

Ann Marie: *They use a couple of portals. They use one from an Aneurin Bevan and one from Cardiff and Vale at the minute.*

Shada: ***Hmmm hmm, but it's not the Welsh Clinical Portal?***

Ann Marie: *It's been rolled out.*

Shada: ***OK.***

Tom: But Cardiff have called theirs their portal, but it's not Welsh Clinical Portal.

Shada: ***OK, yeah, OK. So to which degree do you agree that there is any a need to carefully balance between information availability for clinical decisions and confidentiality to avoid the information from falling into the wrong hands?***

Tom: Yeah, I think that is obviously important.

Shada: ***Since the systems has to be linked now because there is more pressure on information sharing, but at the same time you still want to preserve confidentiality and balance between...?***

Tom: Yeah, I mean just on your presentation, I thought you set that balance sort of - the break glass was too extreme an event, a too common event. So I would've thought that the Surgeon would routinely be able to see all of the primary care information around that event. If they wanted to look into the primary care system around their ante-natal or psychiatric history that may take a break glass, but if it was related to the actual event all people in the whole - anybody that - so the principle should be I think that the information follows the patient at their point of need. And the expectation I think from patients would be that the clinician, of course you should be able to see the information around that event. There could be things like psychiatric histories, genetics histories; there may be things that require a break glass.

Shada: ***So information outside the treatment?***

Tom: Yeah, I'd just set that threshold a bit higher to be that more security, more confidential information that requires a break glass to look at it.

Shada: ***OK, what about emergency cases or more sensitive information? Because we're coming to breaking glass and I want to talk specifically about what do you think***

is needed there? Because I spoke to nurses, oncologists in breast cancer and they had different views about how to use the breaking glass. Some of them said, like you said, there is no need because it is supposed to be there. But maybe if it's not there then it enforces the system to - or maybe others said just for super-sensitive information and it's not all information, so you keep super-sensitive information in the box and then you break it when you need it. So what do you think about it?

Tom: Sort of set up a super-sensitive level.

Shada: ***OK.***

Ann Marie: *That's the common approach that's been adopted, because we do have break glass functionality and it's fully audited.*

Shada: ***OK, yeah. So do you agree on the research problem about the information not flowing sometimes and not available at the point of care?***

Alex: **Well it sounds as though your aim is to make it more available now?**

Tom: Yeah, but frustratingly slowly, but there always a lot of that work going on.

Ann Marie: *There are dependencies, especially for CaNISC that we have to do Nadex authentication to enable us to get WCCGM portal, so it's not as straightforward.*

Alex: **It's not as simple as it sounds [laughter].**

Tom: Yeah, yeah.

Shada: ***Yeah, absolutely.***

Alex: **It's easy to make the statement [laughter].**

Tom: And I think then there is also, I suppose co-dependent in that there was a risk of developing a system that would work for cancer, following a cancer patient through the journey, but then diabetes, stroke and everything else. So we want it all a part of the same system and then as you say, that then necessitates infrastructural support from the Welsh demographics and lists the patients so we're all talking about the same patient, everything carefully.

Shada: ***So it's harder when there are multiple integrated care pathways or in different conditions?***

Tom: Yes, yeah.

Shada: ***OK. So going back to the problem that information is not available, do you think mainly it's because of their systems or people's behaviour? I spoke to an MDT, breast cancer MDT; she said, 'Well the information's always there but people can't find it.' They find it hard to use the system to find it.***

Tom: Yeah.

Shada: ***And the Nurse said, 'No, the information is not there where we want it.' So two different conflicting opinions about the same problem; what do you think?***

Ann Marie: *Probably a bit of both.*

Tom: Yeah. The design of CaNISC is not intuitive; it's on a provider level and not a patient level. So you have to find your way around it and then - so if Cardiff and Vale, the Surgeon put in information, even if they put it into CaNISC, they'd put it under their provider episode. And you have to have a fairly good knowledge to navigate around the case note to find that if you were say a Velindre person.

Shada: ***OK.***

Tom: Sometimes yeah, the information is not there at all; it's just on their PAS system or Merlin or somewhere else, so I suspect it's true, that both are somewhat true. I'll show you a code here, but there's a couple of things, first there's information that flows and there's a balance also between whether it is pushed to somebody or whether it's available to be pulled at the time of need. And I think there is benefits to both ways. So a referral acts not only to give somebody the information, but also to trigger the arrangement of an out-patient appointment. So that needs to be a push system. At the same time, there's the issue of burdening people with information that they don't need either at all or at that time.

Shada: ***So that the breaking-glass come here?***

Tom: Yeah, well for everybody getting an email ten times a day that somebody's glass has been broken is a big issue. But also as I say, a letter has two forms, functions. It gives you information but it also acts as a prompt to make an appointment and things, so you need to have both of those.

Shada: ***Yeah, OK, interesting. So we'll go now to the system, SHarE. What do you think about it in general as a functioning system that can be used in healthcare?***

Tom: Well I think it's great, if it's set at - there were sort of tweaks to how we'd want it to look and run as we've sort of talked about, I think is just what we're trying to achieve.

Shada: ***OK, so do you think it has a potential to address the identified problem?***

Tom: To address identified - yeah, yeah.

Ann Marie: *It looked like it had an element of workflow in it, which is something that would be useful for us.*

Shada: ***To see things from a treatment point of view?***

Ann Marie: *Well that you can move things around the system, that you can then see sort of...*

Tom: Yeah, yeah. Yeah and we haven't really talked around that, the way you build on an information source rather than we start again at every time. So I don't to a certain degree, because when it's allowed to people cut and paste and put information into my referral and I just put, 'further to above', you know she has a sort of fit on everything about cutting and pasting which is bad practice, but because the system doesn't work in other way, it's electronic, somewhere we can put it where we want it. And so for a new patient I just have to say, 'further to above,' put my Oncology additional information in and it takes me about two minutes to type myself. Whereas other people are writing, 'This patient has present...' rehearsing all the information that's been given to them in paper format, starting again; our Secretaries having to type it de novo and it leads to risks of errors. You forget something because you've got four attempts to take somebody's history as it were, so...

Ann Marie: *I think what we don't have is a common grounding do we...*

Tom: Yeah.

Ann Marie: *...in terms of how we capture information and where in fact it is captured in CaNISC?*

Tom: No.

Alex: **Yeah, because one of the things we have been - if you saw, there was State Systems up in the corner; that is a workflow system and that's what we were basing ideas on. It comes from Shada's sister's work with Dave before where we were looking at the information flows and how it might help. And of course your Map of Medicine is our giving you workflows.**

Tom: Yes.

Shada: ***OK, excellent. Do you think that healthcare professionals can use such a system? Because we tend to make it work with the current systems, so it's not replacing it, it works with it. Because people are ready; they know the system and they don't need much you know. This will need a bit of training but we still want the people - don't - we don't want them to change their behaviour and stop...***

Tom: Yeah, you're trying to make it fit into the whole thing.

Shada: ***Yes, exactly and we know that there is a problem with the information sharing mainly, so we want this to work with the current system to help with that bit between the systems.***

Tom: But I mean we're always having to learn new systems and it's really irritating and hard but we accept it. And I think on both sides it depends on what side of the bed you got up on.

Shada: ***Do you think that's going to be an extra burden?***

Tom: I think the prize is pretty good and so I think people would be undergoing some training, make it as intuitive as possible and not additional burden as much as possible. And yeah, they'll always be prepared to learn a different system.

Shada: ***OK, so that's already happening no matter what?***

Tom: Well yeah, well they will - we're either going - we're not going to stay using paper; we're not going to stay with lots of different systems in Wales; we will have to move and merge and see things in different views and yeah, I wouldn't say it's a huge problem.

Shada: ***So does that mean that you think there is a possibility of integration with this with the current systems like CaNISC and the other systems that are used today in treatment? Because this links directly to the database; it doesn't interfere with the interfaces of the other systems, so it's only pulling the right information and saving the right information in the database.***

Ann Marie: *So it's just viewing?*

Shada: ***Yes, yes. And you can still record on it, but it will go to the database that is shared between the legacy systems and this. So there is no replication or like anything, so it's the same information, it's just where you view it.***

Tom: So that is more like a clinical portal then, that that hopes to be the sort of Google of all information about that individual that you look up and orders it and structures it.

Shada: ***Yeah and you won't - if they update it on the other system this will be updated on here as well, so you won't...***

Tom: Yeah, you wouldn't...

Ann Marie: *So you go to a single point as opposed to multiple.*

Tom: Source, yeah which is I presume you've got...

Shada: ***But this will help with the automated referral kind of things?***

Tom: Yeah.

Shada: ***OK, do you think that SHarE does add value to CaNISC or other systems which the functionalities that I've presented?***

Ann Marie: *Could do.*

Tom: Yeah, could do, yeah.

Shada: ***OK, any challenges, obstacles?***

Tom: Well yeah, huge [laughter].

Shada: ***Huge [laughter].***

Tom: That organisation's any worse than anybody else to change. But no, they're just sort of...

Shada: ***What do you think about the main obstacles that can face such an adoption?***

Tom: Sort of getting signup across organisations, across services. So you wouldn't do all of this for cancer without other people having it, for rheumatology or other sort of situations; trying to integrate in with existing developments in Wales. I think those would be the big ones. And governance, we're still not quite sure, well we probably are really, but really sure about how to use emails and information. I know there's various guidance that comes out of the things, but...

Alex: **It keeps changing, like anywhere else.**

Tom: [Laughter] And so NWIS have really struggled to be that central governance body that says, right this is perfectly safe to everybody if you do it this way.

Ann Marie: *Yeah, what it kind of says is tells you what you can't do but doesn't give you an alternative solution.*

Tom: Yeah and if you're going to do this, you'd better do it this way than any other. Rather than be very clear, it's absolutely fine to do that. And then as soon as you get that ambiguity, different organisations, different Caldicott Guardians, some very relaxed like me, other people interpret that they feel that patient safety is in their hands and they're holding it and they mustn't let it go to anybody else in case there's an error. I come to it from a tertiary point of view where we are constantly challenged by not having information available at the point of need to manage the patient that's in front of you. And the reports that we'll hear are where information went to the wrong person, which is very rare, very rarely leads to any harm, unless it's population information, large quantities of it. And it seems to influence more the governance agenda of some.

Shada: ***OK, but I remember you mentioned at the last meeting that there's more harm done to the patient if the information is not available.***

Tom: Absolutely, yeah, yeah.

Shada: ***OK, so last question before we go to each functionality and ask whether it's important and if the current system does it.***

Tom: Yeah.

Shada: ***But do you think that the requirements meet the principles of the Caldicott Guardian? I know in the manual, the Caldicott Guardian manual there are six different [laughter]...***

Tom: Ah yes, I know it so well [laughter]. I could quote it all.

Shada: ***I just printed the very first page.***

Alex: **I'd be interested with the whole lot [laughter].**

Shada: ***Oh no, but that's the shorter one.***

Alex: **I'll take the shorter one.**

Shada: ***Yes [laughter].***

Ann Marie: *Well she's just done another review.*

Shada: ***Did they? OK, OK, so like 2013, this year?***

Ann Marie: *Yeah.*

Shada: ***OK. So this is what I based my investigation on, but I didn't really keep updated, so I should. So on the second page there are six different principles. Do you think that these functionalities, what I'm doing meet with these or conflict with these or...?***

Tom: No, no, I think they're fine and they are in principle. So the tone is all restrictive isn't it?

Shada: ***Yeah, yes.***

Tom: Rather than ensure that everybody in the system who's going to manage an individual patient has access to it, that should be one of the principles shouldn't it, really?

Shada: ***Yes, absolutely. And this comes to the medical side of your job, that you treat a patient you need that information to be there.***

Ann Marie: *It's in the patient's best interests then.*

Tom: Yeah.

Shada: ***Absolutely.***

Ann Marie: *As long as you can evidence that.*

Tom: Yeah and nine times out of ten it is, or you can audit it and have to justify it if called too. So with electronic systems it's much easier to have audit trails than with paper records.

Shada: ***Yes, yes OK. So I'll go through the functionalities, you'll find it on the second page. I'll just ask four questions. Is it important and I want both opinions and do you think the current systems provide the requirements listed?***

Ann Marie: *Oh sorry.*

Shada: ***There, yeah. So those are the requirements. I just want to ask for both opinions, whether you think it's important, if the current systems provide it, if it can be approved, the idea that we have and any challenges or comments or anything that we could do. So I'll start with, 'the information should be patient-centred,' the second one. So, 'Information access is patient-centred and not organisation-centred.' Do you think this is an important requirement?***

Tom: Yes.

Ann Marie: *Yes.*

Tom: It's very important.

Shada: ***OK, do you think the current systems provide such a thing?***

Ann Marie: *Not yet.*

Tom: No.

Shada: ***Not yet, OK. What about the information being organised in chronological order, like a treatment timeline; do you think that is important as well?***

Ann Marie: *I think it's very useful.*

Tom: Yeah, but potentially there should be the ability to re-order it for different needs. So that you may just want a list of all the radiology investigations on their own, so you should be able to...

Shada: ***Yeah, so you can have different views but...***

Tom: The views, yes, yeah.

Ann Marie: *Because it could become very, very, very busy.*

Tom: Yeah.

Shada: ***OK.***

Alex: **So what you're really saying is select sub-sets that would still be in chronological order within the sub-set?**

Tom: Yes, that's right, absolutely, yeah and obviously should be able to do that with various categorisation. I mean there is that we are at a level where we still would prefer to be overburdened with information. I yet have to be, you know, because there is the risk of it. But I'd still prefer to look through and have to trawl through and find the relevant parts than what we have at the moment where it's not available. But it definitely is a risk as more and more healthcare professionals add into the record.

Shada: ***OK, we didn't add just yet the different conditions, so how information can come from different treatment pathways. But this is something that we want to do in the future and do you think it's important to consider in one page or have different pages for different conditions?***

Tom: I think again it's probably you need both, because I think increasingly cancer is becoming a disease of old age, well it always has been, but where patients have other co-morbidities and it's important to see those. And I don't think we've begun to really address the issues of co-morbidity, they're complicated. And so if you're coming down the cancer pathway you're going to need to look into their diabetic history or their other things, so...

Ann Marie: *And we do need that information.*

Tom: Yeah, so again it's an ability to be able to order it in a cancer only but then have views of others as well.

Shada: ***Yeah, various views as well, yeah OK.***

Alex: **And that comes into the other systems that we were talking about at the start.**

Tom: Yes, yes.

Alex: **Needing to know about the other systems but not wanting - you need a button that almost says I don't want overburdened at the moment but I want something that alerts me to the fact that there are others.**

Tom: Yeah, yeah. I think the other thing we're just having to sort of mention is how they're populated, because some of things around having free text and fields. Because the other purpose to it is there's data, there's communication, then there's coding and particularly increasingly giving it financial value, our transactions. And I think it's really important that we try to use an access friendly system. Whenever I've seen summaries built on clinical codes that are pulled off systems, you end up with C4.6X NOS nearly all the time and just write it. So it is a balance I think of getting that free text, which is much more descriptive and meaningful.

Shada: ***So free text is more valuable to the Clinicians?***

Tom: Yeah and I can understand why IT people are designing it. The first thing they say is well it sits in an information somewhere, let's pull that off from there and let's pull it off from there, but you know.

Ann Marie: *They look at the secondary element as opposed to the clinical element.*

Tom: Yes, yeah.

Ann Marie: *So for the reporting requirements, whereas you can't do that with free text.*

Tom: No.

Ann Marie: *So it's doing the both.*

Alex: **But, yeah it's things like records where...**

Tom: Yes, yeah, yeah.

Alex: **We're constraining you in one stage, because you needed it for systems to work efficiently, but we're changing with the clouds and all these other things, the world is changing rapidly around us.**

Ann Marie: *It is, hmmm.*

Tom: I think also the other way around is that if you put good clinical textual information in, the coders would find that easier to be able to code anyway...

Ann Marie: *Absolutely.*

Tom: ...so that in their own systems they - anyway.

Shada: ***Yeah, no that's really, really good. So OK, what about automated referrals? It's here when we said that you can actually see the patient list and you click on a button, you see the information that we believe is needed for the treatment point before you start recording information. And then you click on a button and it goes automatically, gets referred to other...***

Tom: I think we've had that sort of functionality that's never been switched on in CaNISC and I think we've had it in part of the MDTs or something I'm sure. But it is - yeah, it would be really good.

Shada: ***So it is important?***

Tom: But I think you added the ability to add information to it. When you're in an MDT you're deciding on a management plan individually for that patient. When you do a referral you add in other information around that patient in context and things. So it's about having the right information. So I think a lot of people wouldn't accept a referral from an MDT at the moment for that, because there's not enough information. We still get more in the letters. So at the moment many of us do - some do accept the referral because it's just better to get the patient in quickly. Other people sort of say, 'Yeah, we accept the referral but send us a letter as well while the patient is getting...' So people are using it in different ways. So I guess it's taking an information from one form and purpose, it's not always the same as the need for the information in the referral. Having said that, if we had access to all the other information, you know the GP's, that would give you more information. Do you know what I mean?

Shada: ***Yeah, yeah.***

Alex: **But it's sort of shifting a burden across isn't it?**

Tom: Yeah.

Alex: **Because what you're saying there is the person who it's referred to...**

Tom: Would have access to all of that.

Alex: **Has to access all these things...**

Tom: Yeah, all of that, yeah.

Alex: **...and they extract what might be relevant.**

Tom: Yes.

Alex: **Whereas you're doing a relevant thing that you know already in the referral letter. It's a balancing thing all the time.**

Tom: Yeah.

Ann Marie: *From the referral perspective only, we have it in paper format anyway. So by the time it reaches us you've got that time delay, by the time you process, so if it's electronic...*

Shada: ***That will save time?***

Ann Marie: *It will save time and we can audit it, we can manage it electronically. Whereas if you lose a bit of paper.*

Tom: Yeah, yeah. Well we sit in a meeting and if we decide that it needs to be referred, then frequently that'll mean going back, the Surgeon remembering to dictate a letter; dictate a letter; the Secretary types it; sent; so our post was received in our mailbox, gets to us. And realistically that's always going to be a week and that could've been instant.

Alex: **Or nearly instant.**

Tom: Nearly instant, yeah, yeah.

Ann Marie: *Yeah and this is what WCCG does.*

Tom: Yeah, yeah.

Shada: ***OK. So you think that it's important. Does the current system provide it? You said partial.***

Tom: With qualifications, yeah, with sort of - I think it might exist, but I don't think it's ever been switched on. You can email letters, but anyway it doesn't work anyway; we don't use it so in effect it's not there.

Shada: ***What about filtering and gathering the information? So you don't provide or pour all the information; you just then select it and categorise it based on the other***

person who generated that information. Do you think that's important or not? Does the current system provide for - do you they filter the information for you as a healthcare professional or is it there so you're being selective?

Ann Marie: *You can select it, can't you?*

Tom: Hmmm, yeah.

Shada: ***So do you prefer it to be that way, it's there and you select or...?***

Tom: Well I think this will evolve under the system and I think at first I'd love to be in a system where I have too much information.

Shada: ***Have too much, yeah not too little.***

Tom: And then after a bit, they go hang on a sec, it would be helpful if we only had this information. At the moment we don't have enough, so it's...

Shada: ***But it's the organisation of the information as well. So we filter there but you still can access the extra information that you want.***

Tom: Yes, absolutely, yeah.

Shada: ***OK.***

Ann Marie: *I think what would be useful from what Tom mentioned earlier, is where information is copied and pasted into one section so the Oncologist has all the information in one place as opposed to having to look.*

Tom: Yeah.

Ann Marie: *And if there was some functionality that could do that, that could be bring information into a summary page for the Oncologist, I think that would be really useful.*

Alex: **So what you're needing is a sort of filter, but also a filter that can coalesce things or amalgamate them in some way?**

Tom: Yes, yeah, yeah.

Ann Marie: *Absolutely, that would remove the requirement of the - because in clinic it's busy, they've got time and they don't have time to go clicking through records and other systems and if there was a mechanism to summarise information into one place.*

Tom: Yeah.

Alex: **And they normally know what it is that won't take some of the other systems in some general way.**

Tom: Yes, definitely, yeah.

Alex: **It's because you're saying well I'm needing to get that from there because I wonder if they have this. And so it's a sort of filtered and then merge type thing.**

Tom: Hmmm, yeah.

Ann Marie: *Or maybe the opportunity to, I don't know, just select the information that can be configured for oncologists and tailor it.*

Tom: Yeah, yeah.

Shada: ***OK, what about the, well the most important one is the breaking-glass? So we mentioned about the breaking-glass, maybe it should be always there, but maybe super-sensitive information is kept behind the glass.***

Tom: I think so, yeah.

Shada: ***Do you think there is any for justification for accessing sensitive information?***

Ann Marie: *Yes, and there is, it does exist and we do have break glass in national systems, the portal being one of them.*

Shada: ***So how does it work in that system?***

Ann Marie: *The highly sensitive information you have to select and you have to put your password in again and notification is sent to appropriate colleagues so they know that that has been activated, to make sure that it is right and proper.*

Shada: ***Yeah, OK, but they don't justify it but do you think there is a need for justification in text? So when you click on that button there is a box there, 'Justify' and then...?***

Tom: It depends at what level it's set. If it is really, truly break glass i.e. for exceptional reasons, yes you'd want to sort of provide...

Shada: ***Is it after accessing the information or before accessing the information? Because we tend to think maybe in emergency cases like out of patient or out of hours for example, that people may need to access really all information relevant or everything about the patient, especially if he's not conscious.***

Tom: Yeah.

Shada: ***So in this case, you know, this is - and there is a need for an immediate access but there is no time for justification, I can justify it after the emergency. But such cases, do you think...?***

Ann Marie: *I'm not sure it asks for justification; just asks you to re-enter your password so that it's a deliberate act and I think there's a clear definition of what is held behind break glass.*

Shada: ***OK.***

Alex: **I think what you said though that you've got these audit trails that would come back afterwards so there's a post-justification if it's needed is what you're saying.**

Tom: Yes, if needed then yes.

Ann Marie: *That's...*

Alex: **But you're saying you wouldn't ask them because that's getting in the road of the immediate access. Is that what...? Am I hearing correctly?**

Ann Marie: *I think so, yes.*

Alex: **Somebody would come back and say, 'Oy! you did this, why?'**

Ann Marie: *Yeah, yeah.*

Tom: How are we doing time wise, do you...?

Shada: ***Yeah, we're just the last...***

Tom: No, it's OK, I don't want to rush it. It's just that I'm not sure where we are on that.

Shada: ***Last two.***

Tom: So I would still say that issue is around how often you need to do it and as soon as you start needing to do it frequently...

Shada: ***Then it's not...***

Tom: ...asking people to justify it is silly, they don't do it and they'll write whatever, write rubbish in. So if it's exceptional then it's OK to justify it, but as you say I think probably then it's done on an audit basis rather than an all time justification.

Alex: **I think what I'm hearing is that you feel it should not be too big the amount of information that's being put in this super-sensitive?**

Tom: Yeah, no, no, yeah that's...

Alex: **It's got to be done very carefully.**

Tom: Yes.

Shada: ***And this is here I have alerting everyone after the incident of breaking-glass. So maybe in the case of current use it's only alerting through the audit.***

Tom: I would say it doesn't need to be brought, yeah.

Ann Marie: *I don't think it - yes, it doesn't need to alert everybody.*

Shada: ***So you don't need that. Then just the people who will deal with it?***

Tom: So it would be things like a Primary Care Manager or whoever their governance people are and...

Ann Marie: *It normally goes to the Medical Records Manager.*

Tom: Yeah and things, so...

Shada: ***And they can take action if there's...?***

Tom: Yeah.

Shada: ***OK and what about amending the information and updating it after it's been shared and alerting everyone if this happens; do you think this is important?***

Ann Marie: *I think a mechanism to alert is quite useful and then it's up to the individuals if they want to go and look at that information.*

Shada: ***To look, OK.***

Tom: I wouldn't routinely let everybody know that information has been amended, but you just need to be able to see the trail if you want to look for it, who it was amended by and when. And we do that with ERMA forms quite a bit, don't we. You can, I never look at it, but you can find that trail.

Shada: ***So do you say that you don't want the alert or you want the amendment to happen but you don't want alerts too much?***

Tom: Well alerts are always helpful if they're there somewhere and they're functioned to...

Ann Marie: *I don't know if it's alert in it's true fashion, I just think some visual...*

Tom: Warning or sort of - yeah.

Shada: ***Like the icon, the red icon there, showing like there down?***

Tom: Yeah, yeah.

Alex: **Because again, it's something when you want it you'll need it.**

Tom: Yes, yeah, yeah.

Ann Marie: *Yeah.*

Tom: Absolutely, yeah.

Alex: **But you don't want it most of the time?**

Tom: No.

Ann Marie: *Because if you send alerts constantly we'll lose what the true alert is.*

Tom: Yeah, you lose the value of them anyway.

Shada: ***Yes, yes, OK. Very last one is the labelling of information. So we label the sensitivity of information and maybe from a Caldicott Guardian and like a managerial point of view, if you believe that there is a mechanism to label, maybe mark high risk patients or something, some kind of mechanism that the person recording information flag it somehow; do you think that's important? And alerting, not alerting it's communicating***

it to the others. So for example here the GP recording information if there's something really super-sensitive and maybe this can help us implement the breaking-glass. So only those labelled as...

Tom: Yeah, set up at the right level of...

Shada: ***...super-sensitive can be put behind the glass. And then when there's a referral from the GP then you can see the label, only a label and then the breaking-glass for example you can still see the label. Do you think that's important to raise awareness, does the current systems do it?***

Ann Marie: *I think it's restricted who the information goes to initially, so by definition it's managed as sensitive. It's not available to all.*

Shada: ***But these are only care team members, so we always provide information that is needed for them regardless of how sensitive it is. But it's just providing the icon that'll give them the awareness of how sensitive it is.***

Ann Marie: *I'm not quite sure what that's going to add to you as a...*

Tom: No.

Ann Marie: *...as an Oncologist that there's sensitive data in there.*

Shada: ***Like a high risk patient with HIV positive results, for example, so you can deal and communicate with that patient maybe keeping that in mind or maybe you have to speed things, I don't know. Is that important, does it happen?***

Alex: **I think what you're actually asking is the question does the consultant or the people who are possibly going to break glass need to know that that information might be available behind? Because there's no point in breaking the glass if it's not going to be there.**

Tom: Yeah.

Ann Marie: *Well you just break it just to see what it is and it might - yeah.*

Shada: ***Like I spoke to Helen, she said, 'I never broke the glass. It's there but I never dared clicking on it, because I don't think there's anything that I need extra that is not available on the system.' So how can you let...?***

Tom: No, but there will be a time, there's the genetic stuff and things and...

Ann Marie: *And mental health also comes under that category.*

Tom: We're doing psychology, which I think they're wanting to keep separate to some degree, which I'm not sure that they should. But there will be information that some people will have given in confidence and...

Ann Marie: *It's under the Act isn't it, the mental health, paediatrics and gynaecology is all treated differently.*

Tom: Yeah.

Alex: **And as our DNA type research moves forward we're going to find that sort of thing becomes quite important sometimes.**

Ann Marie: *Yeah.*

Shada: ***OK, so still super-sensitive, if it's for the role, it's important for the role you provide it anyway, but you put it behind the glass if you don't think it's important?***

Tom: Yeah.

Shada: ***OK, interesting. Thank you so much for your time.***

Tom: No that's OK; that's all right. I think the default should be to all care providers and then have - and I think what you're talking about a little bit with the break-glass is bordering onto alerts as well, you know, around HIV risk or something else that is routinely available and that you just want somebody to know it and factor that in as opposed to having to break glass to find out the information. I think they're slightly different things.

Shada: ***OK.***

Alex: **So when we talked just now about super-sensitive data being hidden but possibly making the person aware that there is, do they need to know the sort of area that it's in? In other words, super-sensitive data can probably be classified into different areas; should there be something that says there is super-sensitive data of this type or will that encourage people to look at it?**

Tom: Yeah, I don't know.

Alex: **[Laughter] This is your danger isn't it?**

Tom: Yeah, it is.

Alex: **Curiosity.**

Tom: I think you'd have to say there is super-sensitive information but probably not start describing what it's around. I think that'll probably lose the value.

Alex: **So just say there is super-sensitive but not say any more than that?**

Tom: Yeah.

Shada: ***OK, thank you very much for your time.***

Tom: That's all right, really good.

Shada: ***Thank you, that's really, really helpful to evaluate the study.***

Tom: So what is the next - where are you in your project then, in your research and...?

Shada: ***I'm evaluating it, then I'll hopefully just write it down and submit it and hopefully...***

Alex: **And you'll get a copy of the thesis.**

Tom: Yeah, great, it's really, really good.

Alex: **So thank you for doing it.**

Ann Marie: *That's OK.*

Tom: It's great. I mean you've sort of caught the essence of a lot of the problems that we have and so...

Ann Marie: *Is there anything I can do to get information from them in relation to the break-glass that might help you, in terms of what they're doing in current systems?*

Shada: ***Oh yes please. I can email you.***

Ann Marie: *Yeah.*

Shada: ***I can email Jane so she can help me.***

Ann Marie: *Yeah, yeah.*

Tom: There's a few systems there isn't there, the gateway around the sort of you know...

Shada: ***That'd be really great. Thank you so much. I wish you a Merry Christmas [laughter].***

Tom: [Laughter] Thank you very, very - that's - thank you very, very much.

Shada: ***Thank you [laughter].***

Ann Marie: *Thank you.*

Shada: ***Sorry to get the name wrong.***

Tom: It's very kind, it's the first present I've had, so that's very kind.

Shada: ***It's not going to be the last [laughter].***

Appendix G

Hepatocellular (HC) Cancer Integrated Care Pathway

G.1 HC Full ICP

HC cancer has a one-page Integrated Care Pathway (ICP) shown in Fig G.1.

G.2 HC Cancer Selected Treatment Scenario

According to Dr. Tom Crosby [69], Velindre Cancer Centre runs the South Wales service for hepatic surgery for liver surgery. Therefore, for patients who have secondary cancers in their liver, the surgical service is based in Cardiff and the oncology is largely based in Velindre Cancer Centre, but they take patients from all of Wales. This means that patients are referred from West Wales to the surgeon who considers managing them, they send their films along, their x-rays, electronically or by disk to Cardiff but they are discussed at Velindre Cancer Centre's MDT. This scenario was extracted from the HC cancer full ICP and is shown in Fig G.2.

G.3 HC Cancer Treatment Scenario Business Process

The above treatment scenario was used to build a business process model as shown in Fig G.3, which clearly shows the different hospitals, information systems, and physical perimeters of where the information is collected, recorded, and shared.

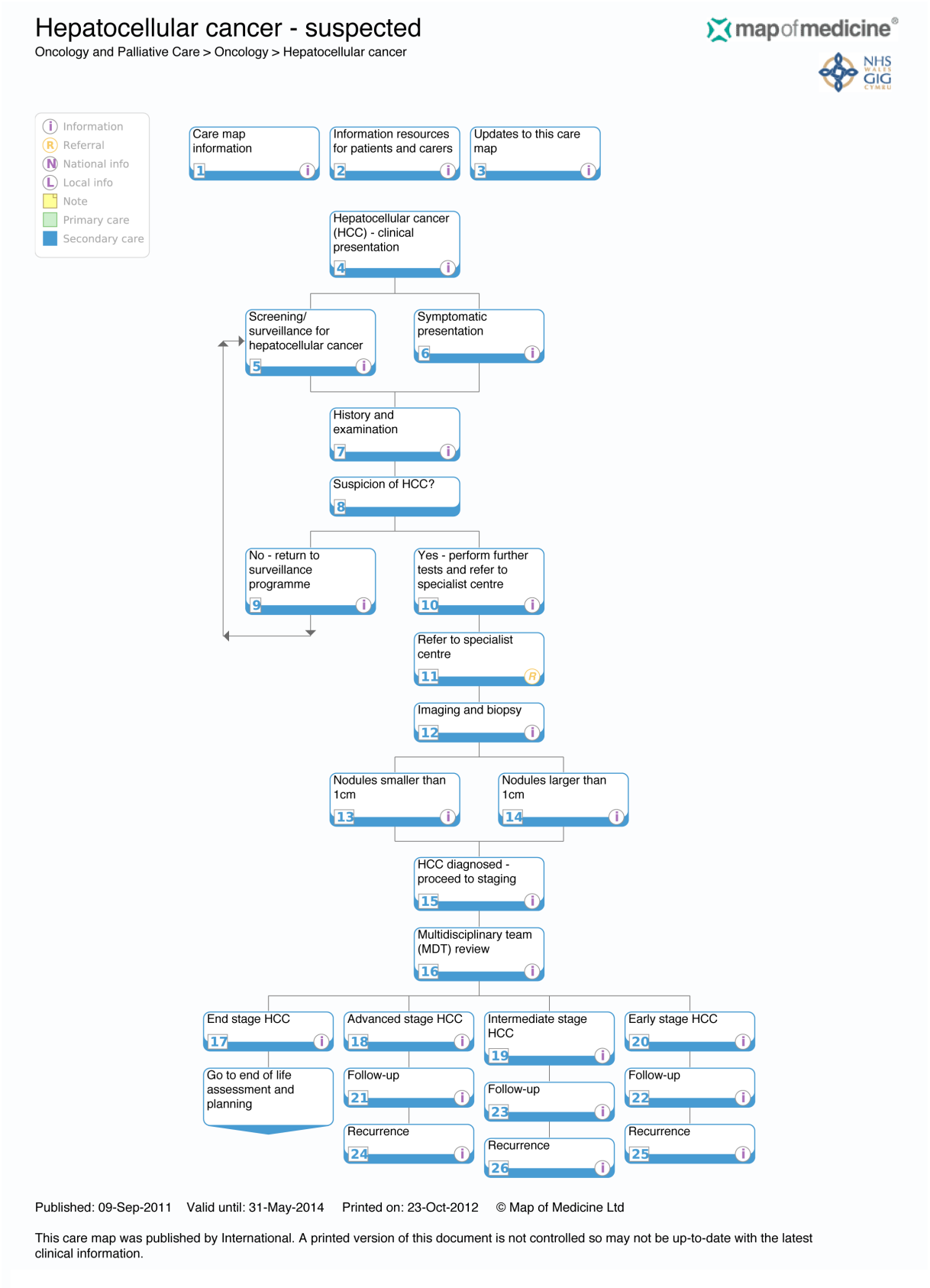


Figure G.1: HC Cancer ICP adopted from MoM [6].

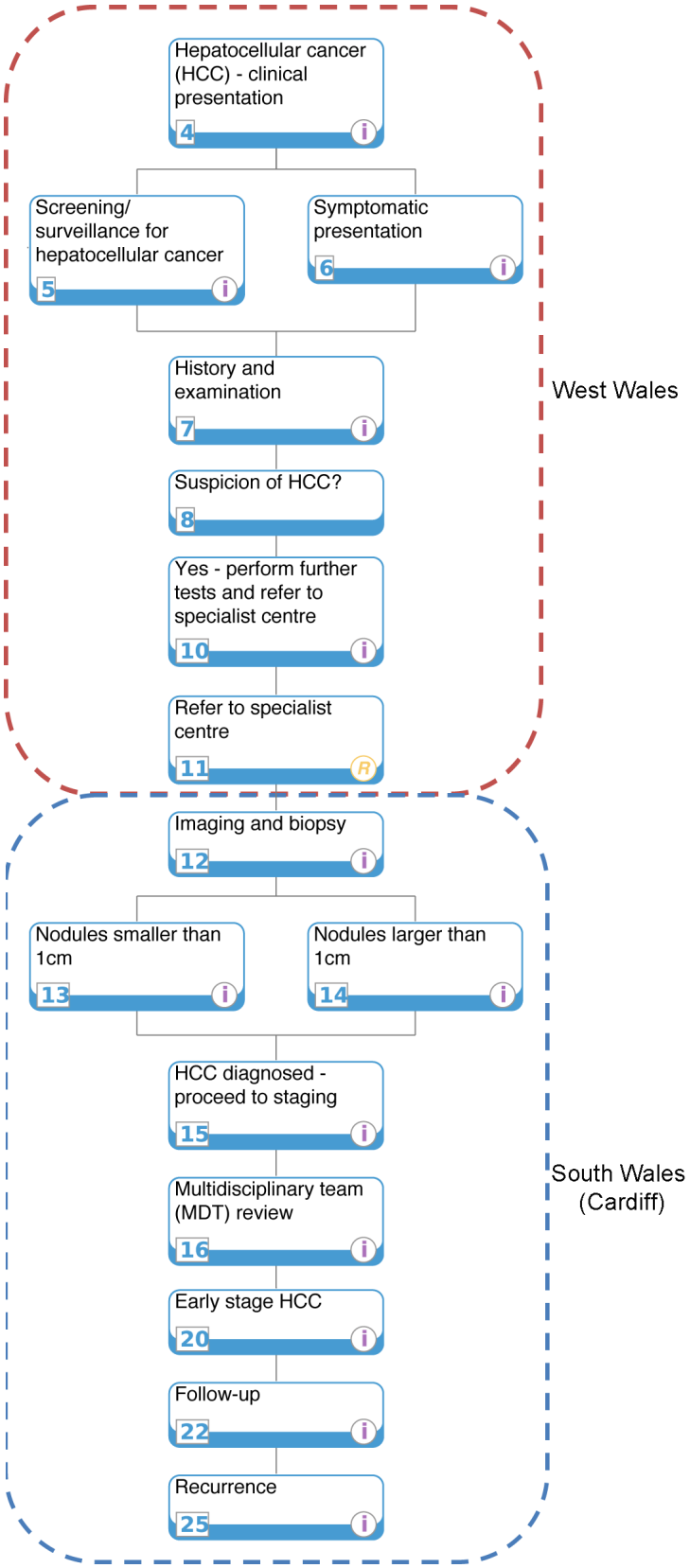


Figure G.2: HC cancer selected treatment scenario.

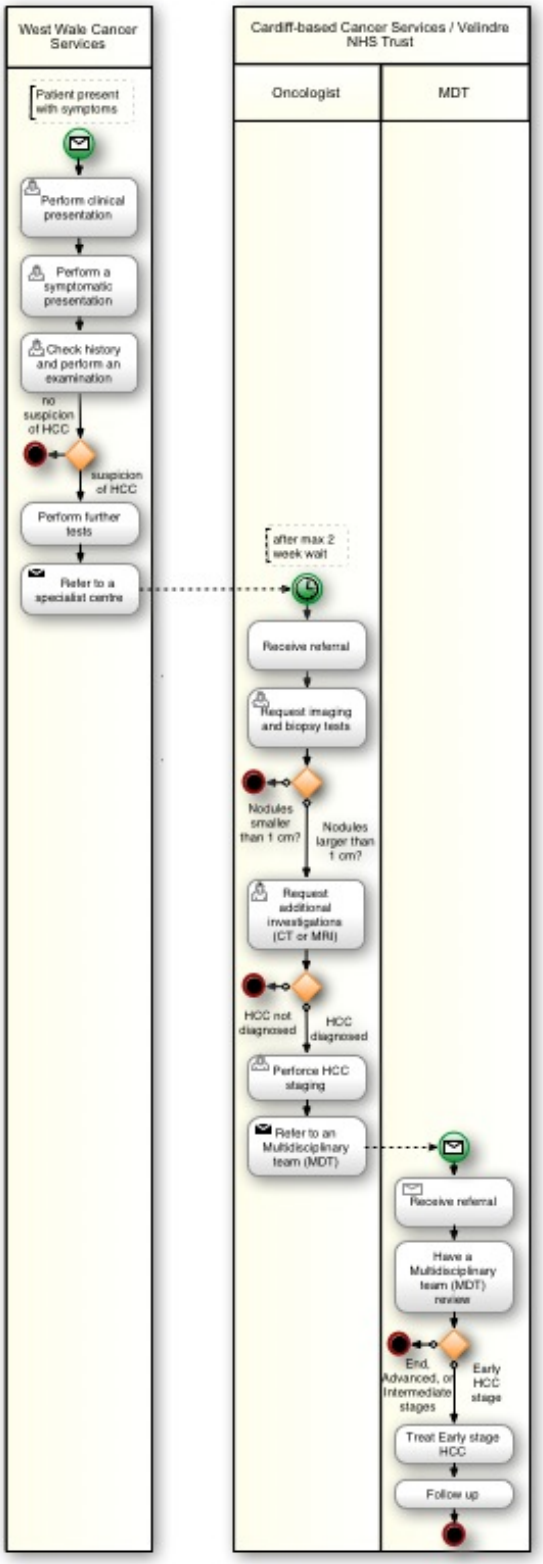


Figure G.3: Business process of the HC cancer selected treatment scenario.

Appendix H

Upper Gastrointestinal (UGI) Cancer Integrated Care Pathway

H.1 UGI Full ICP

UGI cancer has a two-page Integrated Care Pathway (ICP) shown in Fig H.1, and Fig H.2.

H.2 UGI Cancer Treatment Scenario

In Wales a typical UGI cancer treatment scenario is when a patient visits a General Practitioner (GP), say in Swansea, with alarming symptoms, and is referred urgently to a gastroenterologist for oesophageal cancer diagnosis. Diagnostic tests are discussed and recorded at a local MDT review. If the patient is found fit for further potentially curative treatment he or she may be referred to Cardiff cancer service for further staging tests prior to a fuller MDT review to discuss a final management plan. The patient will receive oncology treatment at Velindre NHS Trust, while surgery treatment will be in Cardiff and Vale University Local Health Board. Both treatments are discussed at further MDT reviews. If he or she re-lapses then palliative care may occur locally in another NHS Trust [69]. This scenario was extracted from the UGI cancer full ICP, shown in Fig H.3.

H.3 UGI Cancer Treatment Scenario Business Process

The above treatment scenario was used to build a business process model as shown in Fig H.4, which clearly shows the different hospitals, information systems, and physical perimeters of where the information is collected, recorded, and shared.

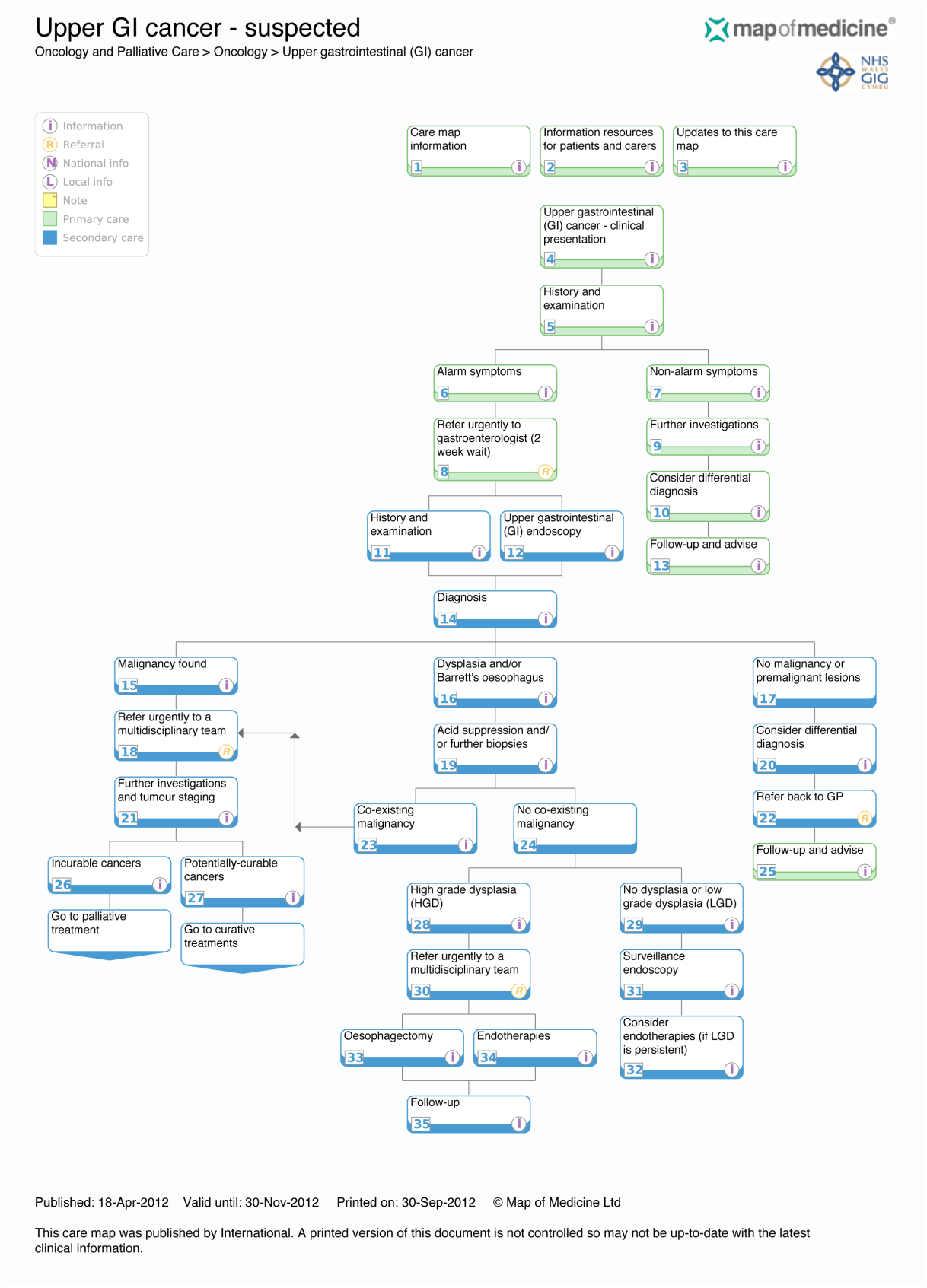


Figure H.1: UGI Cancer ICP (Suspected) adopted from MoM [6].

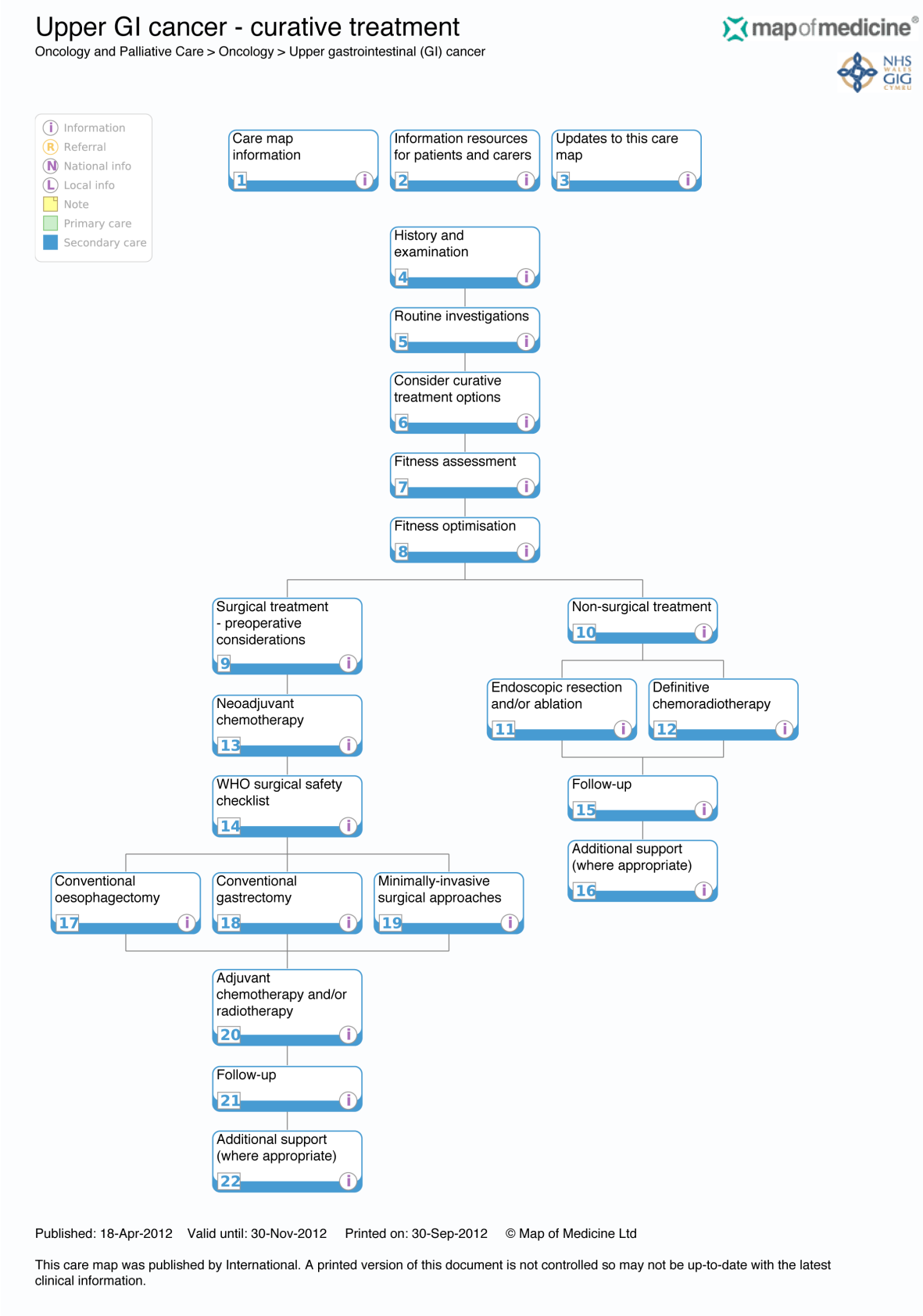


Figure H.2: UGI Cancer ICP (CurativeTreatment) adopted from MoM [6].

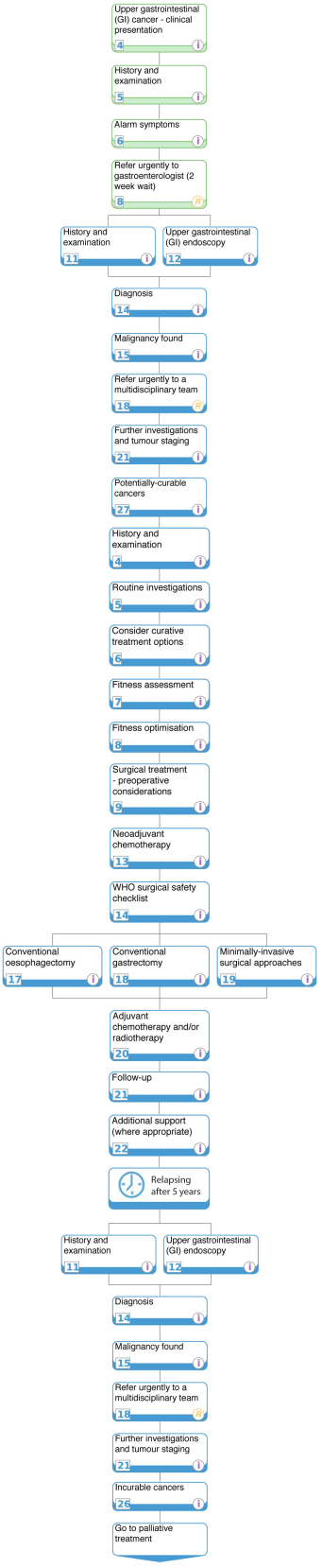


Figure H.3: UGI cancer selected treatment scenario.

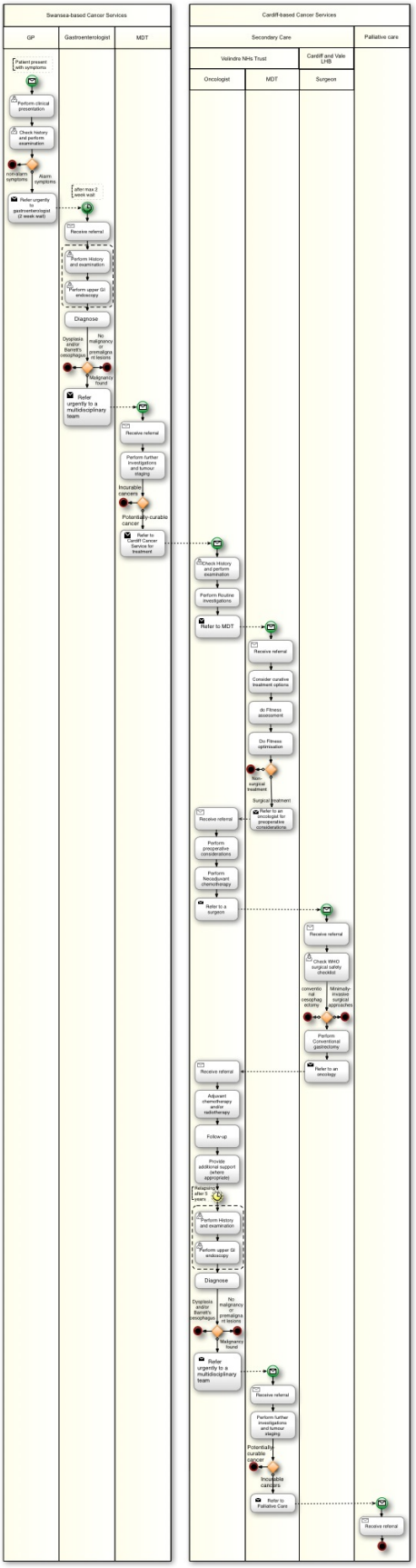


Figure H.4: Business process of the UGI cancer selected treatment scenario.

Appendix I

Breast Cancer Integrated Care Pathway

I.1 Breast Cancer Full ICP

Breast cancer has the most complex of all cancers as it is composed of a six-page Integrated Care Pathway (ICP) shown in Figs I.1, I.2, I.3, I.4, I.5, I.6.

I.2 Conceptual Model of the full Breast Cancer ICP

A comprehensive conceptual model of the full breast cancer ICPs is delivered as shown in Fig I.7

For each breast cancer ICP, an analysis was performed to identify at each treatment point: clinical information collected and recorded, healthcare information systems and health records, and the healthcare professionals' roles. This analysis is summarised in the following sections.

I.2.1 Healthcare Information Systems

There are different healthcare information systems involved in the treatment of patients with breast cancer. These systems are the result of grouping related types of healthcare records into information systems. The records hold different types of information with different levels of sensitivity and they apply different information security rules. Tables I.2.1 lists the different healthcare information systems, types of contained health records, and information stored in these records.

I.2.2 Breast Cancer CT Members

"Breast cancer diagnosis and treatment is a co-operative activity involving a range of professionals, both within and outside the [cancer] unit" [106]. Table I.2 lists the core

Table I.1: Healthcare information systems used in breast cancer treatment.

Healthcare Information System	Health Record Type	Information Stored
GP System	GP records	- Clinical presentation report - Clinical assessment report - Clinical history report - Physical examination report - Filled referral form - Information about referred patients' diagnosis.
Secondary Care System	Secondary care records	- Received filled referral form - Clinical history report - Clinical examination code (e.g. P1) - Tests requests - Test results - Patients cancer TNM staging code - Tumour grade - In general, patient case notes including: (BC diagnostic, staging, pathology information, histology reports, and tests' result reports) - General information addressing the patient's specific situation (in leaflets, audio or video CDs format) - MDT recommendations and treatment plans - Given treatment plan - Follow-up plan - Follow-up visits report
Haematology Laboratory System	- Whole Blood samples (for FBC) - Blood for grouping, antibody screening and saving and/ or cross-matching - Request forms for grouping, antibody screening and cross-matching - Results of grouping, antibody screening and cross-matching - Lab file cards/ working records of test results	- Blood test results report - Blood test results report - FBC report - Renal and liver function test report - Blood Calcium test report

Healthcare Information System	Health Record Type	Information Stored
X-ray System	- X-ray films records - X-ray reports (including reports for all imaging modalities) - Breast screening X-rays records - Ultrasound records	- Mammography report - X-ray images - Ultrasound report - ultrasound images - MRI report - MRI images - Isotope bone scan - CT report and CXR image - Abdomen ultrasound image - Echocardiogram scan report and scan image - DEXA scanning report and image
Pathology Laboratory System	- Pathology records - Human tissue - Lab file cards/ working records of test results	- Biopsy report with diagnosing code (e.g. B1) - FNA report with diagnosing code (e.g. C1) - Tissue samples - The cancer tumour size, nodes, metastasis (TNM) staging code - Tumour grade (I'm not sure if the TNM results are kept in this system, or oncology system) - Histology report with biopsy diagnosing code (e.g. B1)
Oncology System	- Oncology records - Radiation dose records for classified persons	- Cancer TNM staging code - Tumour grade - MDT recommendations and treatment plan - Neo-adjuvant endocrine therapy report - Neo-adjuvant chemotherapy therapy report - Chemotherapy drugs list and dose - Radiotherapy report - Adjuvant chemotherapy report (include the risk analysis) - Hormonal therapy report - Endocrine therapy report - Bisphosphonates report
Surgical System	- Operating theatre registers - Surgical records	- Surgical report - MDT recommendations and treatment plans

Table I.2: Categorisation of breast cancer CT members.

Category	Role(s)
Primary care personnel	- GP
Principle Specialist Personnel	- Breast Cancer Nurse Specialist - Clinical and Medical Oncologist - Radiologist - Pathologist - Surgeon
Affiliated Personnel required	- Liaison psychiatrist and/or clinical psychologist - Palliative care specialists and teams - Physiotherapists and occupational therapists - Surgeon experienced in breast reconstruction - Clinical genetics - Pharmacist - Haematologist

team members of specialised professionals who are directly involved in the diagnosis and treatment of patients with breast cancer (i.e. the role they play), in additional to, other specialists who may at times become involved in the management of a patient with breast cancer.

I.3 Breast Cancer Selected Treatment Scenario

A simple breast cancer treatment scenario in Wales start with a patient seeing a GP at a surgery with worrying symptoms. The GP examines the patient, collects information, and stores it in his information system. If the GP is suspicious, then he refers the patient for a triple assessment. A specialist (i.e. surgeon) starts the triple assessment with further examination and a history check. Then a radiologist performs an ultrasound or a mammogram, and finally a biopsy is performed by a pathologist. The results from the triple assessment are discussed at an initial MDT review to decide a treatment plan. Most patients undergo an operation as the first treatment option, and post-op another MDT review is arranged to decide on any further treatments. Finally, the patient may have further treatment with chemotherapy by an oncologist. This real-life breast cancer treatment scenario was checked by a Breast Cancer Oncologist [87] and Clinical Nurse Specialist in Breast Care [88]. However, due to the complexity of this cancer's ICPs, a decision had to be make regarding which route the scenario must follow. In the above scenario surgery was selected as the first treatment option. This choice was made based on the statistics published at the Breast Cancer Audit [80] report in 2012 which highlights the fact that "45% to 81% (mean=61%) of patients aged 70+ have surgery as primary treatment for

invasive breast cancer; the remainder may or may not have had primary drug therapy," while "67% to 100% (mean = 90%) of patients receiving radiotherapy after breast conserving surgery for invasive breast cancer" [80]. Finally, this scenario was extracted from the breast cancer full ICP, shown in Fig I.8.

I.4 Breast Cancer Treatment Process Model

The above treatment scenario was used to build a breast cancer business process model. The whole model is drawn using BPMN's notation as shown in Fig I.9.

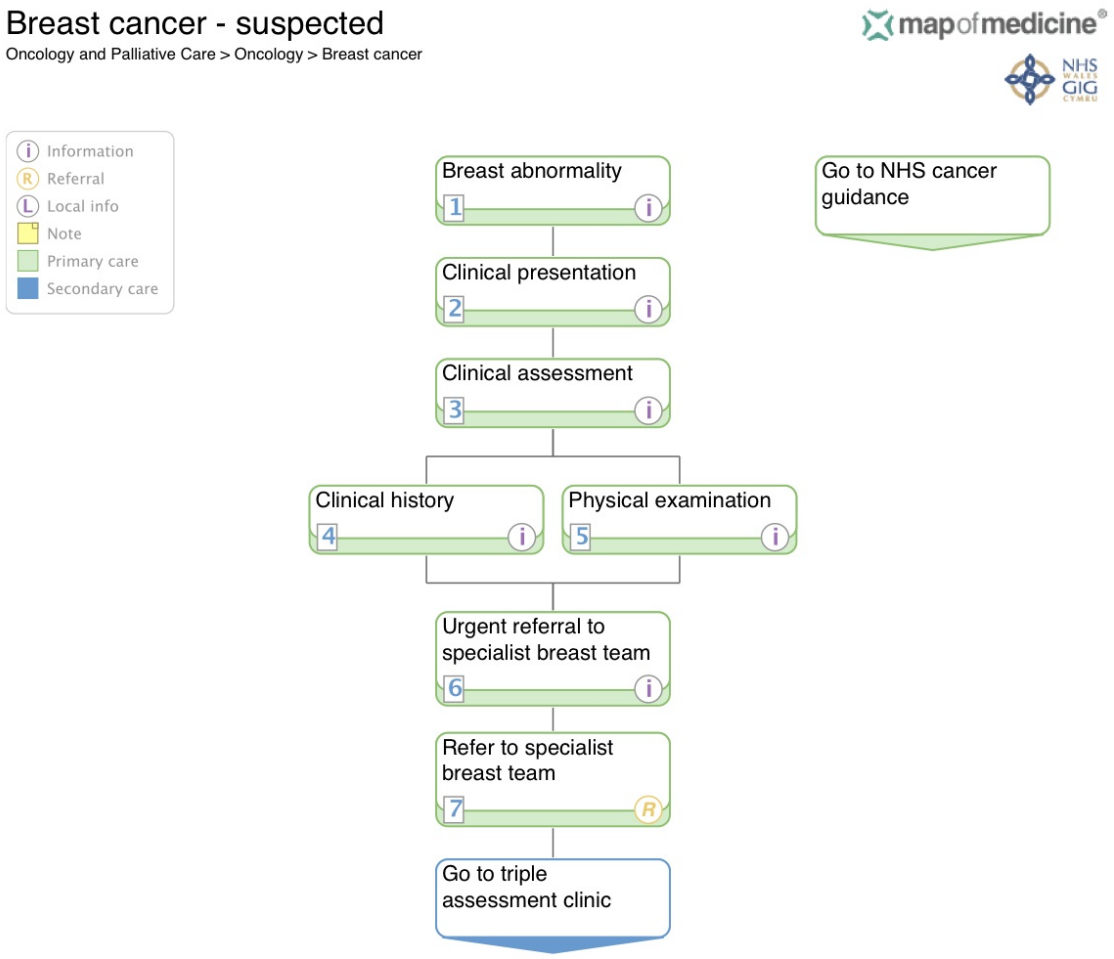


Figure I.1: Breast Cancer ICP (Suspected) adopted from MoM [6].

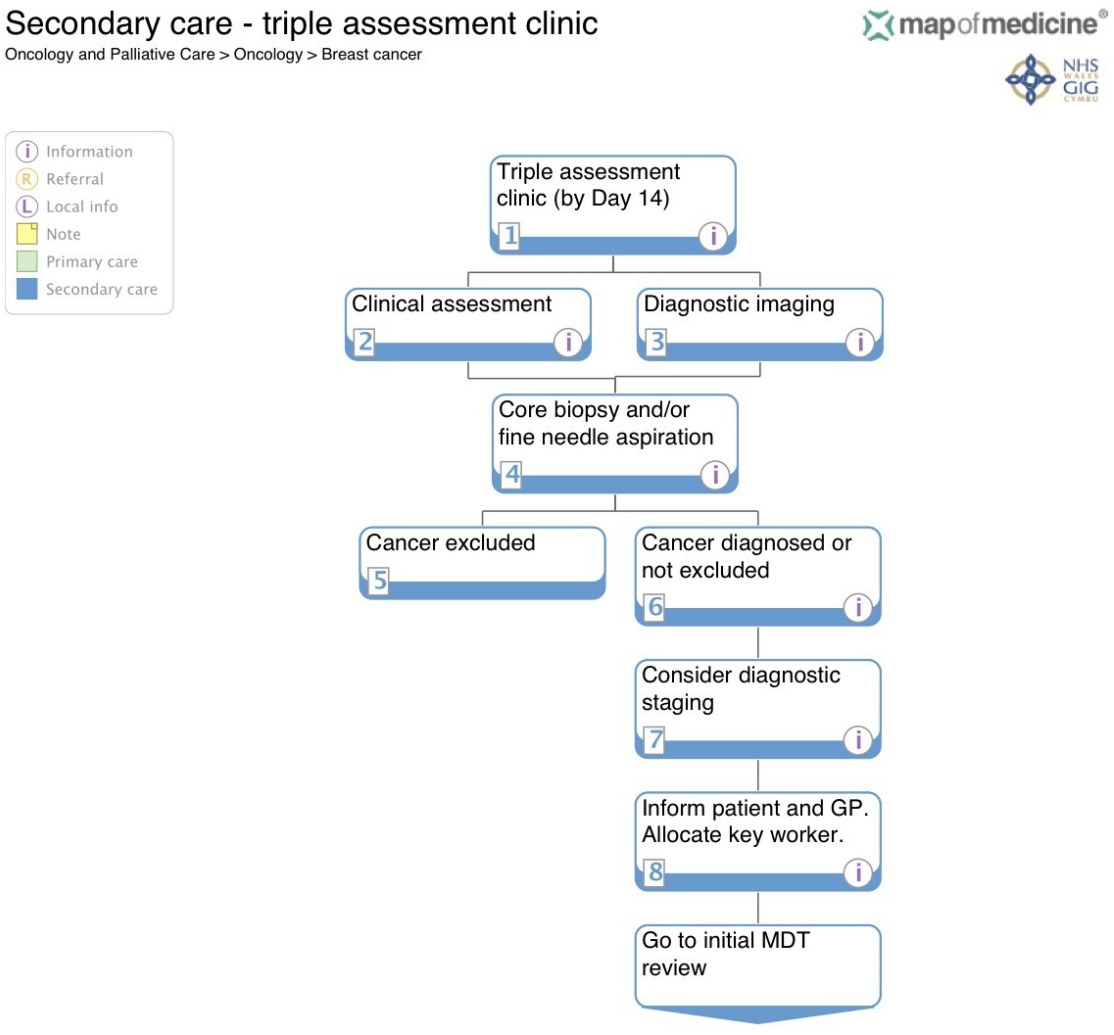
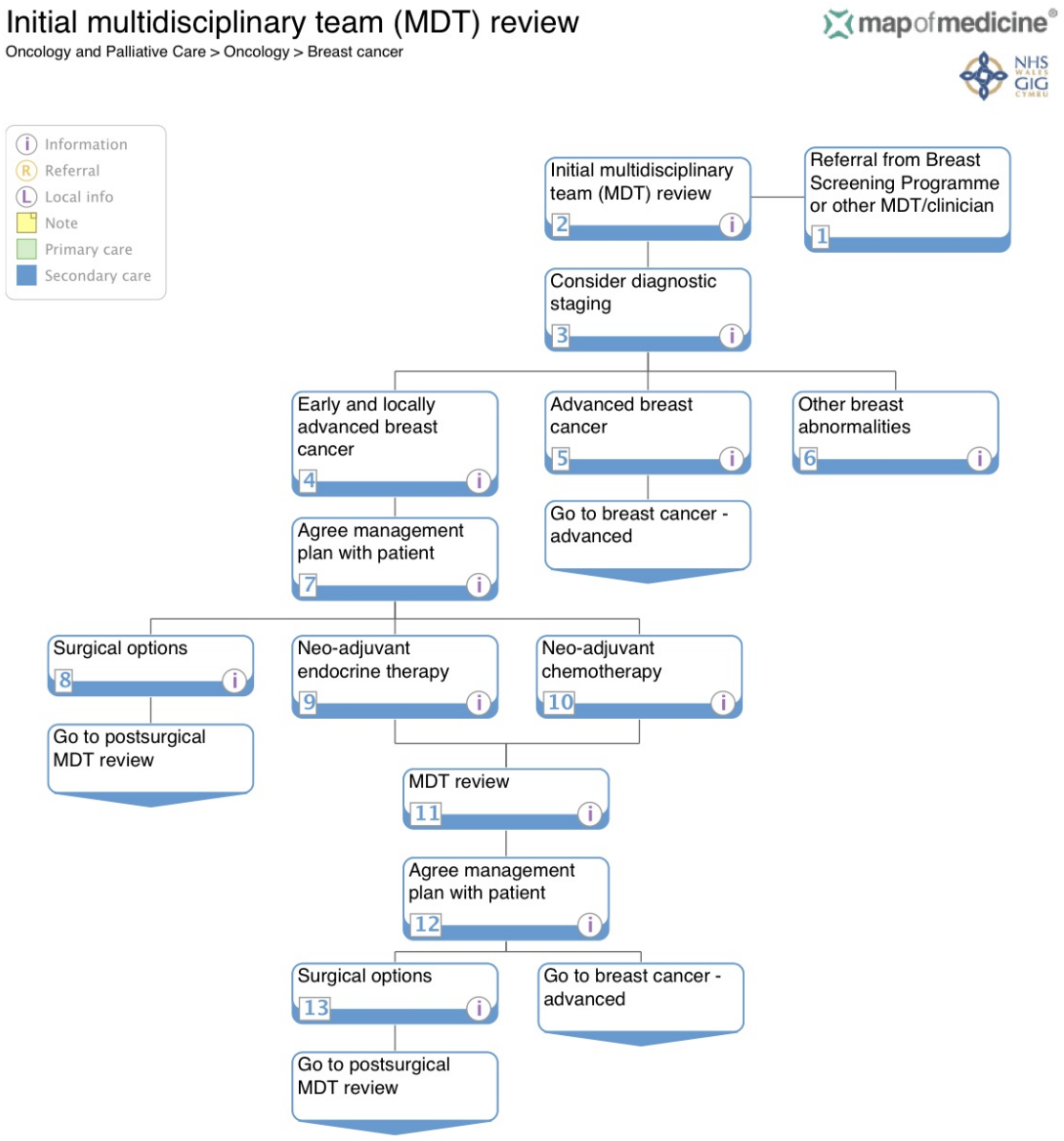


Figure I.2: Breast Cancer ICP (Triple Assessment Clinic) adopted from MoM [6].



Locally reviewed: 21-Aug-2009 Due for review: 30-Oct-2010 Printed on: 31-Mar-2010 © Map of Medicine Ltd

IMPORTANT NOTE
Locally reviewed refers to the date of completion of the most recent review process for a pathway. All pathways are reviewed regularly every twelve months, and on an ad hoc basis if required. Due for review refers to the date after which the pathway on this page is no longer valid for use. Pathways should be reviewed before the due for review date is reached.

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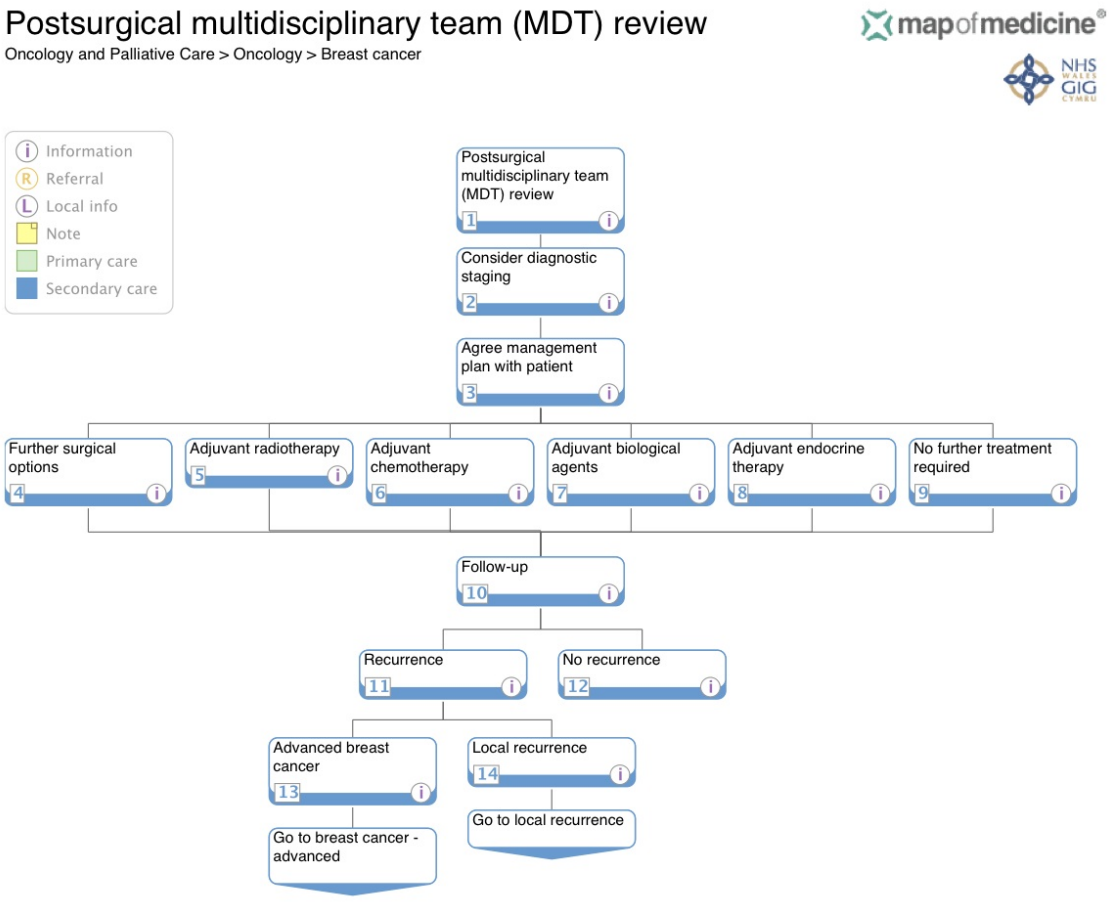
Figure I.3: Breast Cancer ICP (Initial MDT Review) adopted from MoM [6].



Locally reviewed: 21-Aug-2009 Due for review: 30-Oct-2010 Printed on: 31-Mar-2010 © Map of Medicine Ltd

IMPORTANT NOTE
Locally reviewed refers to the date of completion of the most recent review process for a pathway. All pathways are reviewed regularly every twelve months, and on an ad hoc basis if required. Due for review refers to the date after which the pathway on this page is no longer valid for use. Pathways should be reviewed before the due for review date is reached.

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Figure I.4: Breast Cancer ICP (Postsurgical MDT Review) adopted from MoM [6].

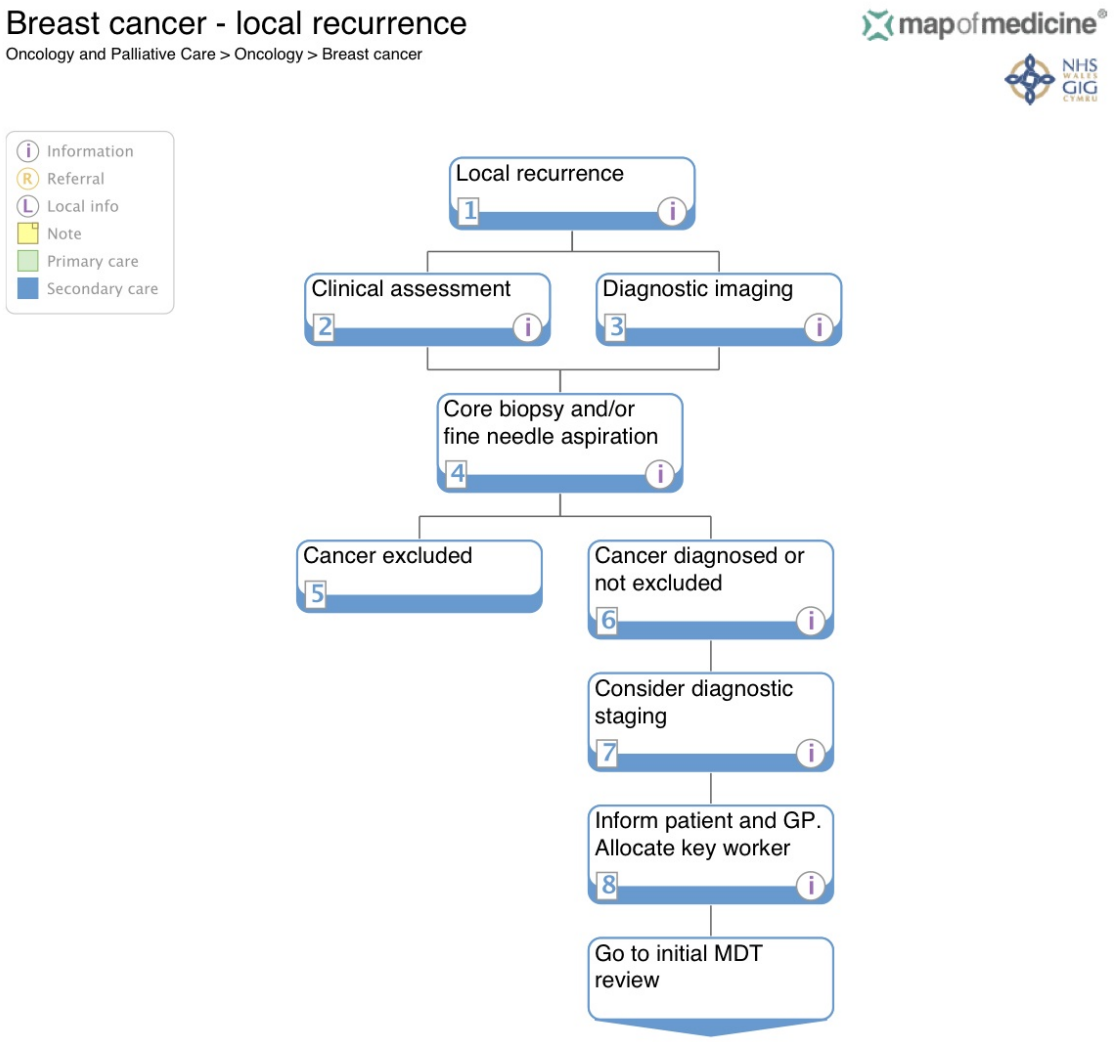

Figure I.5: Breast Cancer ICP (Local Recurrence) adopted from MoM [6].

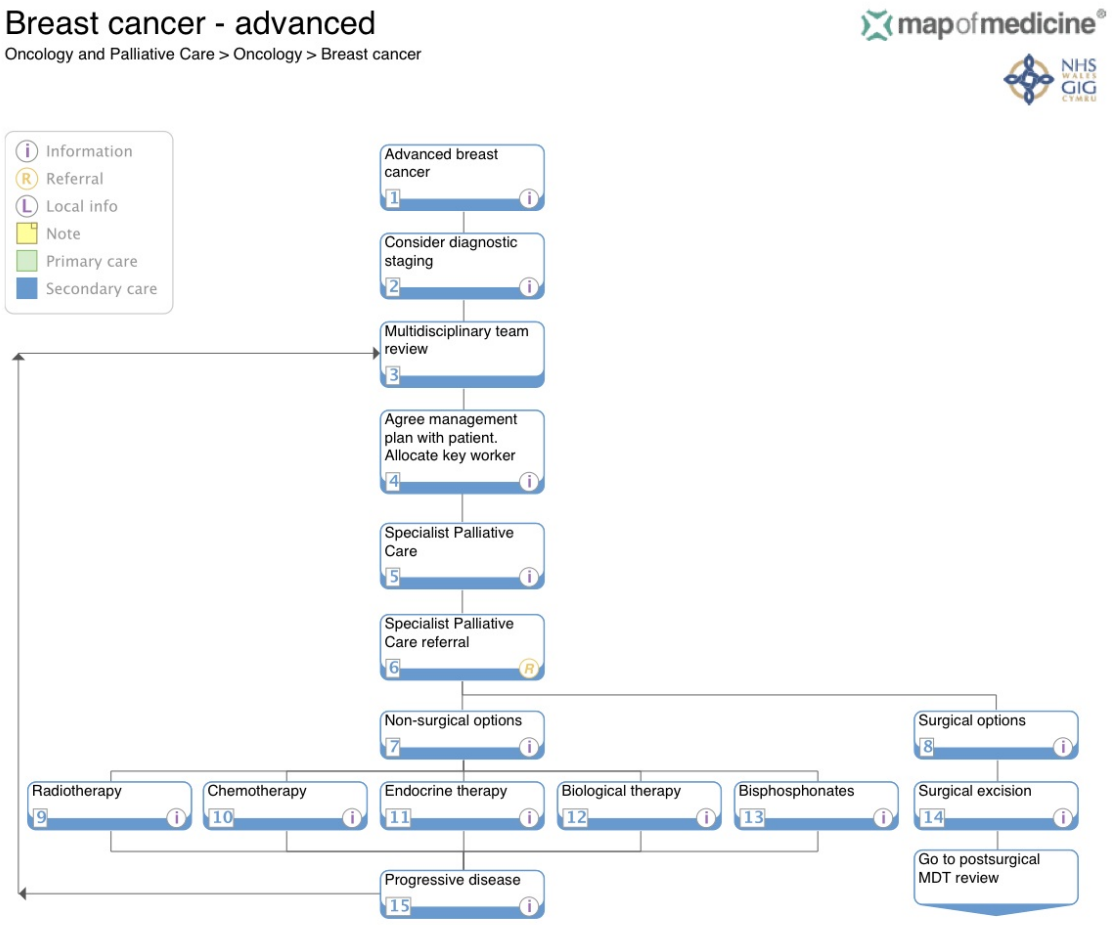

Figure I.6: Breast Cancer ICP (Advanced) adopted from MoM [6].

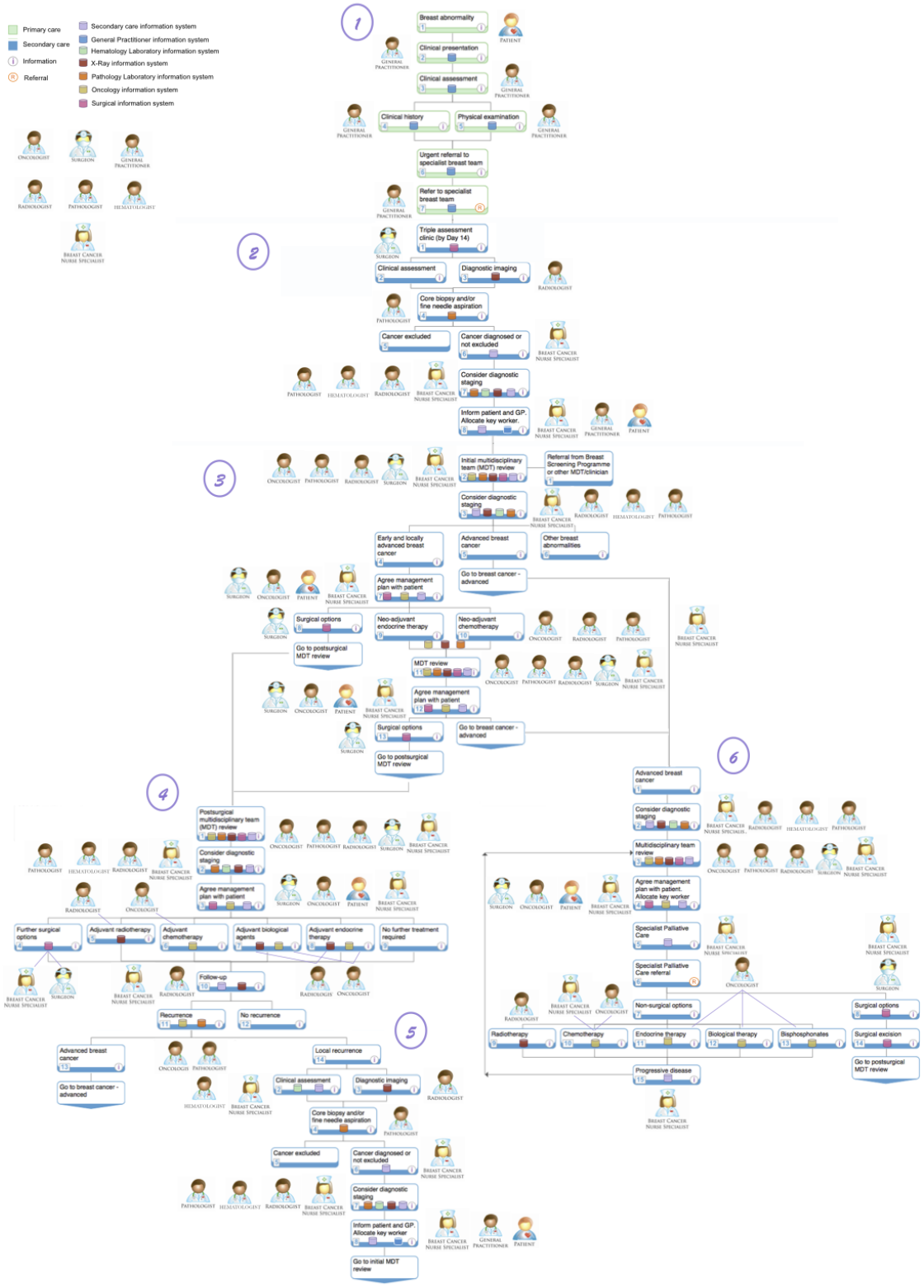

Figure I.7: Conceptual model of full breast cancer ICPs.

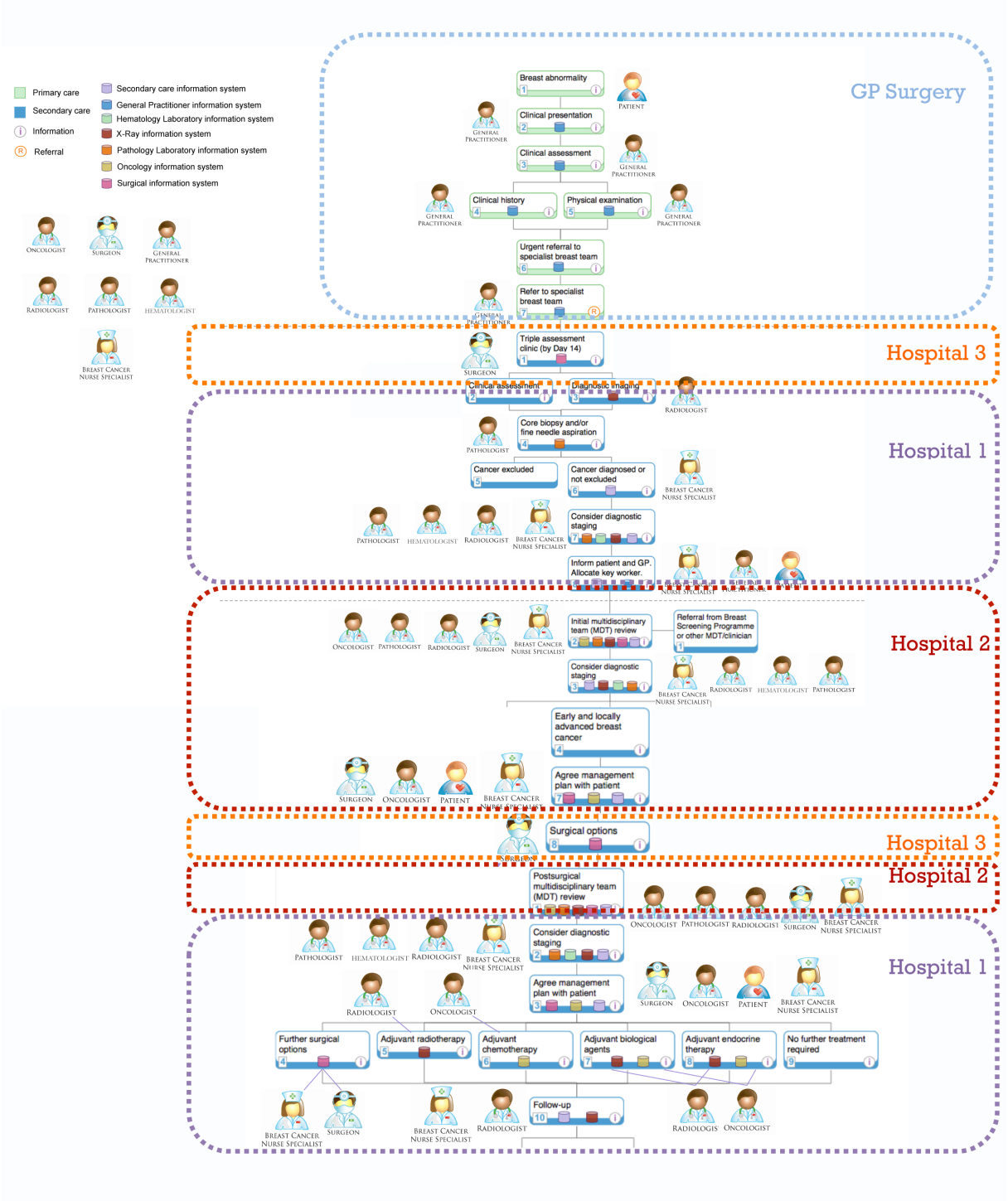

Figure I.8: Breast cancer selected treatment scenario.

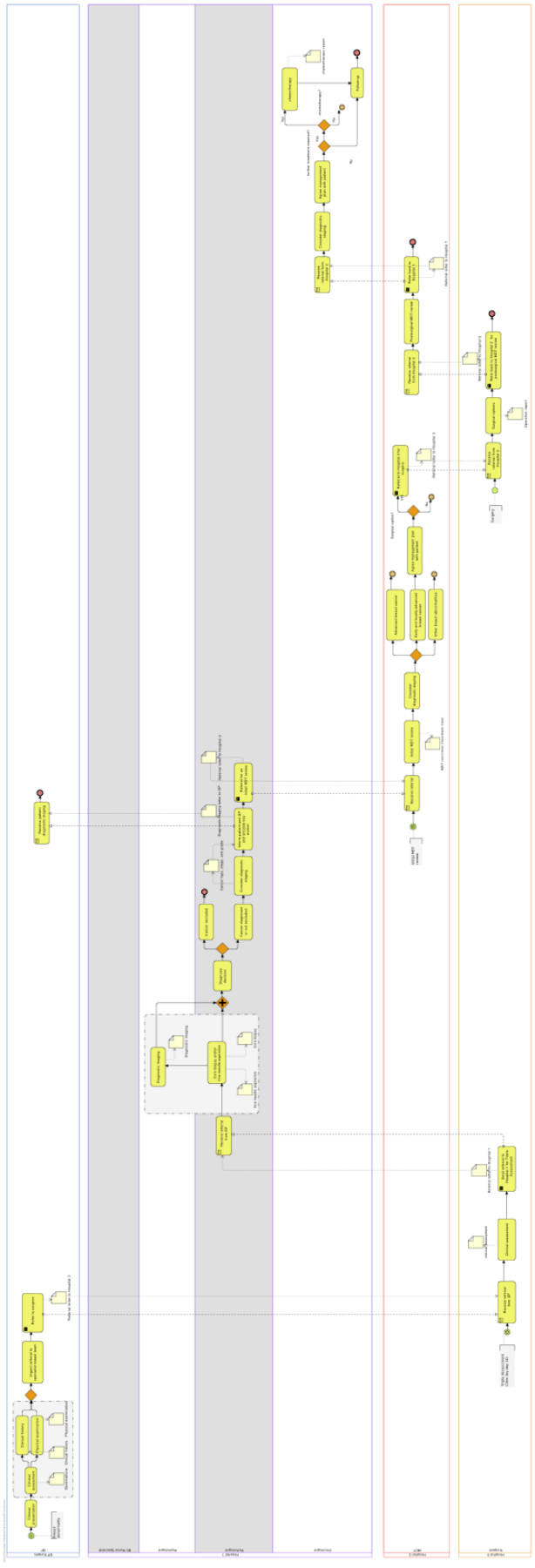

Figure I.9: Breast cancer treatment scenario process model.

I.5 Mapped Breast Cancer Treatment Process

The above treatment process model was mapped into the WffICP. This model is extremely lengthy and complex, hence, it was broken into 12 smaller figures to fit the pages in this thesis. The figures are Fig I.10, I.11, I.12, I.13, I.14, I.15, I.16, I.17, I.18, I.19, I.20, I.21. They clearly shows the different hospitals, information systems, and physical perimeters of where the information is collected, recorded, and shared.

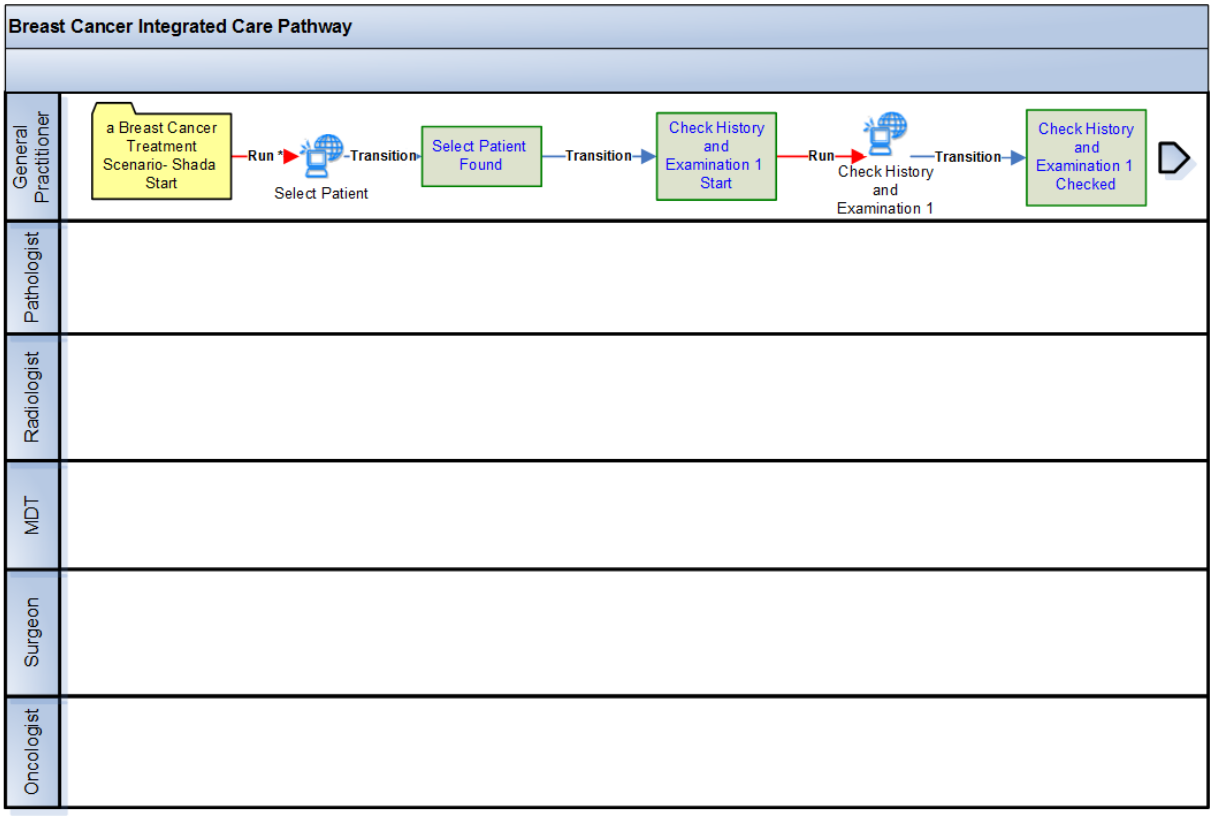

Figure I.10: Business process of the breast cancer selected treatment scenario- page 1.

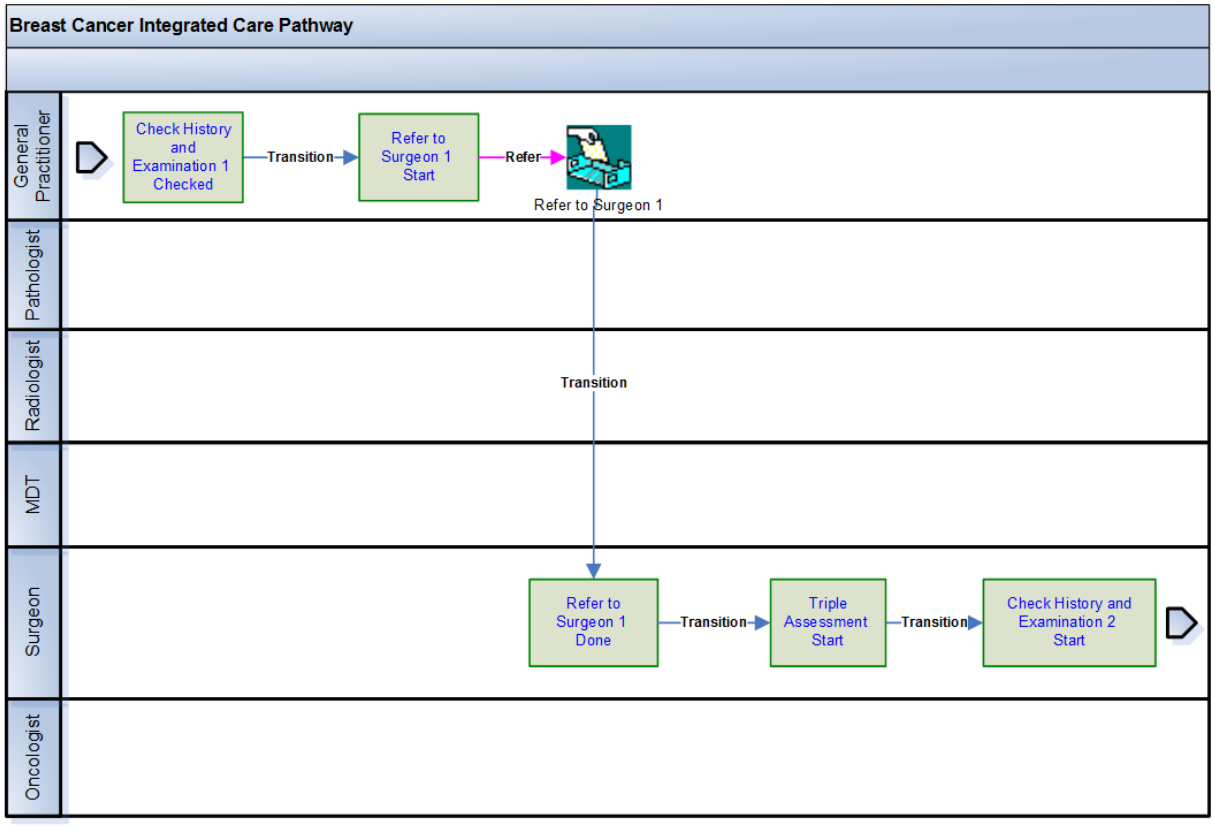

Figure I.11: Business process of the breast cancer selected treatment scenario- page 2.

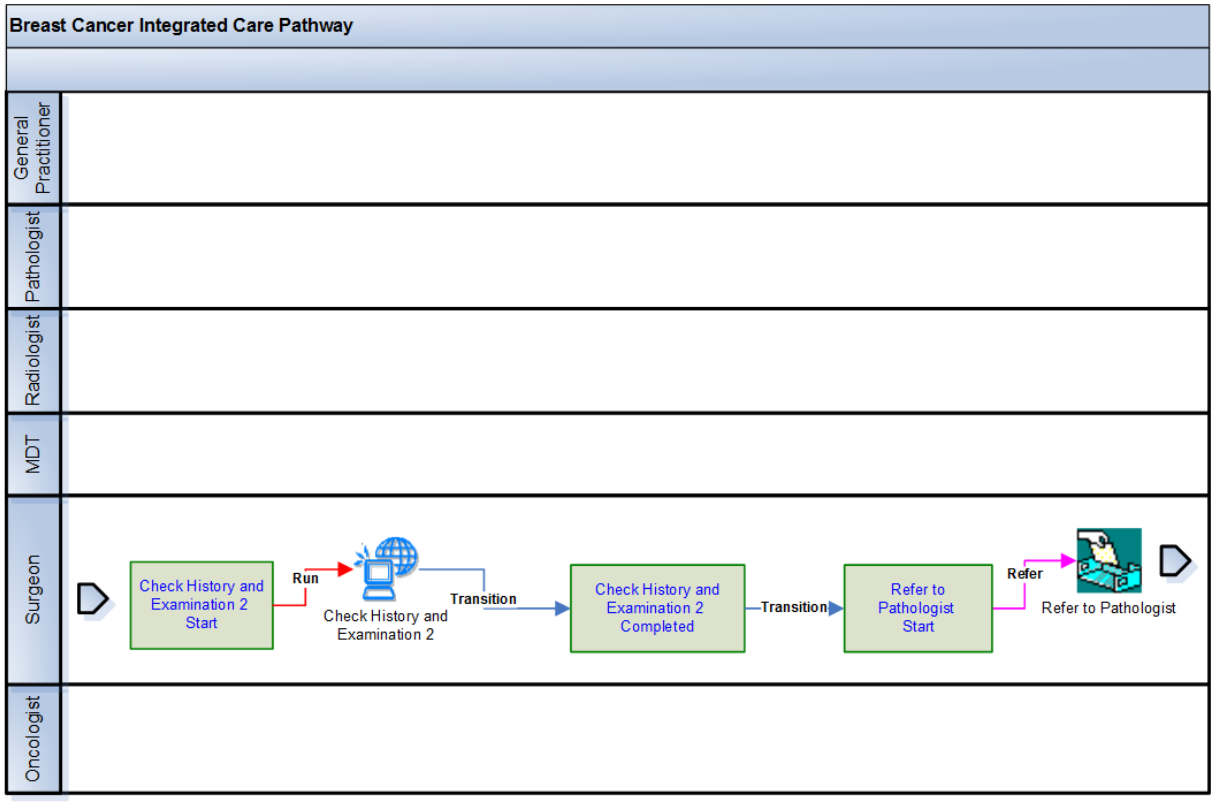

Figure I.12: Business process of the breast cancer selected treatment scenario- page 3.

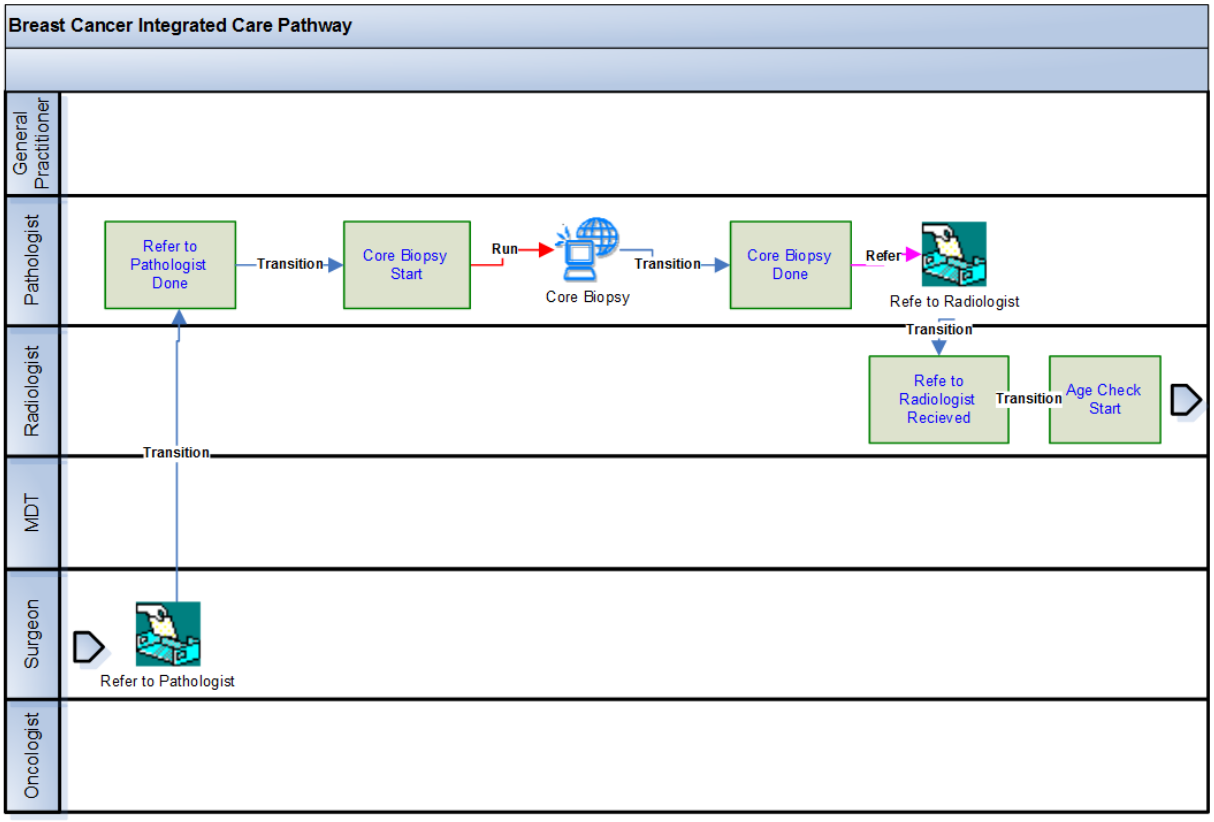

Figure I.13: Business process of the breast cancer selected treatment scenario- page 4.

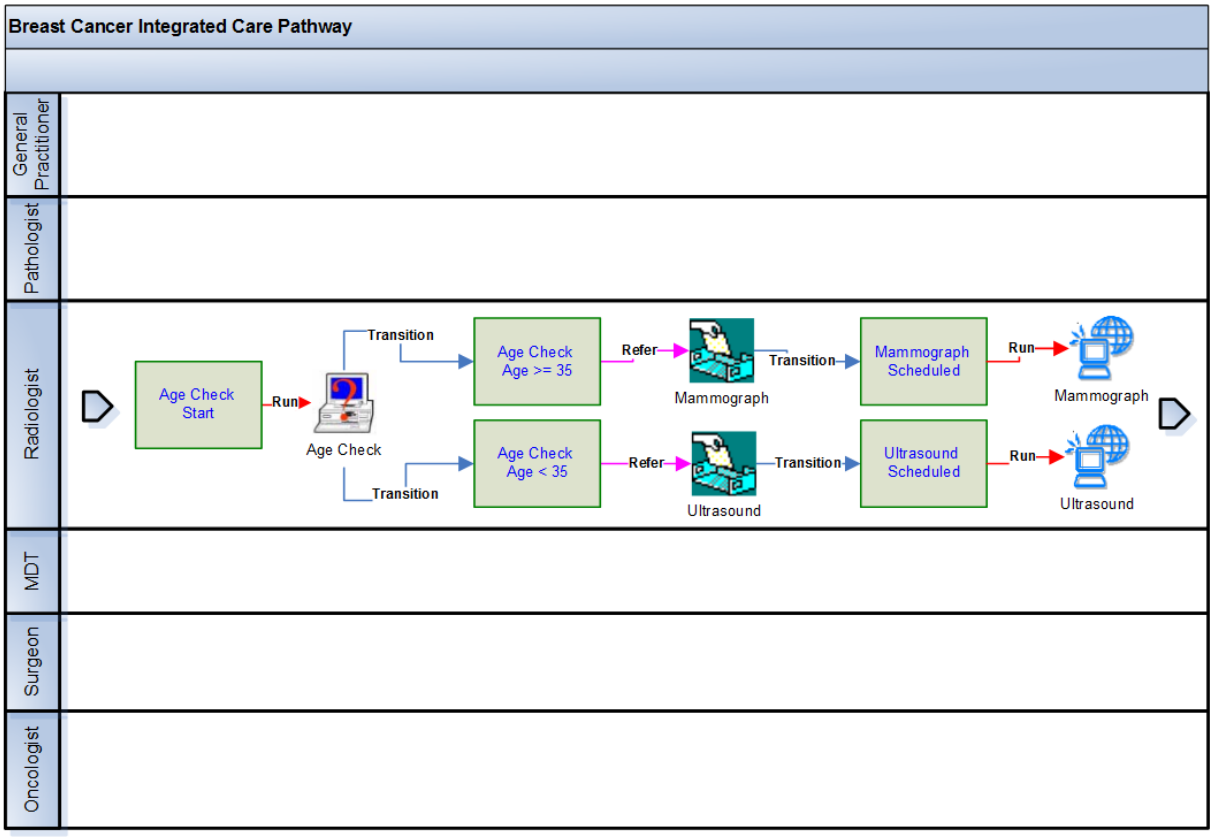

Figure I.14: Business process of the breast cancer selected treatment scenario- page 5.

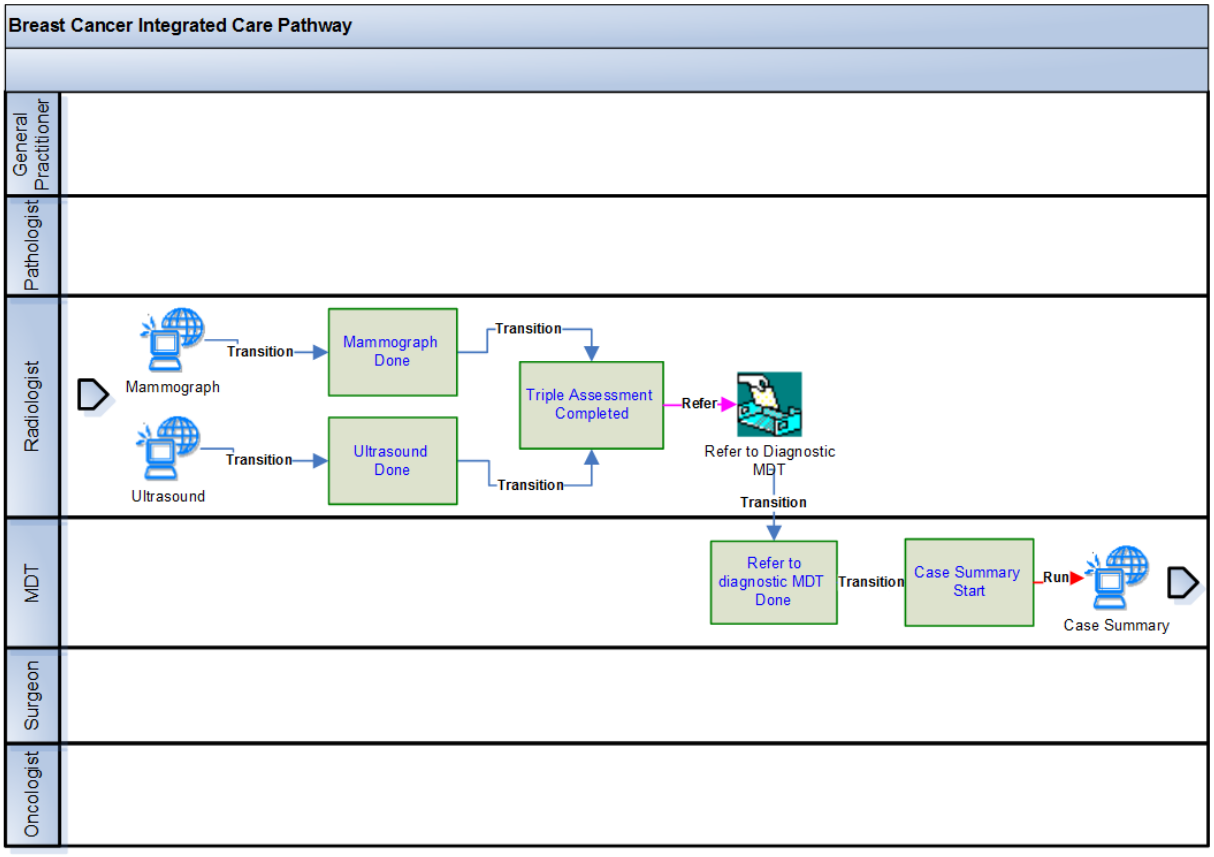

Figure I.15: Business process of the breast cancer selected treatment scenario- page 6.

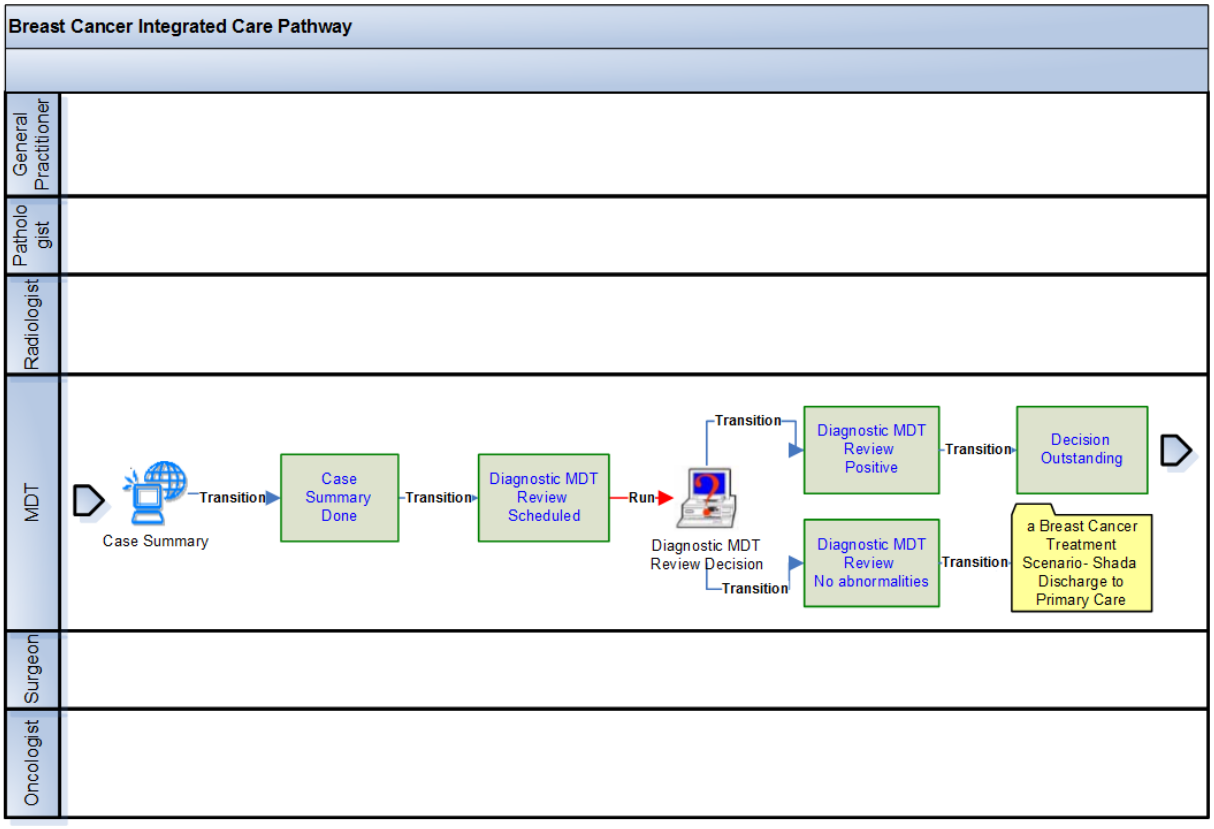

Figure I.16: Business process of the breast cancer selected treatment scenario- page 7.

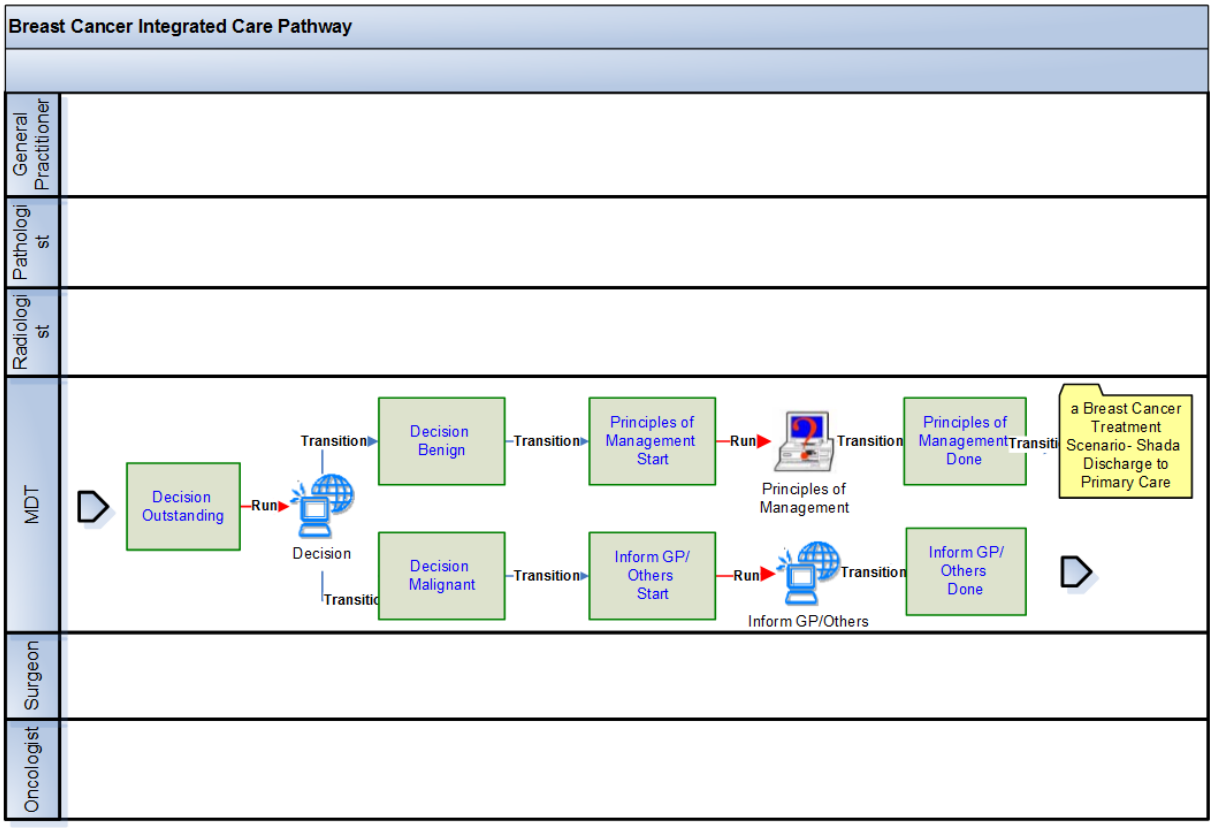

Figure I.17: Business process of the breast cancer selected treatment scenario- page 8.

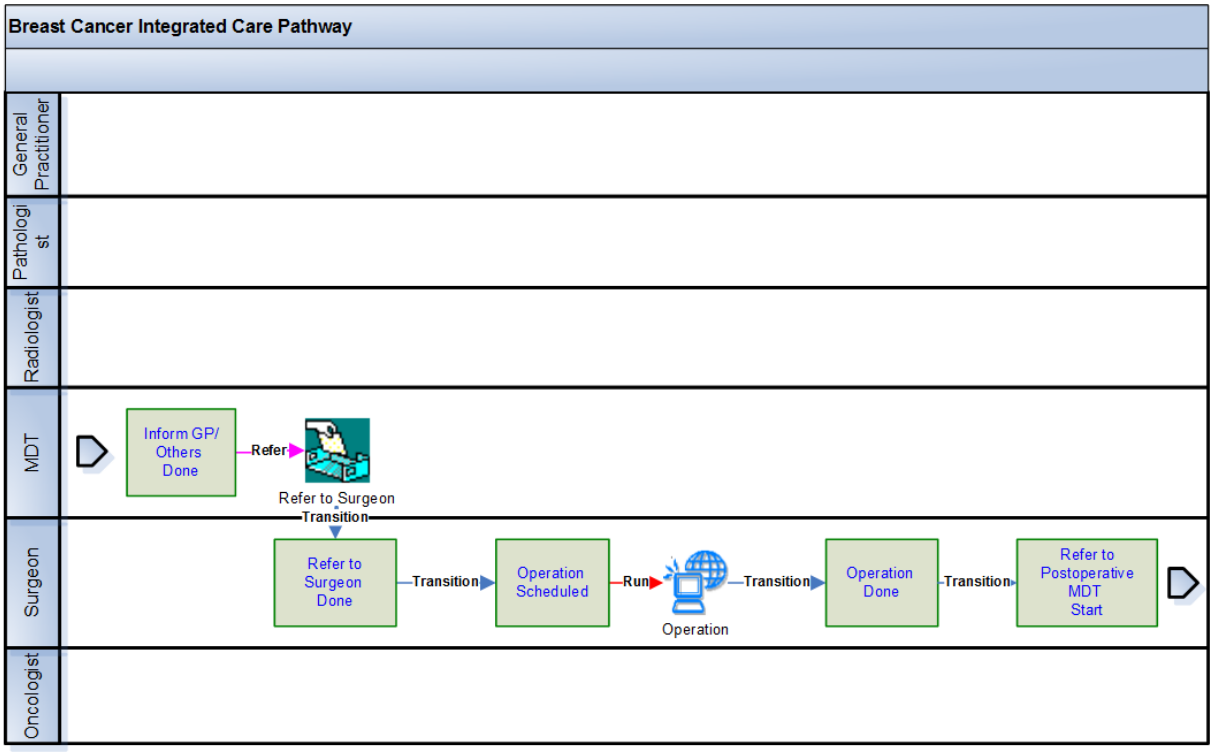

Figure I.18: Business process of the breast cancer selected treatment scenario- page 9.

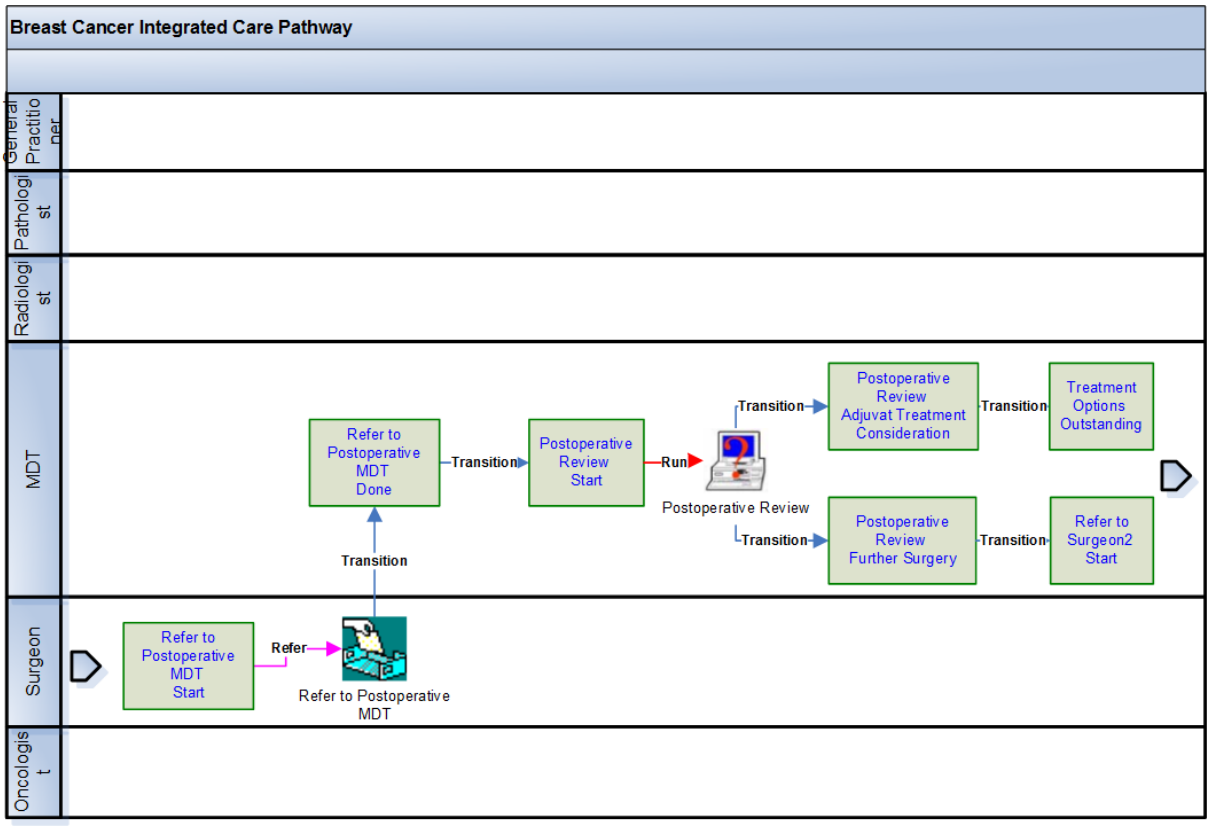

Figure I.19: Business process of the breast cancer selected treatment scenario- page 10.

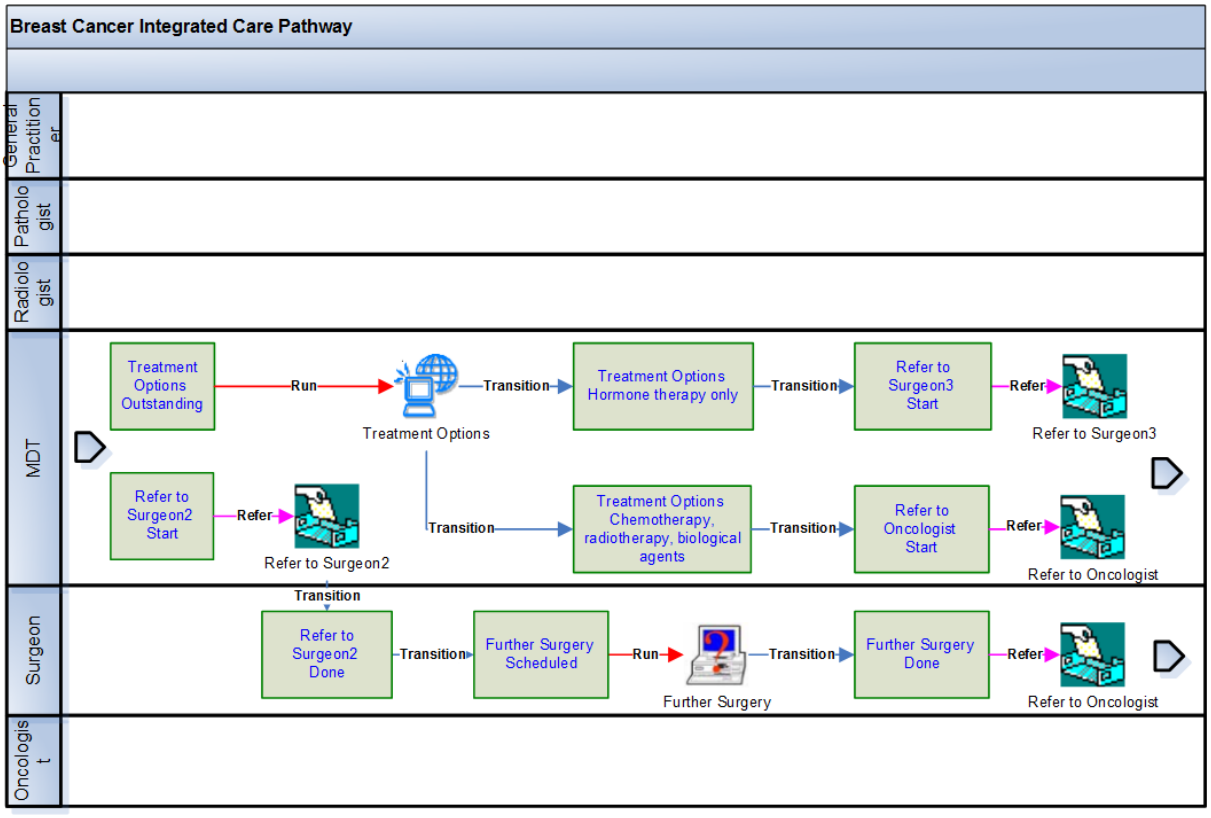

Figure I.20: Business process of the breast cancer selected treatment scenario- page 11.

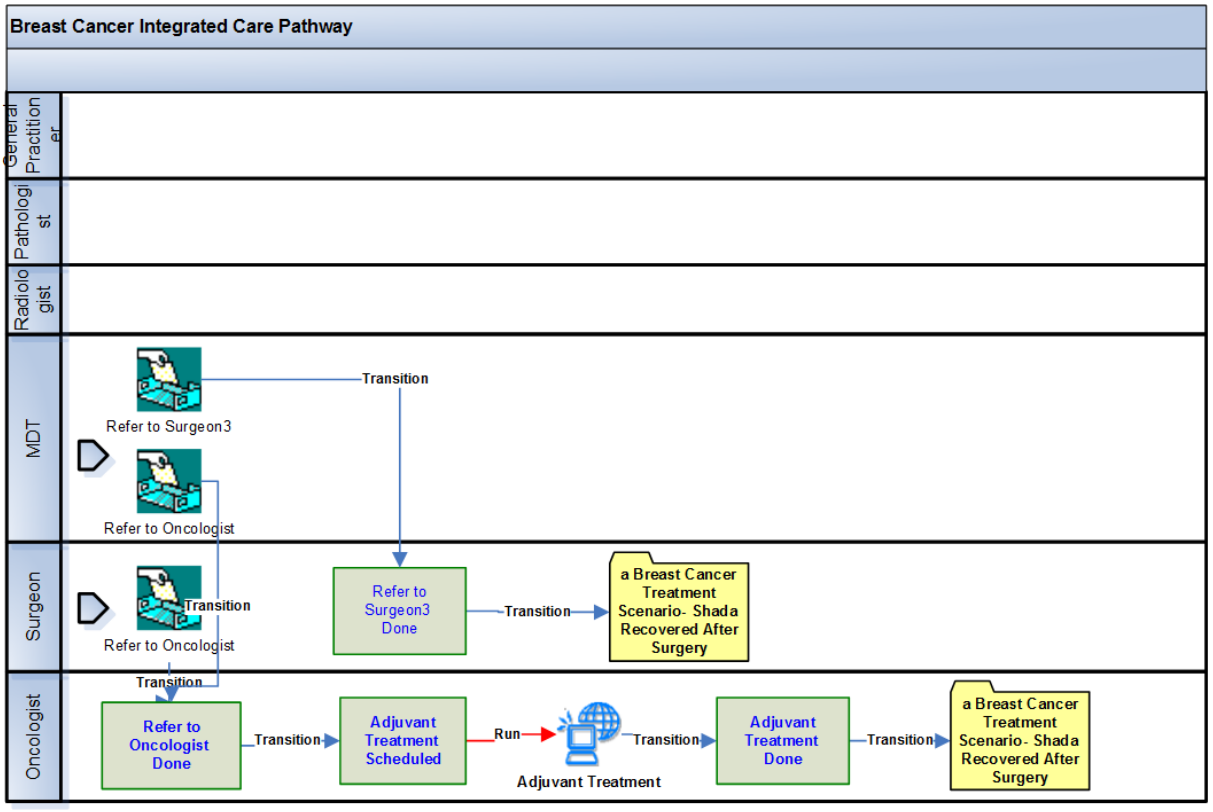

Figure I.21: Business process of the breast cancer selected treatment scenario- page 12.

Appendix J

Bringing SHarE to Life Through the Breast Cancer Treatment Scenario

SHarE serves healthcare collaborative environments where patients have to follow a treatment pathway where there are different healthcare professionals each playing a different role in this treatment, and information is recorded at each point of treatment from multiple geographically distributed hospitals each using various information systems. This means SHarE aims to meet both, the information sharing and security contexts. In this appendix, a number of screenshots are used to show how SHarE creates and activates a breast cancer treatment process through a unique instance. This treatment follows the scenario shown in Fig 6.3 for a new patient named Susan Smith, NHS number 123.

J.0.1 Care point 1: GP

Susan sees her GP, Hessah Alsalamah, with alarming symptoms. The GP logs into SHarE (Fig J.1) and creates a new case (Fig J.2) since Susan has never been treated with breast cancer, and this is her starting point in the treatment pathways. Here SHarE creates a new instance for Susan where the process connects to the workflow database to read the different activities in the Susan's case based on the mapped workflow logic [5]. She tries to link this new case to Susan's health record using her NHS number, assuming Susan is already registered in her GP's system.

So once the patient is found, the GP examines the patient asks questions, records medical history and examination information in the text area in Fig J.3 and Fig J.4.

After recording the information, the GP should decide how sensitive this information is based on the Traffic Light Classification Scheme as shown in Fig J.5. This scheme is selected in this research to demonstrate how to raise awareness around security among CT members. If information is Not Sensitive, then the GP should select the white icon, green is for Care Team Wide sharing (the default if the CT member does not have the time to choose), amber for Sensitive information, and red is for Highly Sensitive information.

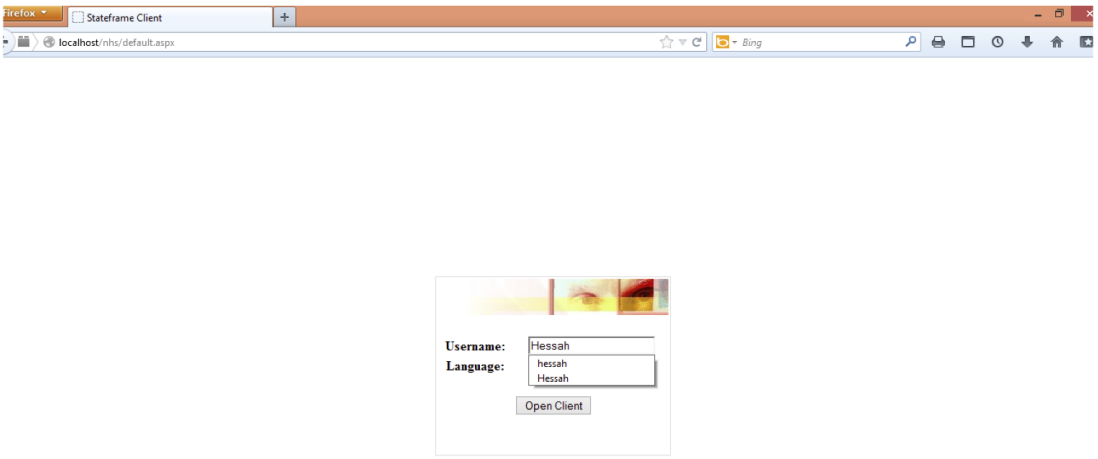

Figure J.1: GP logs into SHarE.

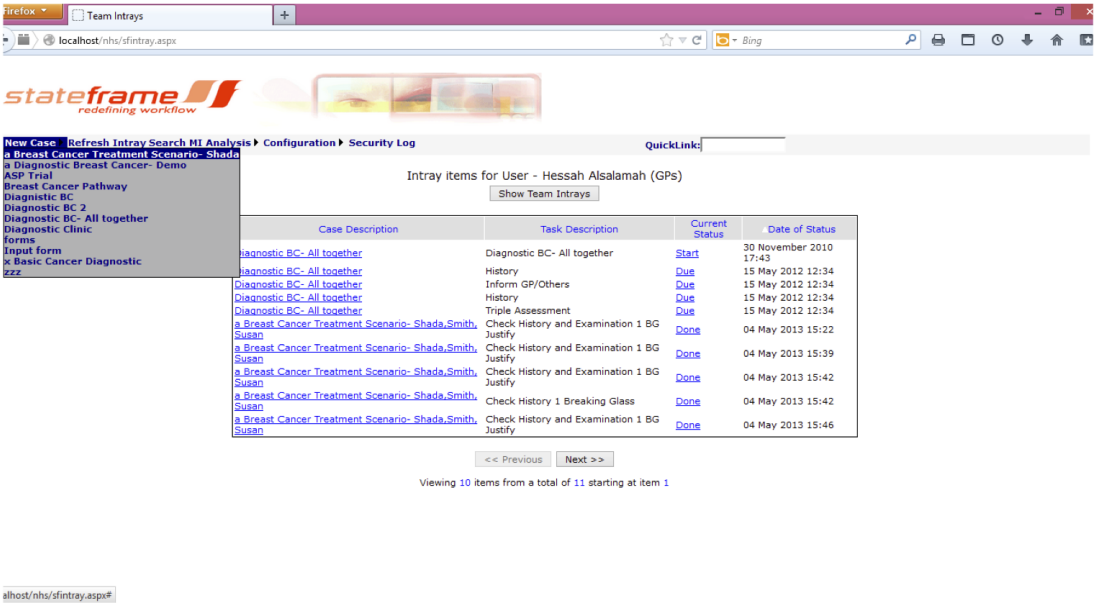

Figure J.2: GP creates a new case in SHarE.

Once done, the patient's case is automatically referred to the next care point carried out by the specialist, Carl Passant, shown in Fig J.6.

J.0.2 Care point 2: Specialist (Surgeon)

SHarE automatically referred Susan and her information to a specialist in secondary care, Carl Passant. Carl logs into SHarE at the point of care when Susan sees her Fig J.7, and she finds SHarE holding Susan's case with the required information (based on breast

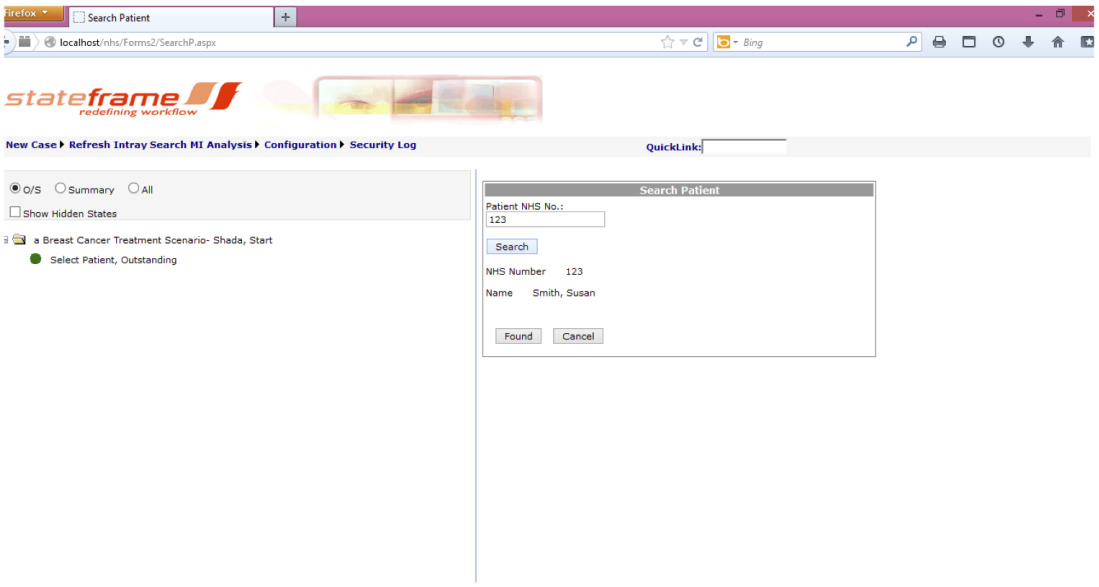

Figure J.3: GP records medical history details into SHarE.

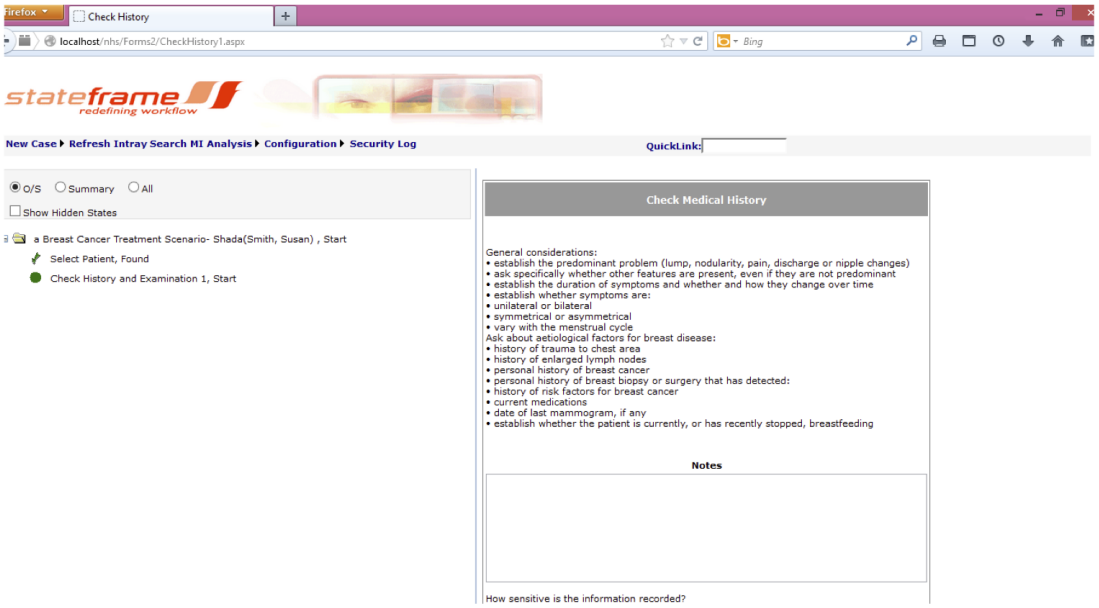

Figure J.4: GP records examination details into SHarE.

cancer ICP) outstanding in the Intray as shown in Fig J.8. Each healthcare professional has his/ her own Intray on the first page once they log in with all outstanding cases or warnings that need attention. SHarE uses the Intray as a notice board to inform healthcare professionals about any break-glass incidents to their information or if information has been amended by other healthcare professional on which they can take any necessary actions.

Once Carl clicks Susan's outstanding case, she can start caring for Susan by checking

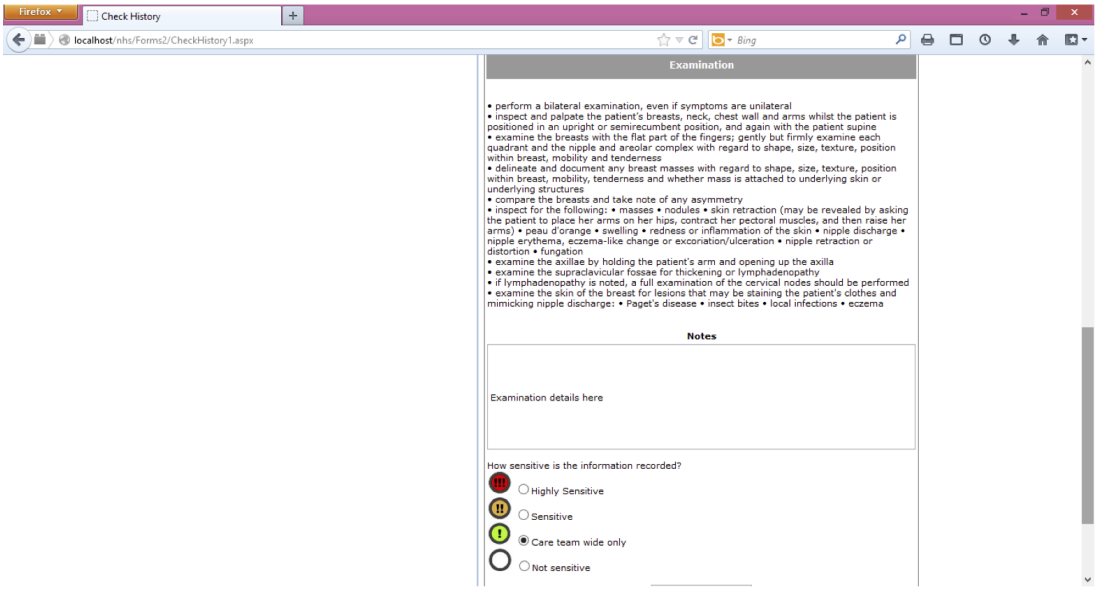

Figure J.5: GP selects the level of sensitivity.

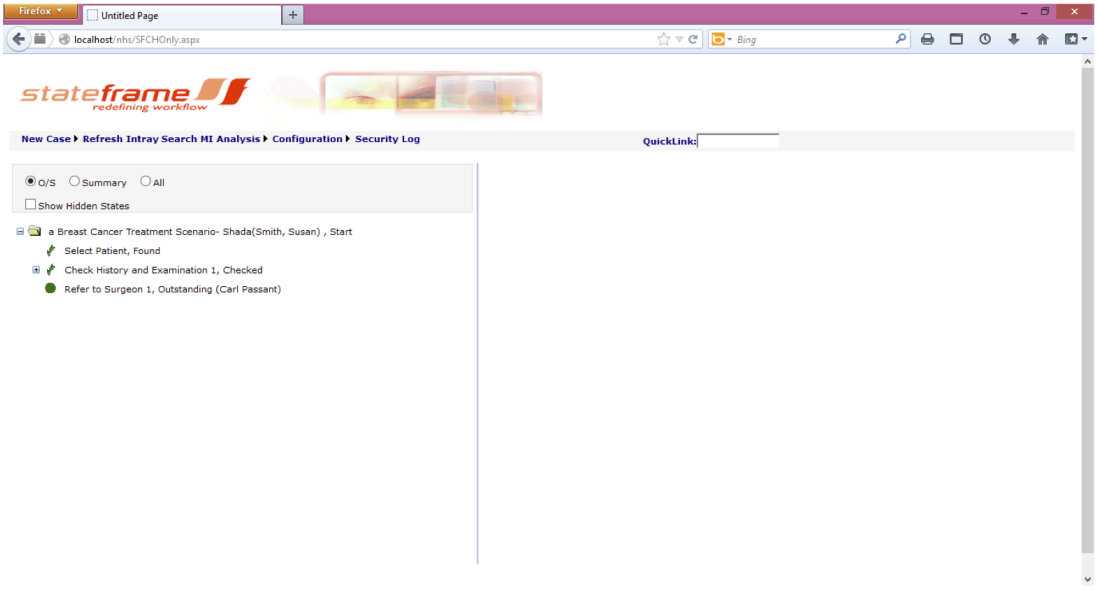

Figure J.6: SHarE automatically refers Susan's case to the next care point.

information received from the GP along with the icon stuck with the information to show in a visual human-level the sensitivity level of this information this is illustrated in Fig J.9. Since this activity involves information access, a policy trigger is activated [5] in SHarE where all access rules are stored to make appropriate access decisions based on the predefined access rules [5].

Carl can read the information she receives from the GP, she starts with further examination and history check, records that information, and labels the information (Figs J.10, J.11). Once done, Susan's case is automatically referred to the third care point to a radiologist

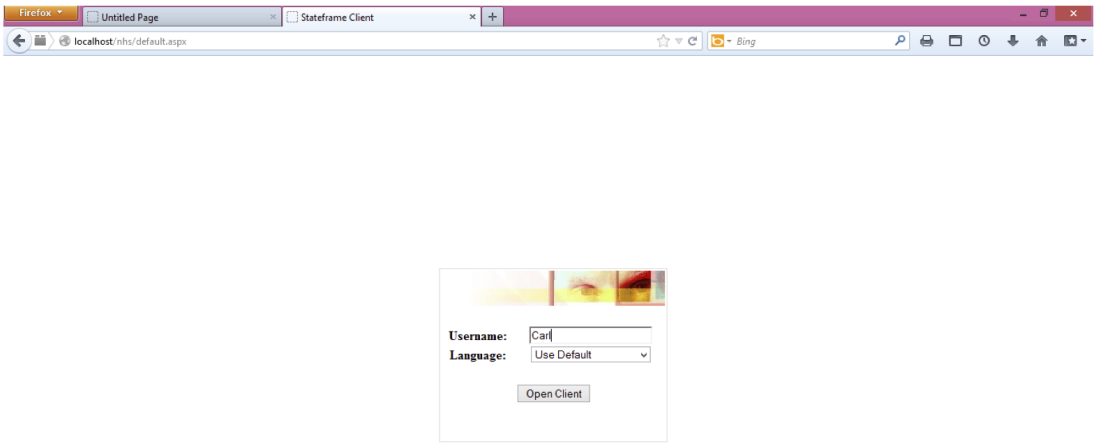

Figure J.7: Specialist logs into SHarE.

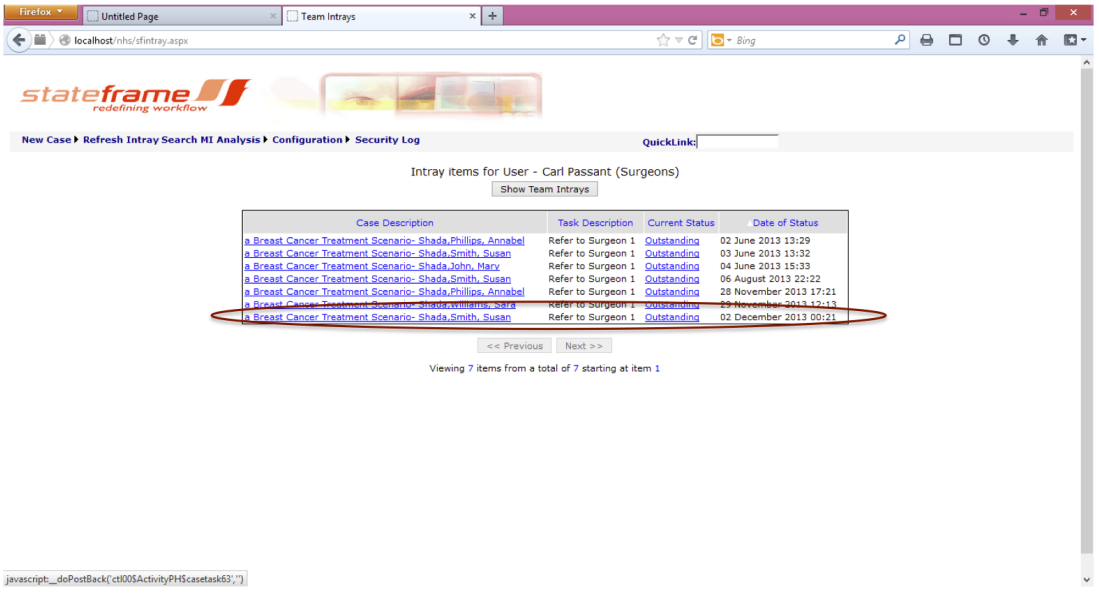

Figure J.8: Specialist access automated referral through an Intray.

to perform an ultrasound or mammogram as part of the triple assessment, see Fig J.12.

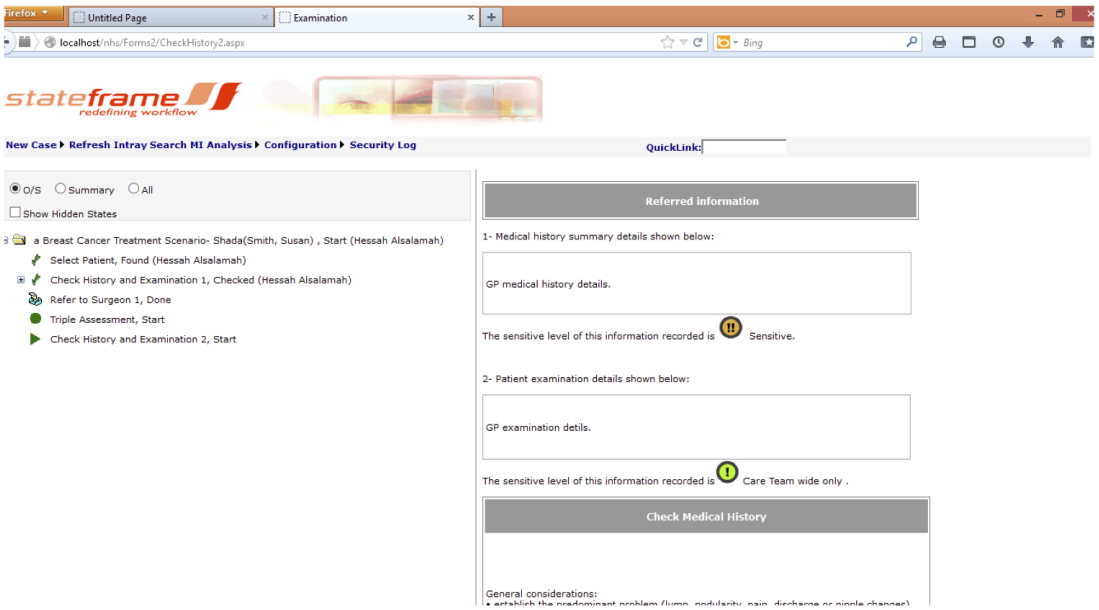

Figure J.9: Specialist access Susan's referred information.

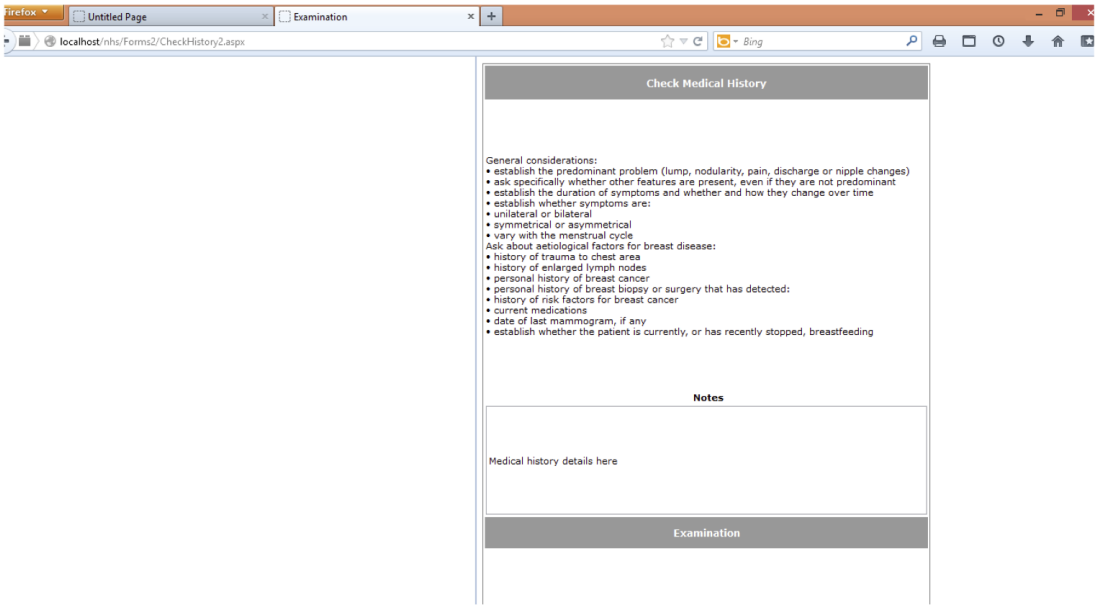

Figure J.10: Specialist records further examination information into SHarE.

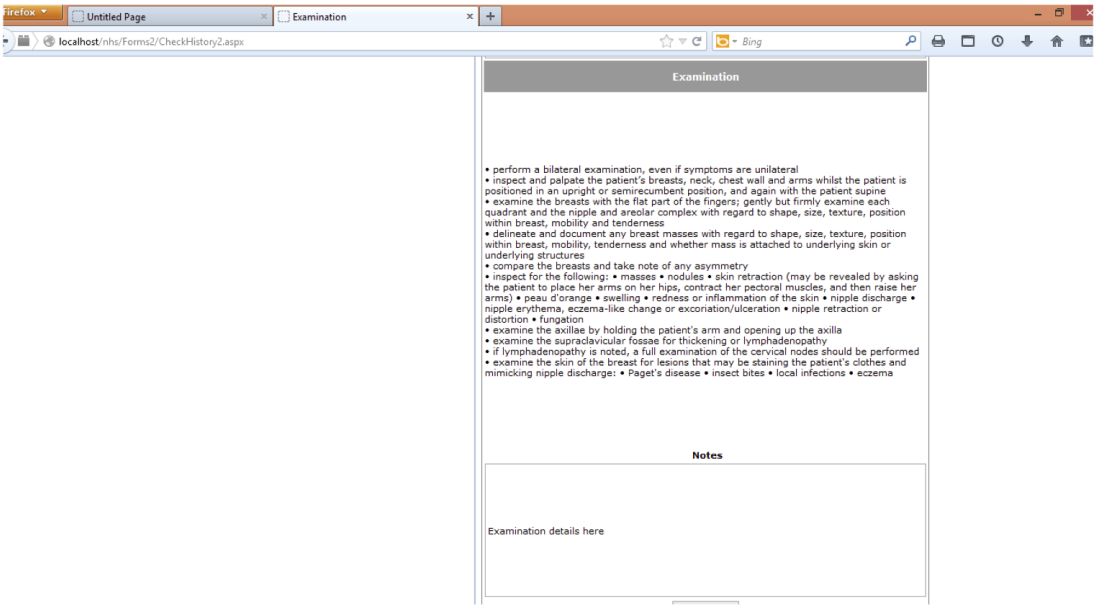

Figure J.11: Specialist records history information into SHarE.

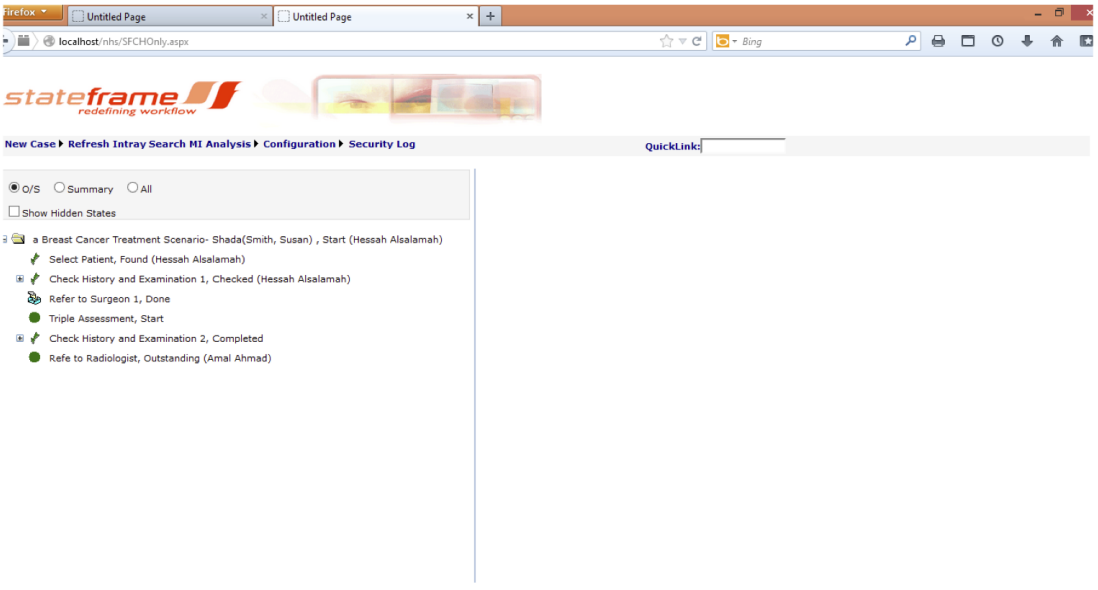

Figure J.12: Susan's case is automatically referred to the third care point.

J.0.3 Care point 3: Radiologist

The radiologist, Amal Ahmed, performs the ultrasound or a mammogram based on the patient's age. After she logs into SHarE and picks up Susan's case, she checks Susan's age, according to the ICP, if she is older than thirty five Amal performs a mammogram, otherwise an ultrasound is performed (Fig J.13). Since Susan is younger, Amal manually chooses ultrasound as shown in Fig J.14 (the system can automate this as well). Amal writes a report about the image, and presses done to refer Susan's case to the fourth care point to Kate Jones for a biopsy (Fig J.15).

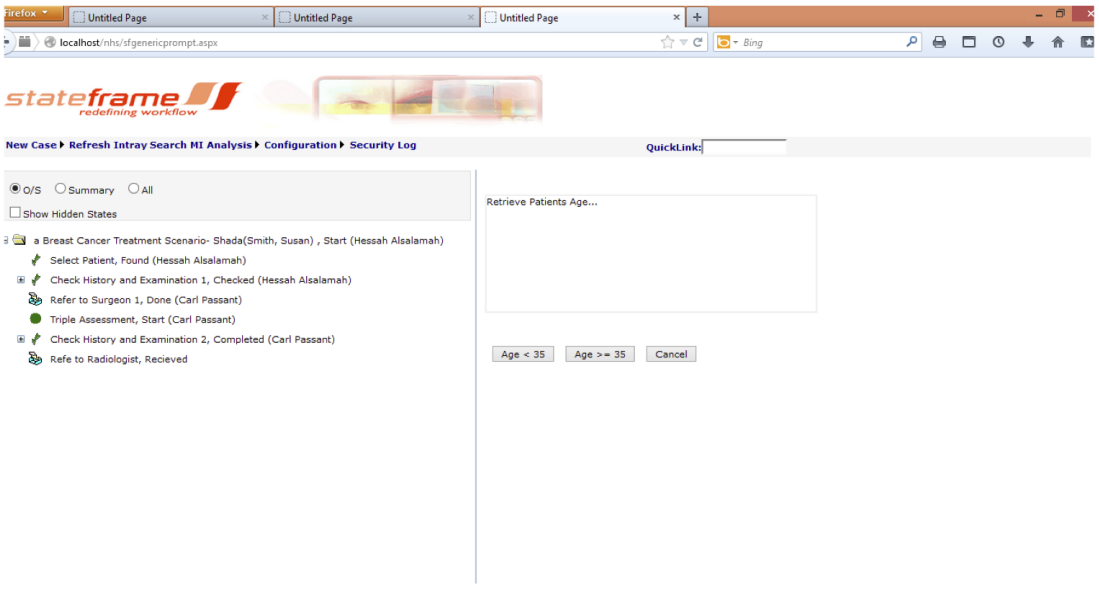

Figure J.13: Radiologist makes a decision on the image type based of Susan's age.

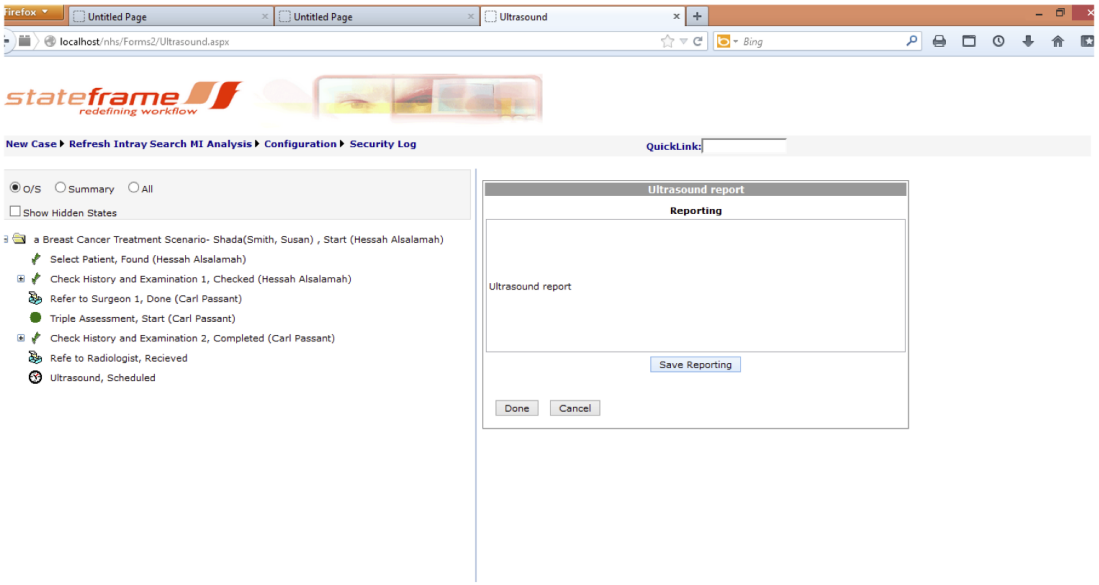

Figure J.14: Radiologist performs an ultrasound and writes a report in SHarE.

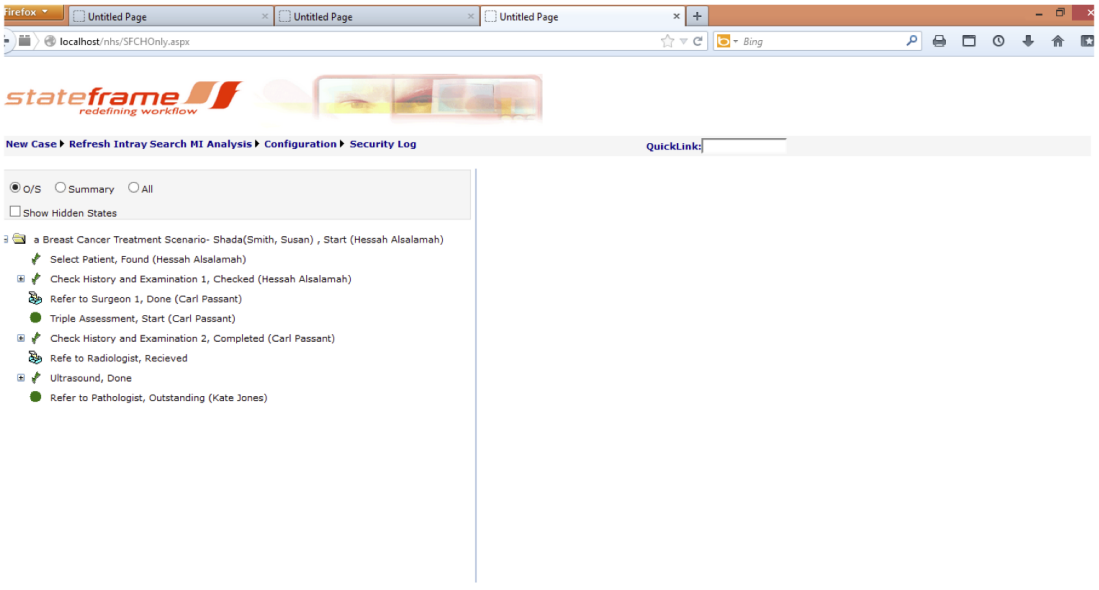

Figure J.15: Susan's case is automatically referred to the fourth care point.

J.0.4 Care point 4: Pathologist

Kate Jones, the pathologist, logs into SHarE and picks up Susan's case from her Intray. She reads through the referred information she needs then she performs a biopsy as part of the triple assessment, records information about Susan's tissue in SHarE as shown in Fig J.16, J.17. Once this is done, the triple assessment is over and Susan's case is ready to be discussed at an initial MDT review. Therefore, it is automatically referred to Claire Miles, the MDT coordinator, see Fig J.18.

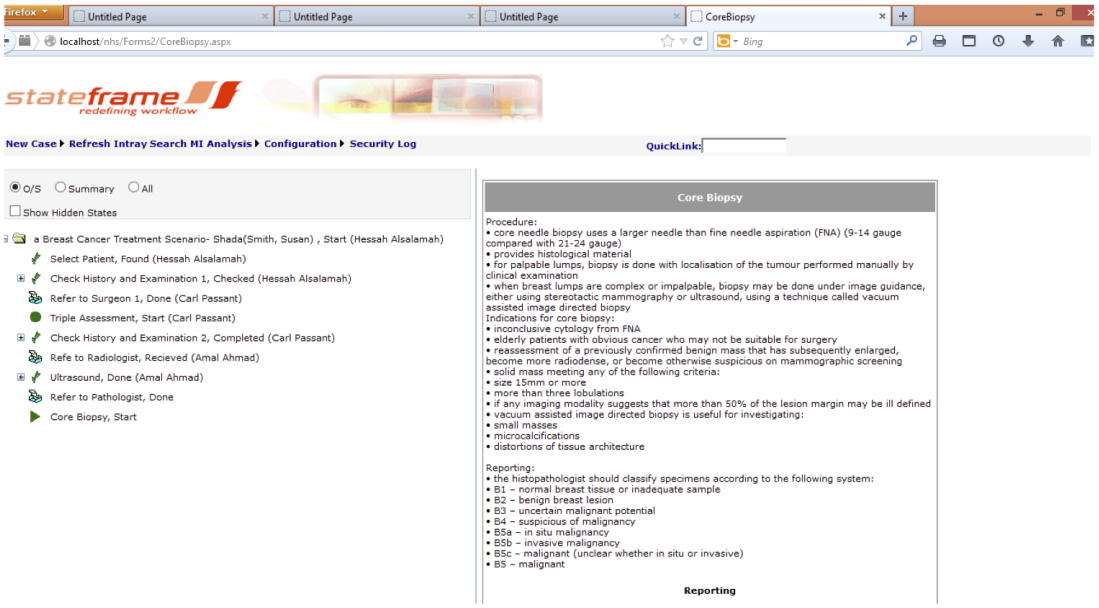

Figure J.16: Pathologist records information about Susan's tissue in SHarE- page1.

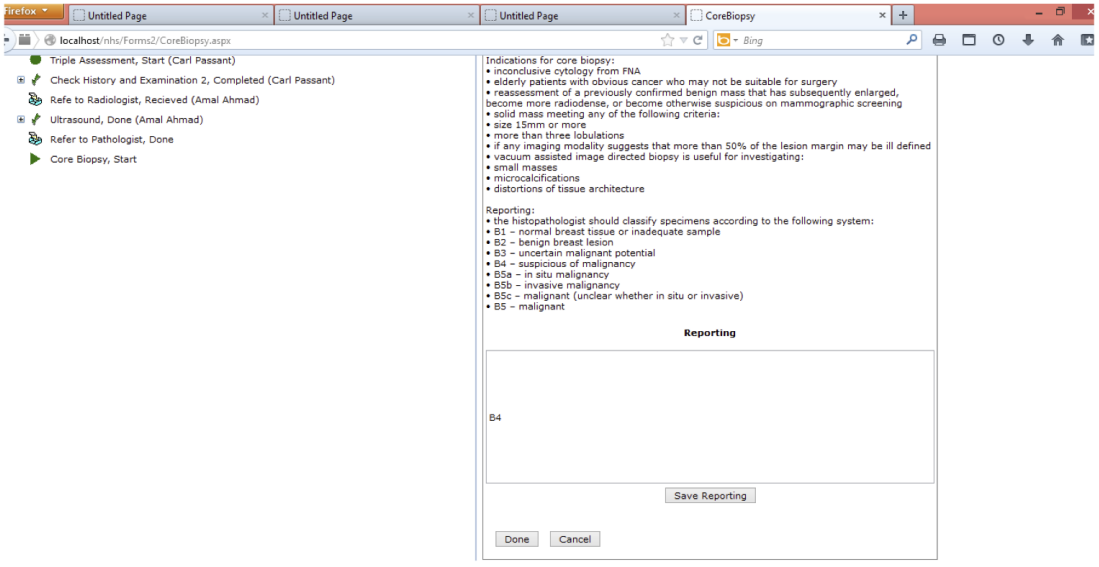

Figure J.17: Pathologist records information about Susan's tissue in SHarE- page 2.

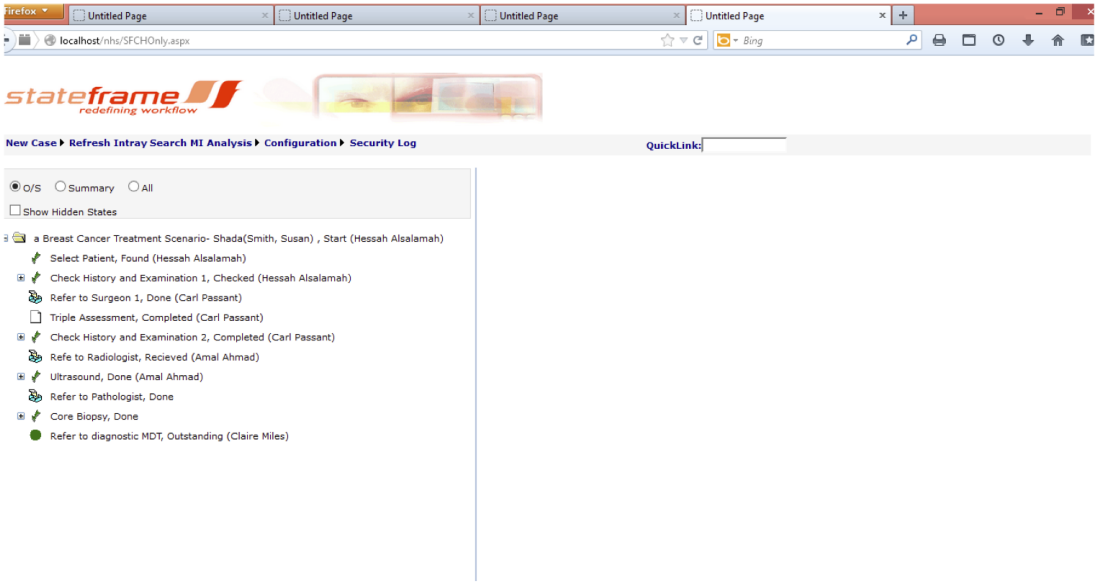

Figure J.18: Susan's case is automatically referred to the MDT coordinator to be discussed at the upcoming Initial MDT review.

J.0.5 Care point 5: Initial MDT

Claire Miles is the MDT coordinator, and after she logs into SHarE and picks up Susan's case, she can access all the information needed from the triple assessment see Fig J.19. She selects the information she needs by clicking on the button where the information is ready for her to see it. The first piece of information comes from primary care, if she needs to see any notes from the GP for example. The second piece is from secondary care from the specialist. Third is the biopsy results, and finally the imaging report. So she clicks on the right button then she sees the information that she wants.

Susan's case is discussed by the CT members in the review, who make a shared-decision about the treatment plan and the best treatment option for Susan based on the triple assessment results. Therefore, Claire writes down a treatment plan and selects the final decision button in SHarE whether it's malignant or not Figs J.20, J.21. Susan, like most cases in early breast cancer diagnosis, undergoes an operation as the first treatment option. Before the case is referred to a surgeon, the GP is informed (see Fig J.22) since GPs do not attend the MDT reviews. Finally, Susan's case along with the treatment plan is referred to the sixth care point (Fig J.23).

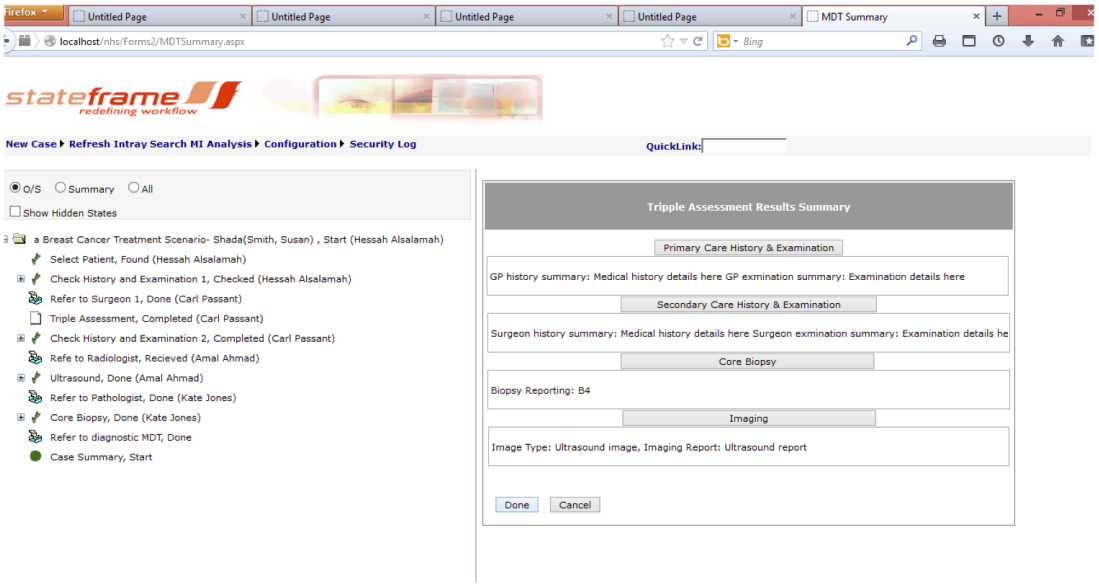

Figure J.19: MDT Coordinator selects treatment option for Susan (i.e. treatment plan) in SHarE.

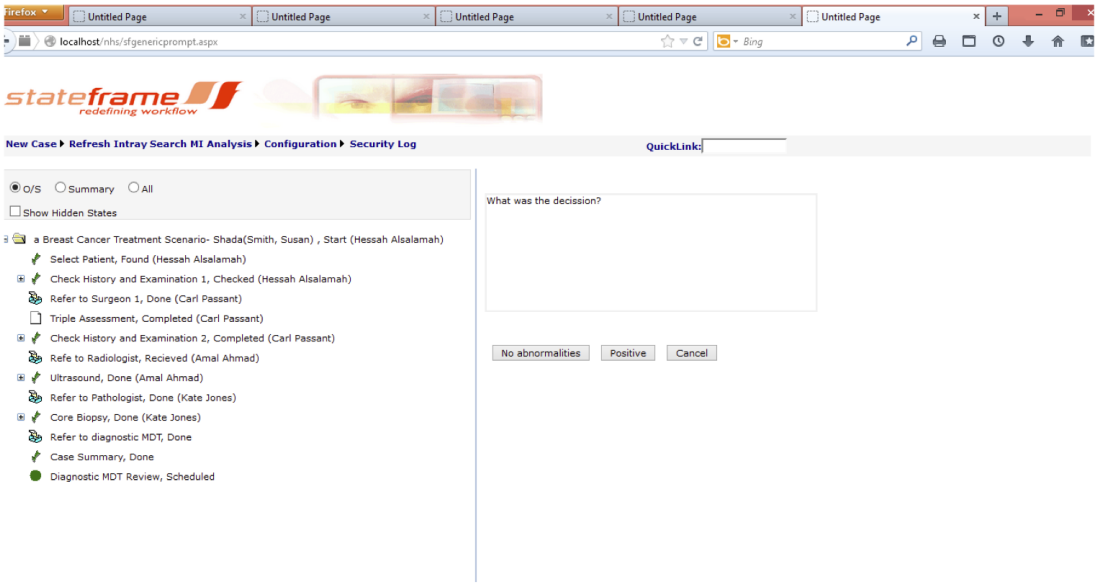

Figure J.20: MDT Coordinator accesses triple assessment results in SHarE for review discussion.

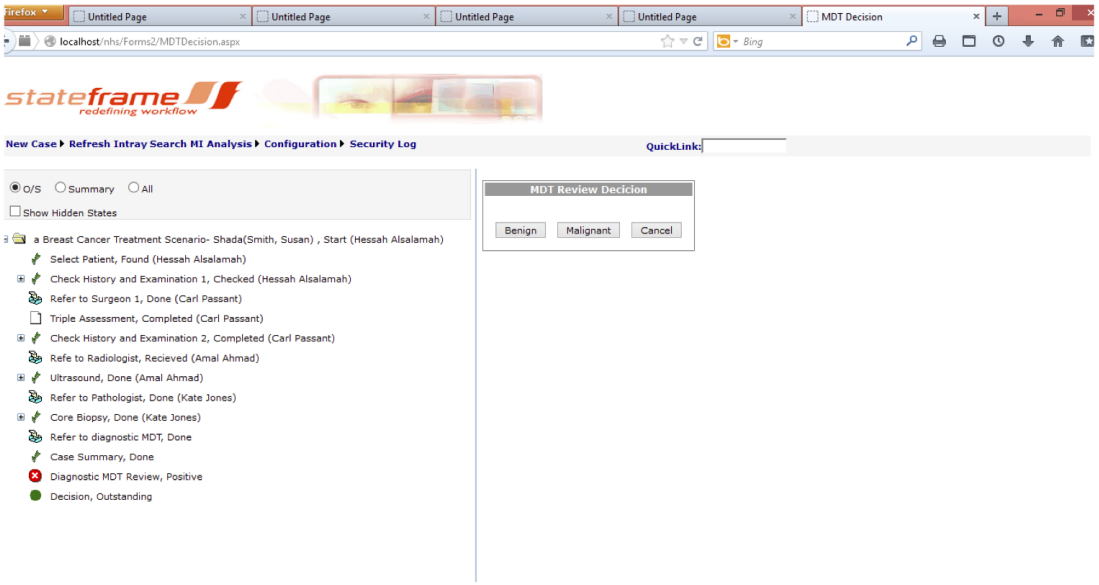

Figure J.21: MDT Coordinator selects treatment option for Susan (i.e. treatment plan) in SHarE- page 1.

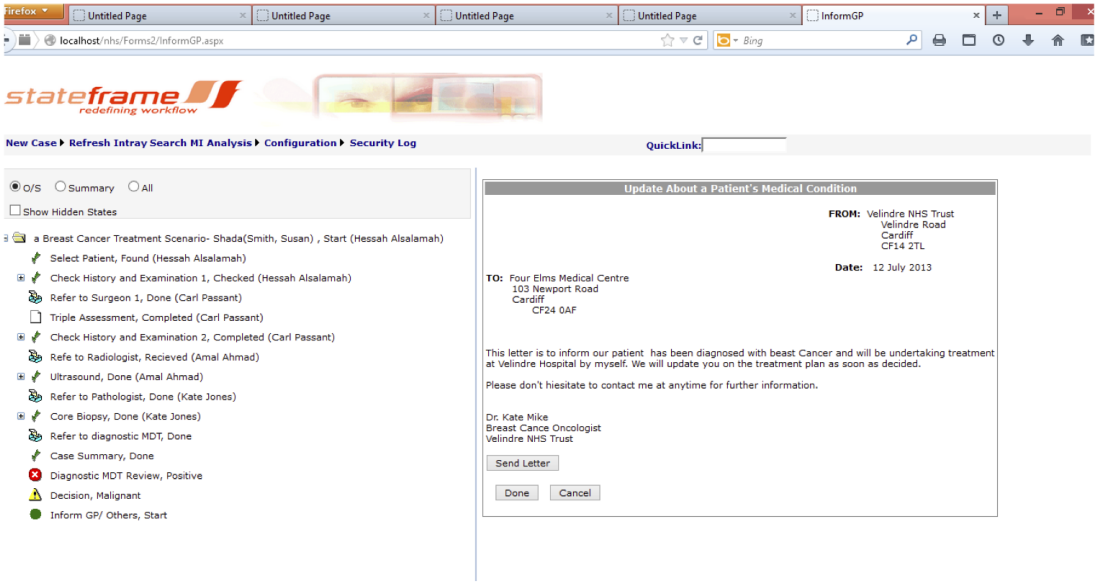

Figure J.22: MDT Coordinator selects treatment option for Susan (i.e. treatment plan) in SHarE- page 2.

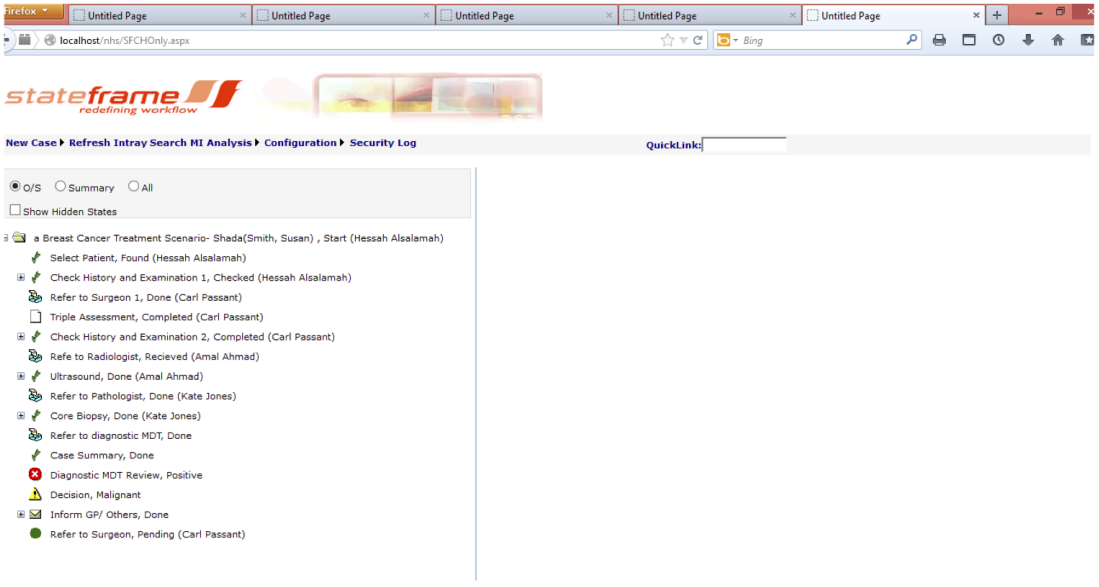

Figure J.23: Susan's case is automatically referred to a surgeon for operation.

J.0.6 Care point 6: Surgeon

Carl, the surgeon, performs an operation on Susan as planned for her at the initial MDT review. After that she logs into SHarE, picks up Susan's case, and writes a report about the operation and Susan's health status in Fig J.24. Once this is done, Susan's case is automatically referred to a post-operation MDT Fig J.25.

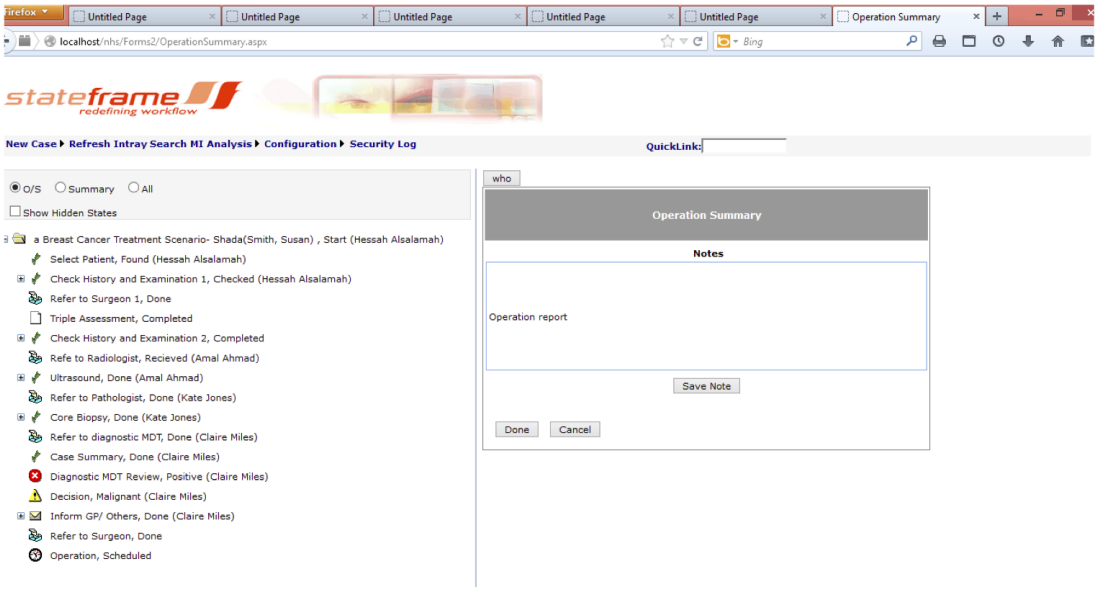

Figure J.24: Surgeon write a report about the operation in SHarE.

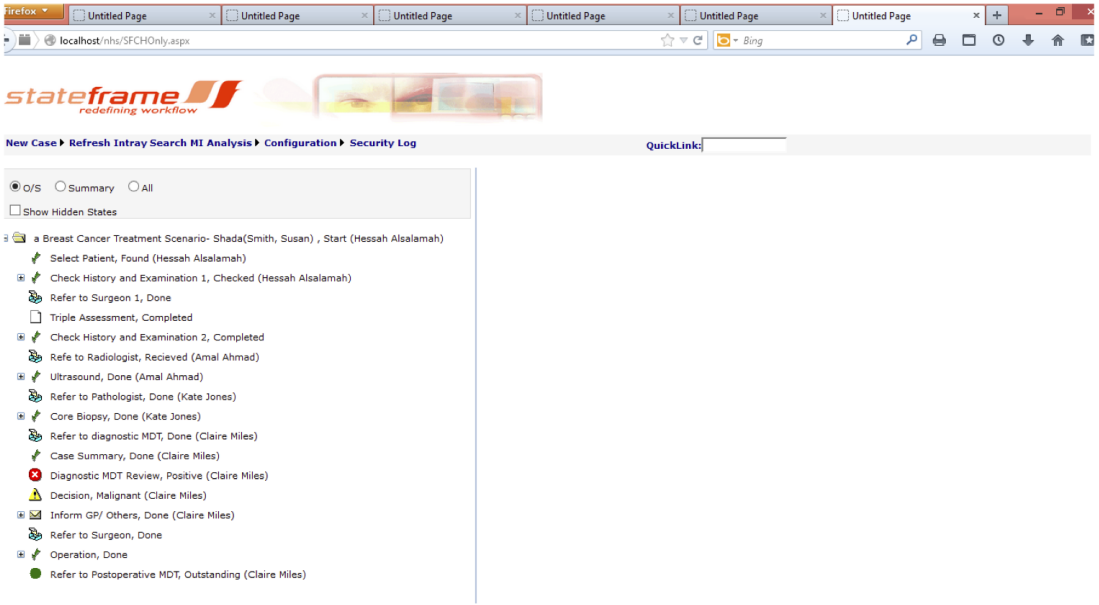

Figure J.25: Susan's case is automatically referred to a post-operation MDT review.

J.0.7 Care point 7: Post-Operation MDT

Claire logs into SHarE again at the time of the post-operation MDT review, picks up the case, accesses the operation report, and records the next treatment option to update the treatment plan, see Figs J.26, J.27. In this case chemotherapy is selected as the second treatment option. Finally, the case is referred to the oncologist see Fig J.28.

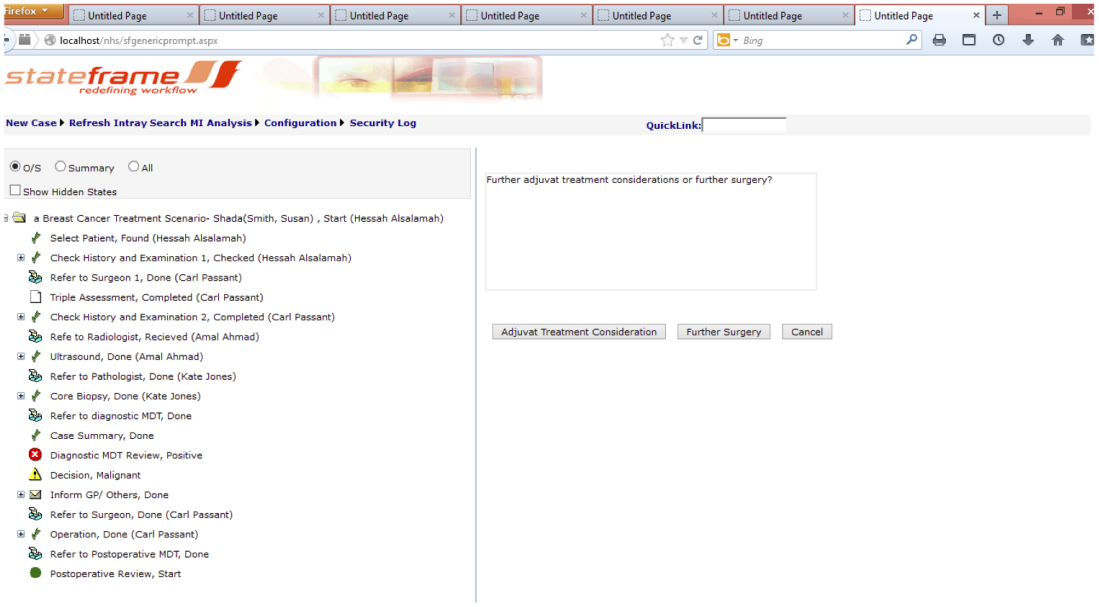

Figure J.26: MDT coordinator selects treatment option that is decided at a post-operation MDT review- page 1.

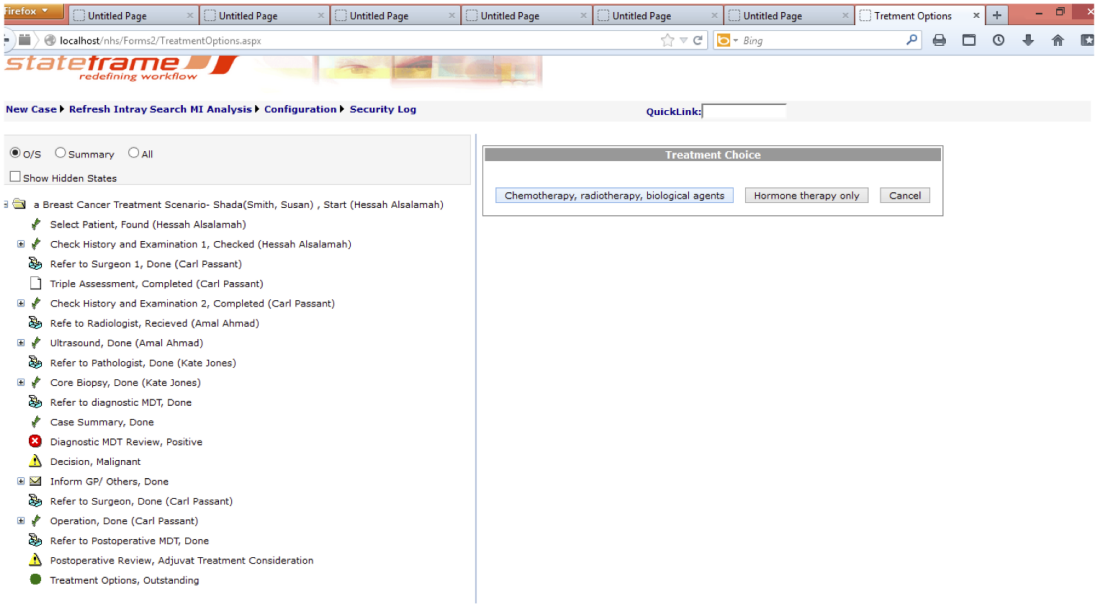

Figure J.27: MDT coordinator selects treatment option that is decided at a post-operation MDT review- page 2.

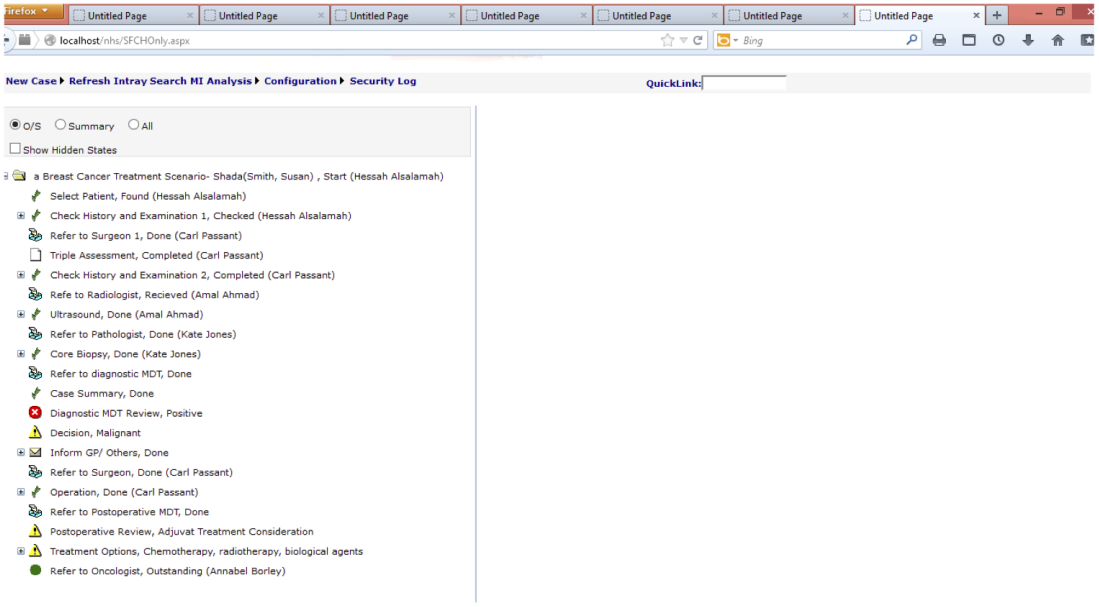

Figure J.28: Susan's case is automatically referred to an oncologist for chemotherapy.

J.0.8 Care point 8: Oncologist

Finally, Annabel Borley, the oncologist, treats Susan with chemotherapy and writes a report for every treatment session in SHarE as shown in Fig J.29. Once the treatment is complete and Susan fully recovers, then the treatment process is terminated as shown in Fig J.30.

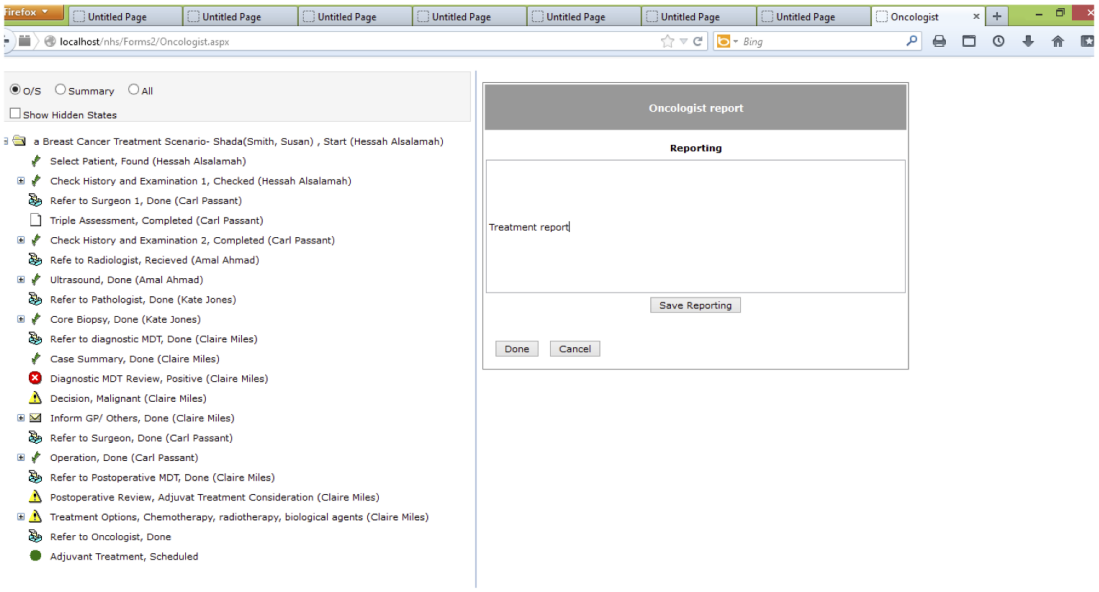

Figure J.29: Oncologist writes a report for every treatment session in SHarE.

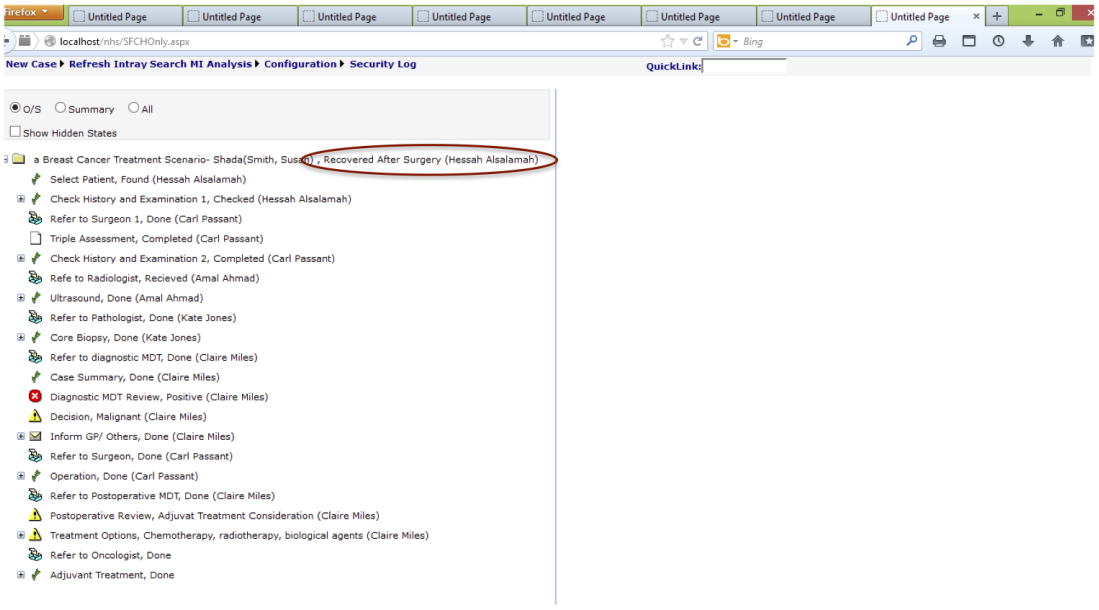

Figure J.30: Case is complete and closed after Susan's recovery.

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