A Holistic Analysis Approach to Facilitating Communication between General Practitioners and Cancer Care Teams

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This thesis is submitted in partial fulfilment of the requirement for the degree of Doctor of Philosophy

July 2006

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This work has not previously been accepted for any degree and is not being concurrently submitted in candidature for any degree. Parts of the thesis have been published, or have been submitted for publication in journals or conference proceedings, as detailed in the Bibliography under my name as lead author, or as a co-author in W. Ivins, O. Allam, H. Al-Salamah and W.A.Gray (2006).

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Summary

In the last decade, the healthcare delivery model for many diseases has been changing from a *disease centred approach* to a *patient centred approach,* where healthcare provision is tailored around an individual patient's needs. This is leading to a situation where many diseases are now being treated by multidisciplinary teams of healthcare professionals working across the three care sectors: primary, secondary and tertiary. This is known as an integrated care approach.

Cancer is recognised by the National Service Frameworks as a key model of the integrated care approach. This has meant that the information systems supporting the care process need to evolve to reflect these changes. Particularly, all members of the cancer care team, including GPs, should work together seamlessly and communicate in a timely and effective manner to maintain the continuity of cancer patient care and ensure it is delivered without unnecessary delay.

This thesis investigates the current situation in Wales against this changing scenario in order to identify the problems hindering the communication between GPs and other members of cancer care teams. It then specifies a new system to overcome these problems, and support the integrated care approach with a particular emphasis on the role of GPs in the care domain. This proposed system provides a common Electronic Patient Record System with the aim of supplying required information to all care sectors according to the needs and working practices of the clinicians in each care sector. It is demonstrated that this new system will give better support in the future to the team members than the current systems.

Acknowledgments

I must in first instance thank Professor Alex Gray, my first supervisor for all his support during this research, without his constant advice and enormous help this thesis would have not been completed. I must also thank Professor Nick Fiddian, my second supervisor, for his continuous encouragement and support.

I am also grateful to Velindre Clinical Information Unit for their kind accommodation and technical help throughout this project. Special thanks go to Dr. David Morrey, Dr Anthony Bater, Mrs Wendy Jones, Mrs Hazel Bailey and Mrs Dawn Alan who all provided me with insight knowledge of the South East Wales Cancer Network, and being very supportive co-authors.

I am also grateful to Mr. Steve McIntosh who kindly spared hours of his valuable time teaching me SSM and more importantly changed my thoughts to a system thinker.

I must also acknowledge the thirty five stakeholders who significantly contributed to this work; kindly spending hours of their time discussing the models presented in this thesis and encouraging the progress of my project.

Thanks go to all members of the Healthcare Computing Scientific Program Committee who always kept me busy refereeing papers, assessing bursary applications and chairing sessions at the conference.

I am particularly grateful to my colleagues at the Knowledge and Information Systems research group specially Dr Mikhaila Burgess and Dr Wendy Ivins who nicely played dual role being very supportive friends and critical colleagues who enriched my work with their discussions. I am also very grateful to Ben Sissons and Anas Tawileh for the productive debates that shaped my ideas and for being providing constant support. Many thanks also go to Sarah Jenkins-Jones for her great support.

Special thanks go to my friend Helen Philips who very patiently listened to me during the hard times and supplied lots of coffee and chocolate.

I must not forget Mrs Margaret Evans who was always a continuous support and she also managed very successfully to arrange many unexpected meetings with my very busy supervisor. Mrs Pat Ryder and Mrs Elaine Slater who both encouraged and supported me. Mrs Tracey Lavis who never failed to cheer me with her big smile.

I am very grateful to my friends, Mona Baiuomy, Salwa Azuz and Rabab Saleh for all their support to me and my family, especially during the hard times.

At last I must say that this project could not have been accomplished without the constant support of my family, my parents who gladly travelled to the UK many times to support me and look after my children, my very supportive husband Maged who always encouraged my career and fully appreciated the difficulties I passed through during this project, and my daughters Menna and Yomna who never showed any interest in the health informatics research, however they nicely accepted the fact that I had to be away for many hours because I am doing important work.

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List of Abbreviations

BASO	British Association of Surgical Oncology
BCS	British Computer Society
CaNISC	Cancer Network Information System Cymru
CC	Cancer Centre
CCs	Cancer Centres
CIF	Cancer Information Framework
CM	Conceptual Model
CPTM	Consensus Primary Task Model
CSCG	Cancer Services Coordinating Group
CSEC	Cancer Services Expert Group
CRW	Cancer Research Wales
CUs	Cancer Units
DFD	Data Flow Diagram
DGHs	District General Hospitals
DoH	Department of Health
EHR	Electronic Health Record
EPR	Electronic Patient Record
EPRS	Electronic Patient Record System
ERDIP	Electronic Record Development and Implementation Program
ETHICS	Effective Technical and Human Implementation of Computer-based Systems
FSM	Formal System Model
GEHR	Good European Health Record
GP	General Practitioner
GPs	General Practitioners
HIMandTD	Health Information Management and Technology Division
HISS	Hospital Information Support System
ICRS	Integrated Care Record Service
IS	Information Systems
IT	Information Technology
ISAC	Information Systems work and Analysis of Changes

ISCO	Information System for Clinical Organisations
LHBs	Local Health Boards
MDTs	Multidisciplinary Teams
NCR	National Care Record
NELH	National Electronic Library for Health
NHS	National Health Services
NICE	National Institute for Clinical Excellence
Pal C	Palliative Care
PAS	Patient Administration System
PEPRS	Proposed Electronic Patient Record System
PCO	Primary Care Oncology
PMC	Planning, Monitoring and Control activities
RD	Root Definition
RDs	Root Definitions
SHAs	Strategic Health Authorities
SSADM	Structured System Analysis and Design Methodology
SSM	Soft Systems Methodology
SUHT	Southampton University Hospital NHS Trust
UML	Unified Modelling Language
WAG	Welsh Assembly Government
WCISU	Welsh Cancer Intelligence and Surveillance Unit
WCTN	Wales Cancer Trial Network
WfMS	Workflow Management System

Chapter One

Introduction

1.1 Research background

The NHS modernisation in the last decade [62], has led to changing the healthcare delivery model from a *disease centred approach* towards a *patient centred approach* where healthcare provision is tailored around an individual patient's needs [106].

As a result, the cancer care process has moved from a traditional approach that focused on oncologists and surgeons only, towards an integrated care approach that involves a full range of healthcare professionals working in the primary, secondary and tertiary care sectors.

This change has coincided with the growing acceptance of a policy that whenever possible cancer patients should have treatment in their local environment because treating locally rather than in a remote central institution reduces the patient's and the family stress levels.

All these factors have evolved and enhanced the role of General Practitioners (GPs) in the cancer care process and encouraged their participation in preventing, diagnosing, treating and following–up cancer.

Hence, in an ideal situation all members of a cancer care team, including GPs, should work together seamlessly and communicate in a timely and effective manner to maintain the continuity of patient care and ensure it is delivered without unnecessary delay.

However, while members of cancer care teams in Wales, apart from GPs, currently share a cancer patient's information in almost real time via an electronic Wales-wide cancer network information system [23, 33, 98, 129]. GPs do not have access to this system. They instead have to communicate with other team members via posted mail, which can take up to two weeks to reach its destination. During this time a clinical situation may change dramatically and the information received may be radically out of date when it arrives at its destination, either the GP or the other care team member [Personal Communication 3 to 5, 9 to 18].

This thesis will investigate the current situation to identify the problems hindering the communication between GPs and other members of cancer care teams in Wales and specify a solution system to tackle the identified problems.

1.2 Research hypothesis and aims

This project is influenced by the author's relatively unique position, as she played dual roles being practitioner and researcher, this is described by SchÖn [145] as a reflective practitioner role. Her experience of the user domain gained by her previous work as a hospital doctor for seven years provided her with a profound understanding of the medical care process. Additionally, her recent academic training in the computing domain enabled her to investigate the problem domain as a system designer to identify different possibilities and thereby reveal many technical issues in the current systems.

The main goal of this project was to facilitate the communication between GPs and other members of cancer care teams in Wales. Hence, we investigated how other projects tackled the communication problems in the healthcare domain with the aim of identifying an appropriate method to undertake our project. Developing an Electronic Patient Record System (EPRS), to be shared by all members of a cancer care team in Wales, was the chosen approach to overcome the limitations of the current communication between the two groups. The research presented in this thesis proposes a solution system which satisfies the identified system requirements and specifies the system's functional, behavioural and structural aspects.

It is hypothesised that:

'‘A holistic analysis approach that investigates the whole cancer treatment journey in Wales and addresses both human (soft) and technical (hard) aspects of the requirements will identify a more complete set of requirements in comparison to the traditional analysis approach that investigates certain treatment stages and addresses the technical aspects of the requirements only’.

The aims of the research are:

1. To use a holistic analysis approach to investigate the whole cancer treatment journey in Wales, while taking account of the human and technical aspects of the requirements.
2. To determine the key information that must be communicated between GPs and other members of cancer care teams in Wales.
3. To specify a system which overcomes the communication problems inherent in the existing system, thereby helping solve these problems.

1.3 Research achievements

The main achievements of this research were:

- Specifying a new system that can overcome the limitations of the current communication between GPs and other members of cancer care teams in Wales (see section 2.8).
- Specifying a shared system that provides information across the three healthcare sectors (see sections 5.3, 5.4 and 5.5). This system showed that information could be provided to all care sectors according to the needs and working practices of the clinicians in each care sector (i.e. it tackled the lack of a shared system that information required by potential users’ across the healthcare spectrum).
- Utilising the soft system approach within the cancer care domain to address the (soft) human aspects of the requirements, this provided a way to resolve conflicting requirements by addressing and accommodating different

viewpoints (as detailed in section 4.4). These conflicts and differences arise because staff from different healthcare sectors have different view points, and even within a sector there can be differences of perspectives.

- Determining the GPs key clinical activities at each stage of the cancer treatment pathway (see section 4.5) and identifying the information required to support these activities. These were agreed with the thirty five stakeholders having various roles in the cancer care domain in Wales (GPs, cancer specialists, practising and research nurses, managers and IT professionals) [Personal Communication 1 to 35] (see section 4.6). This provides an embryonic Primary Care Cancer Dataset for Wales [18].
- Creating a holistic analysis approach tailored to meet the needs of the problem domain by selecting and combining techniques from existing system analysis methodologies so that the whole cancer treatment pathway is investigated; and both soft (human) and hard (technical) aspects of the new system requirements were considered.

1.4 Research scope

Information systems in the health care domain usually handle two types of information:

- Clinical information; required by clinicians to support clinical activities and provide evidence for decision making. This is usually labelled and stored as patient records, medical records or case notes.
- Management information; required by managers for planning, delivering and monitoring health services. This is usually referred to as management information and handled by management information systems. Examples of such systems are: Patient Administration systems (PAS) [138], finance systems [86] and resource management systems [77, 137].

With the agreement of Cancer Research Wales who funded this project, we decided to limit our work to clinical information. This decision did not affect the

thesis conclusions because the proposed EPRS will be used by healthcare staff and not by administrative staff.
We also focused on providing the necessary information at this stage (i.e. the information required to support key clinical activities) to avoid information overload and to allow time to overcome many cultural and organisational challenges facing the emerging clinical discipline of Primary Care Oncology (PCO) [18].

1.5 Thesis structure

The thesis consists of seven chapters which cover the following aspects of the work:
Chapter one introduces the research.

Chapter two explains the emerging role of GPs in the cancer care process and emphasises the need to improve the communication between GPs and other members of cancer care teams in Wales. It also explains why we decided to evolve the current Wales-wide cancer network information system to tackle the communication gaps between GPs and other members of the care team.

Chapter three reviews different approaches to information systems development and explains why a traditional, based around a combination of the waterfall and evolutionary models, was chosen for this project. It describes the work undertaken using this approach. It then highlights the limitations of continuing the system development in this way, investigates alternative approaches and concludes that a holistic analysis approach is required for this project's domain of research.

Chapter four explains in detail how a holistic analysis approach which investigated the whole cancer treatment journey and achieved a consensus view of the problem under investigation was adopted to identify the information requirements. It also investigates the problems that hindered the provision of the required information.

Chapter five describes how the holistic approach was employed to specify the requirements. It reviews different specification techniques, described in the software engineering literature, and explains why UML modelling techniques were selected in this project. It describes the use of UML use cases to specify functional requirements; UML activity diagram to specify behavioural requirements and UML class diagrams to specify structural requirements.

Chapter six evaluates the achievements of the research against the hypothesis. This was undertaken in a number of ways including: assessing the use of both traditional and holistic analysis approaches as well as assessing the attainment of a more complete set of requirements.

Chapter seven assesses the achievements against the research aims, describes the contribution to research and highlights possible areas for future work.

Chapter Two

Communication between GPs and Cancer Care Teams

2.1 Introduction

This chapter gives an overview of the healthcare system in the UK. It describes how healthcare delivery is moving towards an integrated approach involving the three care sectors (primary, secondary and tertiary), and the impact of such a move on the communication between various healthcare providers.

It focuses on cancer care as an example of the integrated care approach. It highlights the growing role of General Practitioners (GPs) in cancer care and discusses the necessity to facilitate communication between them and other care team members. It then investigates different ways of facilitating communication in the healthcare domain to identify the best available solution for tackling communication problems between GPs and other members of cancer care teams in Wales.

2.2. Brief outline of the UK healthcare system

Healthcare in the UK is delivered by two systems: the National Health Service (NHS) and the private healthcare sector. The National Electronic Library for Health (NELH) states:

> "The standards of clinical care are generally the same in the two systems but private patients can see the specialist of their choice at a time convenient to them" [121].

The majority of UK patients are cared for by the NHS which provides health services free of charge at point of delivery[1] to all UK residents regardless of their ability to pay[121].

In addition, there are many voluntary organisations that provide physical and moral support to patients and their families, whose aim is to improve their quality of life.

The NHS is not a single organisation but a loose confederation of different autonomous units e.g. thousands of independent GP practices, pharmacies, hospitals and clinics. It operates through three sectors of care: primary, secondary and tertiary.

- **Primary care** refers to the care provided by GPs –also known as family doctors - and other healthcare professionals (e.g. health visitors, district nurses and midwives) who provide the first point of contact[2] for non-emergency medical conditions.
- **Secondary care** refers to common specialist services (e.g. general medicine, paediatrics and general surgery) provided in general hospitals.
- **Tertiary care** refers to highly specialist services (e.g. Cancer Centres (CCs)) provided on a regional basis by one of the large hospitals or a specialist centre.

GPs are self employed in either single handed or group practices. They usually deal with the vast majority of medical problems presented to them, as the government plan Improving Health in Wales reveals:

> "More than 90% of people who use the health service do so through primary care" [166].

When special care is required, a patient gets referred to a specialist in the secondary or tertiary care sectors. Under this system secondary and tertiary care hospitals (uniformly managed by the NHS Trusts) act as healthcare providers in

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[1] Paid for by taxes.

[2] People injured in accidents or suffering an acute illness usually go straight to one of the hospital accident and emergency units situated across the country.

an internal market. Whereas GP practices (independently managed) [65] [1] act as purchasers of specialist services within given budgets. A detailed description of the NHS structure and management is included in Appendix A.

2.3 Healthcare modernisation: towards an integrated care approach

In the past, each healthcare speciality (i.e. provider) used to work independently and deliver treatment in isolation. Accordingly, an individual patient might have received different treatment packages not in optimal agreement with each other (e.g. although certain medication can work well in isolation, combining them may result in an adverse reaction). Following the White Paper 'The New NHS' [62], the healthcare delivery model changed from a *disease centred approach* towards a *patient centred approach* where healthcare provision is tailored around an individual patient's needs [106].

This was followed by the NHS-Wales White Paper 'Quality Care and Clinical Excellence: NHS Wales' [165] that highlighted the need for further collaboration between healthcare providers and recommended additional work to achieve greater consistency of availability and quality of services at the national level.
This has led to the development of National Service Frameworks for medical conditions recognized by the UK government as having the highest priority. These include cancer, child health, coronary heart disease, long term conditions, mental health, older people and renal services [5, 6].

As a result, the conditions mentioned above and many other diseases are currently treated by multidisciplinary teams of healthcare professionals working together to deliver multiple collaborative services that help people to remain in control of their treatment and live independent lives. For instance, a diabetic

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[1] Under the regulation of the Strategic Health Authorities (SHAs) in England [8] and the Local Health Boards (LHBs) in Wales [123]

patient is jointly treated by a multidisciplinary team (MDT) which includes a diabetic specialist, a dietician and his/her GP [3]. Haemophilia is frequently treated by a haematologist and a physiotherapist working in collaboration with each other.

2.4 Impact of integrated care on communication between healthcare providers

In earlier decades, as healthcare providers used to work independently, each speciality within an organisation had its own clinical information system [46]. These ranged from paper collection exercises, through to spreadsheets and stand alone databases (known as uni-provider[1] Electronic Patient Record System (EPRS)). This resulted in heterogeneous EPRSs using a variety of software applications within the same organisation. For instance, an EPRS in the pathology department was different from an EPRS in the radiology department of the same hospital. Often a patient's information was inaccessible to all healthcare professionals involved in the care.

In the 1980s, the growing interest in improving communication and reducing administrative work culminated in the start of a movement to integrate different electronic information systems within the same hospital [162]. An example is the Hospital Information Support System (HISS) project by the Department of Health in 1988 [163]. This project aimed at integrating all operational areas within the same hospital.

In the 1990s, the multidisciplinary care approach required the establishment of robust communication links between team members working in different care sectors:

> "Care delivered by a variety of providers does not, in itself, constitute team care. A functional team is characterised by regular communication among its members" [3].

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[1] An EPRS used by one department is known as a uni-provider system, while an EPRS used by more than one department is known as a multi-provider system

As a result EPRSs expanded to provide information to various providers in order to allow timely and consistent information sharing between them. These systems are usually known as multi-provider EPRSs.

Examples of multi-provider EPRSs are:

- **The Good European Health Record (GEHR) project (1991-1995).** This involved 21 participating organisations in seven European countries [55, 80].
- **Oxford GP links project** [66, 71]. This system connected 30 GP practices in 1991 to the John Radcliffe Hospital EPRS to provide access to pathology reports.
- **The Southampton University Hospital NHS Trust (SUHT) Hospital Integrated Clinical Support System** [46]. This system has provided a clinical intranet, since 1998, to communicate pathology results of diabetic, renal failure and vascular surgery patients between hospital departments and primary care clinicians.

Despite the existence of many multi-provider EPRSs, none as yet supports complete sharing of information across the healthcare spectrum [135], as Rashbass states:

> "Currently, health information is held as a mixture of paper based and computer records that can't easily be shared. Even records held electronically are effectively 'locked away' on computers that can't talk to one another" [7].

More recently, national initiatives to investigate and pilot the feasibility of a single comprehensive care record system have appeared with the aim of building one health and social care record for each individual from birth to death [7, 13, 78, 79, 82, 130, 139, 140, 161]. It is anticipated that this single care record will improve communication between healthcare providers by facilitating information sharing between them.

> "The NHS Care Records Service will allow information to be shared safely across the NHS. For the first time ever there will be a central record of a patient's care" [7].

2.5 Cancer care: key model for integrated care

> "More than one in three people in England will develop cancer during their lives. One in four will die of it. So, better prevention, detection, and treatment of cancer matters to us all" [1].

Cancer is still a major killer in the UK. It is the second[1] cause of death in England and Wales[75]. It accounts for 25 percent of the identified causes of death in Wales [166].

The Department of Health (DoH) estimate that 200,000 people are diagnosed with cancer every year in England [63] and the Welsh Cancer Intelligence and Surveillance Unit (WCISU) state that on average 14,700 new malignancies are registered per year in Wales [168].

It is not a single disease; but can develop from any cell type, hence presents in different ways and at different stages. Both the disease and its treatment can cause severe complications. Despite developments in its treatment, and improvements in its mortality rates over recent years, it still represents one of the main health challenges in Wales:

> "Cancer, coronary heart disease, diabetes, mental health services, children, oral health, and old age are all highlighted as being the major challenges faced by the NHS in Wales" [166].

2.5.1 Cancer care: last decade

Prior to 1995 cancer outcome was relatively poor in the UK compared to other developed countries [83]. Furthermore, cancer services varied widely across the country [47]. A full revision of cancer services in England and Wales took place in 1995 aiming to improve cancer outcome and provide equitable cancer care. This is detailed in the Calman-Hine report[2] [47]:

> "We must do everything we can to ensure that those who do develop the disease have access to skilled and appropriate treatment delivered promptly and with humanity" [47].

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[1] Circulatory diseases (coronary heart disease and stroke) were the first cause of death (39 percent).

[2] The Calman Hine report is a report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales to outline the direction in which cancer services in England and Wales should be developed.

The report outlined the directions in which cancer services in England and Wales should be developed to ensure high standards of care. As the report states:

> "The aim of this report is to create a network of care in England and Wales" [47].

It acknowledges that establishing cancer networks that link the three care sectors (primary, secondary and tertiary) will facilitate the attainment of a uniform high standard of care for cancer patients wherever they live. Although the report called for the creation of cancer networks, it did not include details of how this should be done.

Wales followed in 1996 with the Cameron Report [48] that included the Welsh plans for implementing the Calman-Hine recommendations. The Cancer Services Coordinating Group (CSCG)[122] was established in 1997 to guide the development of the cancer networks[1].

In 1999, cancer was identified as a 'top priority condition' by the National Service Frameworks [5, 6] and new resources were committed to its treatment and care. In 2000, the Department of Health (DoH) published the NHS cancer plan [63] which set out the first ever national strategy to reorganise and rejuvenate cancer services in the UK. This cancer plan re-emphasised the need for cancer networks as it pointed out:

> "Cancer networks will be the organisational model for cancer services to implement this Cancer Plan" [63].

Table 2.1 summarises the impact of these strategies on the cancer care process in Wales.

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[1] A Cancer Network brings together -through partnership working- the organisations, both NHS and non-NHS (voluntary and private) involved in commissioning, planning and providing cancer services to the population it cover [127]]

Date	Event	Target			Outcome	The impact on the care process in Wales
		Healthcare in general	Cancer care in the UK	Cancer care in Wales		
1995	Calman Hine report [47]		√		A framework for improving cancer care delivery. It recommended that cancer services should be organised at three levels: primary, secondary and tertiary care	- Called for establishment of cancer networks to link primary, secondary and tertiary care - Emphasised the *central* role of GPs in the care process
1996	Cameron report [48]			√	A plan for implementing the recommendations of the Calman-Hine Report in Wales	Cancer networks were no longer viewed as an optional choice in Wales and the Cancer Services Coordinating Group (CSCG)[122] was established in 1997 to guide the development of these networks
1997 1998	The White paper 'The New NHS' [62] The White Paper 'Quality Care and Clinical Excellence: NHS Wales' [165]	√			A basis for a ten year programme to renew and improve the NHS was formed. - Establishing the 'integrated care' model - A proposal for the development of national frameworks	The healthcare delivery model is changed from a *disease centred approach* towards a *patient centred approach*

Date	**Event**	**Target**			**Outcome**	**The impact on the care process in Wales**
		Healthcare in general	Cancer care in the UK	Cancer care in Wales		
1999 /2000	The development of the National Service Frameworks [5] [6]	√			Agreed long term strategies for improving specific areas of care	Cancer was identified as a 'top priority' condition and new resources were committed to its treatment and care
2000	The NHS cancer plan [63]		√		The first ever national strategy to reorganise and rejuvenate cancer services.	- Emphasised further need for cancer networks. - Widely recognised the important role of GPs in the care process and recommended lead clinicians for cancer in the primary care group.

Table 2.1: The impact of the strategic policies on the cancer care process in Wales

As a result of these reports cancer care is currently provided by multidisciplinary teams of healthcare professionals working across the three care sectors. For instance, a cancer patient may receive a package of care including surgery (delivered by secondary care) and chemotherapy (delivered by tertiary care), with a follow up by the GP (primary care). Figure 2.1 demonstrates the different organisations currently involved in the cancer care process in Wales.

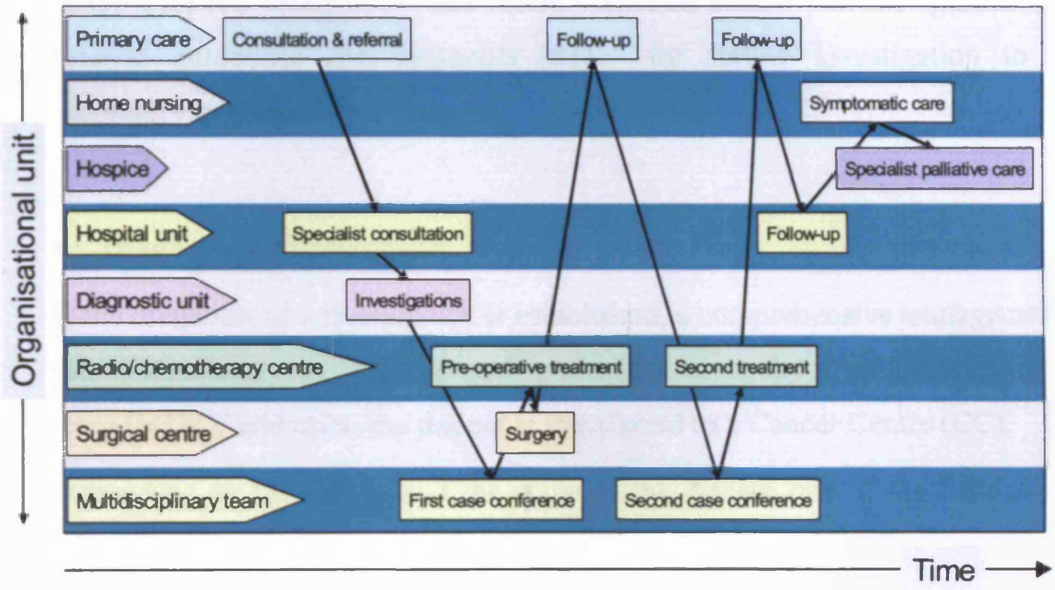

Figure 2.1: Illustrative 'journey' of a cancer patient in Wales showing many health events across organisations and over time [11]

2.5.2 Patient treatment pathway

In Wales, cancer care is currently provided by three Cancer Networks, each based around a Cancer Centre (CC) which delivers tertiary care. They are:

- South East Wales Cancer Network based at Velindre NHS Trust in Cardiff [127].
- South West Wales Cancer Network based at Singleton Hospital in Swansea [128].
- North Wales Cancer Network based at North Wales Cancer Treatment Centre in Rhyl [126].

The usual pathway for cancer patients in the three Cancer Networks in Wales is fairly consistent, however it must be emphasized that exceptions are possible.

The common cancer treatment pathway in Wales can be described as follows [20, 24, 90]:

- **Referral stage**

> "For cancer to be diagnosed, people must pass through a number of stages. Having first recognised that there is a problem, almost all go to their GP, who must decide whether there is a possibility of cancer and refer them to a hospital consultant" [4].

A GP suspects malignancy and refers suspected cancer patients -guided by referral guidelines and protocols [81] - for further investigation to a secondary or tertiary care hospital.

- **Diagnosis and treatment**

If the diagnosis of a malignancy is established, a comprehensive management plan individually tailored for each patient is set up by a multidisciplinary team (MDT)[1] and often the patient is transferred to a Cancer Centre (CC).

Depending on the nature and the stage of the disease one of the following happens:

A If the condition is curable, the individual management plan is discussed with the patient. When agreed, appropriate treatment is offered. This would consist of surgery, chemotherapy and radiotherapy individually or in combination in an appropriate sequence.

B If the disease is incurable, Palliative Care referral would be made aiming at achieving the best possible quality of life for patients and their families [9]. GPs are at the heart of this process.

> "It is well documented that most people with cancer would prefer to die at home... GPs and district nurses tend to take on a more active role when patients are terminally ill, visiting them and their families" [12].

- **Follow up**

Treated cancer patients need long term follow up. This is provided by both the cancer specialist and the GP [41, 94].

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[1] An MDT includes specialist doctors, nurses, and other professions allied to medicine (e.g. pharmacist, dietician and social worker).

2.6 Impact of integrated cancer care on communication

Before the publication of the Calman-Hine [47] and the Cameron [48] reports cancer care was mainly provided by oncologists. Therefore the only existing cancer EPRS[1] in Wales at the time (the Information System for Clinical Oncology (ISCO)) provided information to the local oncology department [33, 38]. Communication between oncologists and other healthcare professionals who may get involved in a cancer patient's care (e.g. surgeons) was maintained by letters and telephone conversations.

With the introduction of the integrated multidisciplinary care approach and the development of cancer networks, the ISCO system grew and expanded to become a multi-provider EPRS. This allowed almost-real time communication across the networks. As the system crossed organisational boundaries, its name was modified to 'Information System for Clinical *Organisations*'.

Since 1997, the system has expanded and is able to support linking cancer care team members working at secondary and tertiary care sectors (see Figure 2.2). it even provides links to other specialities (e.g. movement disorders). It then expands to become a Wales-wide cancer network information system (the Cancer Network Information System Cymru (CaNISC)) [129] that records and distributes the information identified in the Cancer Information Framework (CIF) [81]. The ISCO/CaNISC system is currently in use by:

- Oncologists [23, 33, 150].
- MDTs [23, 33].
- Palliative care [23, 33, 35, 117].
- Wales Cancer Trial Network (WCTN) [23, 33-35].

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[1] Despite the availability of many electronic cancer information systems in Wales at the time, ISCO was the only one used for clinical purposes. Other systems were used for administrative and management purposes

- Colposcopy[1] Service [23, 32, 33, 35, 51].
- All-Wales Cancer Genetics Service [23, 33].
- Wales Cancer Bank [33, 112].
- WCISU Cancer Registry [33].
- Breast Screening [33, 35].
- Wales Movement Disorders e-Network [33].

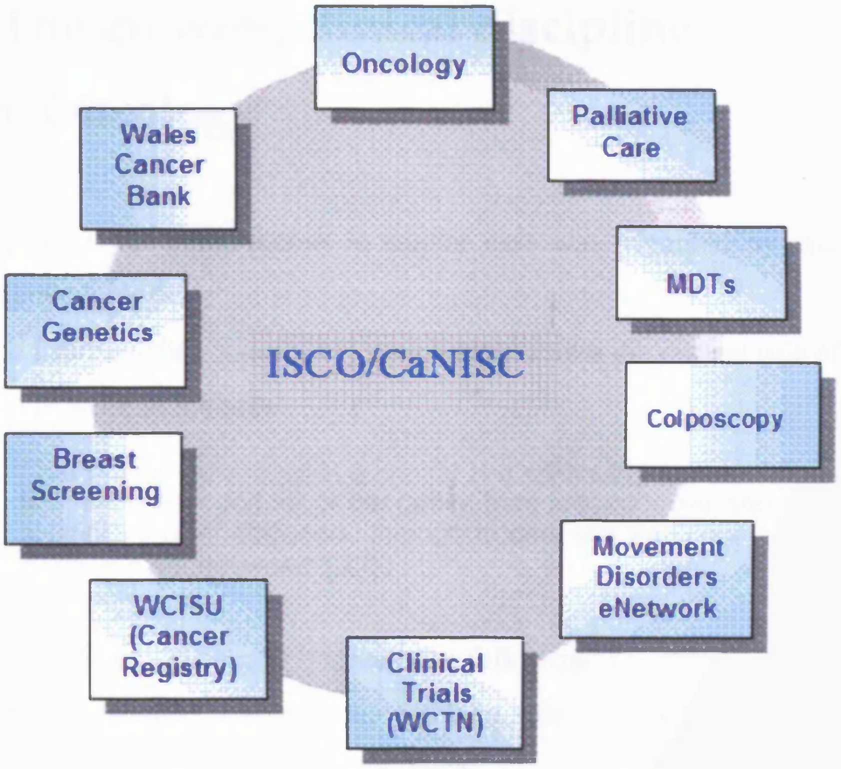

Figure: 2.2 Current users of ISCO/CaNISC [99]

When the ISCO system started to expand in the 1990's across and between different secondary and tertiary care organisations there was a common view that GPs did not need access to the cancer information system as they did not diagnose or follow-up a significant number of cancer patients:

> "An average GP sees only two new cases of skin cancer and only one new case each of breast and colorectal (bowel) cancer per year. Furthermore, a GP will see a new case of leukaemia only once every five years, one brain tumour every seven years and one testicular cancer every twenty years" [146].

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[1] The method of examining the vagina and cervix by means of the binocular instrument known as the colposcope. It is used to screen for cancer of the cervix

This view has gradually changed over the last decade and the role of GPs in this field has been expanding. With this greater involvement, the weak communication links between them and other cancer care team members became evident. Still, GPs in Wales have no access to the current ISCO/CaNISC system.

> "As cancer care continues to shift to the community and away from hospitals, it will become even more important that all health care providers involved in care of cancer patients have sufficient information to fulfil their unique roles" [41].

2.7 The growing clinical discipline 'Primary Care Oncology'

The growing GP participation in cancer care was triggered by many strategic documents, including:

- The Calman-Hine report [47] which emphasizes the central role of GPs in the care process as it states:

  > "The primary care team is a central and continuing element in cancer care, for both the patient and his or her family, from primary prevention, pre-symptomatic screening, initial diagnosis, through to care and follow-up or, in some cases, death and bereavement" [47].

- The NHS cancer plan [63] covers the following:
  - It noticeably confirms the growing role of GPs in the care process, as many sections of the plan reveal:

    > "There have been undoubted improvements in service delivery, but there is still a sense that progress has been patchy and that much has yet to be achieved.....primary care teams have been insufficiently involved in shaping cancer services.....primary care will play a central role in the new cancer networks".

  - It re-emphasizes the need for GP's and other care team members' involvement:

    > "People with cancer spend much more of their time living in their own home than in a hospital or hospice. GPs, district nurses, social services, home nursing services and community specialist palliative care teams provide essential support for patients and their families at different times".

  - It establishes a policy that whenever possible cancer patients should have treatment in their local environment because treating locally rather than in a remote central institution reduces patients' and their families' stress levels.

- The National Service Framework Work Assessments NO.1: 'NHS Cancer Care in England and Wales' [12] that highlights many roles of GPs in the care process as shown in Table 2.2. This table illustrates the involvement of GPs throughout the treatment journey.

The role of GPs in cancer care continues to grow [49, 136] as their participation in preventing [143, 158], diagnosing [87, 94, 143] and following-up cancer [41, 87, 94] is encouraged.

Lewis [108] identifies the key stages for GPs in a cancer patient's treatment journey. These include:

- Early detection and referral of suspected patients.
- Providing support for the patient and family at the time of the diagnosis.
- During the treatment, a GP provides follow up. If a cancer patient suffers any other medical problem his/her GP represents the link between the cancer specialists and the other specialists involved in his/her treatment.
- If palliative care is needed, then the GP is heavily involved with the patient and his/her family.

Stage:	**Initial contact and referral**	**Diagnosis and options for treatment**	**Treatment and care**	**Palliative and terminal care**	**Monitoring and follow up**
What might happen	• discussion of symptoms causing concern • routine screening tests • examination in A&E	• tests: - scans – CT, MRI - x-ray - endoscopy - pathology (eg blood test) • information and advice • discussion of options	• radiotherapy • chemotherapy • surgery • counselling/ psychological support • information	• palliative treatment eg non curative drug or radiotherapy treatment • therapy eg physiotherapy • counselling/ psychological support	• tests (scans, x-ray, pathology) • check up
Where	• ***GP surgery*** • A&E unit • screening service • home – may receive information/advice by post, internet or phone from voluntary or NHS organisations	• hospital • ***GP surgery*** • home – information/advice from voluntary or NHS organisation	• hospital • home • clinics • ***GP surgery***	• hospital • home • hospice • private hospital /nursing home	• ***GP surgery*** • Home • Hospital outpatient clinic

Stage:	**Initial contact and referral**	**Diagnosis and options for treatment**	**Treatment and care**	**Palliative and terminal care**	**Monitoring and follow up**
Who may be involved	• ***GP*** • practice nurse • A&E staff • screening service staff: radiographer, nurse, doctor	• oncologist • surgeon • physician • specialist nurse • radiographer • radiologist • pathologist • ***GP***	• oncologist (clinical or medical) • surgeon • specialist nurse • allied health professional (e.g. physiotherapist, dietician) • ***GP*** • palliative care nurse • palliative care doctor • social worker • psychologist or counsellor	• palliative care nurse • palliative care doctor • social worker • community nurse • psychologist or counsellor • allied health professional (e.g. physiotherapist, dietician) • ***GP*** • radiotherapist • radiographer	• ***GP*** • surgeons • physicians • oncologist • specialist nurse • pathologist • radiographer • radiologist

Table 2.2: Different roles of GPs according to the National Service Framework Work Assessments NO.1 [4].

2.8 Primary Care Oncology: communication challenges

In an ideal world, all members of a cancer care team working across the primary, secondary and tertiary care sectors should work seamlessly to provide patient care.

> "Cancer care in many countries is delivered by various partner organizations, often with complementary functions. Providers' failure to communicate effectively can threaten cancer patients' care" [41].

As they all have important complementary roles to play in the early diagnosis and optimum treatment and long-term care of a cancer patient [148], they need to share information in an appropriate manner that supports the care process. The need for robust communication between GPs and other cancer care team members has been recognised by the NHS cancer plan as it points out:

> "GPs need ready access to up to date information on the investigation, treatment and care of patients with cancer" [63].

In reality, however, the quality of information transferred between GPs and hospitals has for long been a contentious issue [17, 84]. It presents a fundamental challenge to the value and safety of patient care [124].

GPs regularly complain about the consistency of and the delay in providing information from hospitals [131], the National Service Framework Work Assessments NO1 points out:

> "Hospital discharge is not always undertaken with proper planning, so that GPs and district nurses can be unaware that a patient has gone home, sometimes without necessary services or equipment being arranged" [4].

For their part, hospitals are equally critical about the inadequate and incomplete information given in GP referrals [136].

Our investigations identified the existence of three main problems in the communication between GPs and other members of cancer care teams. This section provides examples of the identified problems.

2.8.1 Delays in information transfer

In England, although cancer patient information is usually stored electronically in the GP and oncology EPRSs, computerised hospital letters and discharge summaries cannot normally be sent to GPs electronically; instead they have to be printed and sent in paper format. Primary care staff have to scan them back into a patient's electronic record. Majeed and Lusignan [109, 111] question the waste of time and the possibility of mistakes being introduced in scanning hospital correspondence into GP computer systems.

Additionally, a recent study of discharge and outpatient's letters from the Wellington Hospital to 12 local GPs between June and August 2003 revealed a significant delay in information flow from the hospital to GPs [103].

In Wales, as explained in section 2.6, members of cancer care teams *-apart from GPs-* are currently communicating via the Wales-wide cancer EPRS (the ISCO/CaNISC system) in almost real time. GPs do not have access to this system. They instead have to communicate with the rest of the team members via posted mail[1] which can take up to two weeks to reach its destination. During this time a clinical situation may change dramatically and the information received may be radically out of date when it arrives [Personal Communication 3 to 5, 9 to 18].

2.8.2 Lack of a shared system to provide the required information

The lack of a shared system that provides the information identified by potential users as appropriate was highlighted by the Information for Health Strategy in 1998 [124]. This has not been addressed as each healthcare organisation still collects, records and maintains its patient information in different ways [85, 156]. The information currently shared between a GP and other members of a cancer care team is inconsistent. It does not follow laid down guidelines, but varies

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[1] Occasionally they communicate via faxes or telephone depending on the two parties being available at the same time [96]

widely according to the collecting or producing healthcare professional's preference. [Personal communication 1 to 18, 27, 28].
Despite many projects to integrate the ISCO/CaNISC system with other existing secondary and tertiary care EPRSs e.g. integration with the North Glamorgan Telepath pathology system [74], none of these projects have yet attempted to integrate the system with primary care. This is mainly due to the considerable diversity -in design and implementation- between primary and secondary/tertiary care systems based on the different needs, roles, and clinicians working patterns in each sector as illustrated in Table 2.3.

Recently, this has been addressed in England in the Connecting for Health initiative which is a technically focused project aiming to provide a single health record for every NHS patient from birth to death [78]. This is an ambitious project which if successful will create a common record structure to link the three care sectors. The proposed structure for this single record has not been fully defined yet, but there are indications that it will be similar to our proposal [19]. This means that our conclusions will not be affected if Wales adopt this system in the future, as it will be possible to transfer our record contents easily to the single care record.

	Primary care	**Secondary and tertiary care**
Role	▪ Treating a known patient with any combination of problems ▪ Providing first contact, continuous, comprehensive and coordinated care [110]	▪ Treating selected patient with a specific problem ▪ Providing special care with a defined beginning and end
Focus of treatment	▪ Any combination of problems that have to be dealt with simultaneously [85]	▪ Specific disease episode related to his/her speciality [85]
Clinicians' need	▪ Chronological and general overview of information about all illnesses affecting the patient	▪ In-depth focused information about the illness being treated for this patient
Presentation style	▪ Free text style [85]	▪ Structured record e.g. filling in a form [85]

Table 2.3: Diverse EPRS requirements in the different care sectors

2.8.3 The information to be shared is not identified yet

A Canadian study assessing communication between cancer specialists and GPs showed that cancer specialists' letters do not satisfy GPs' information needs because they often lack important information while frequently containing unnecessary details. The study concludes that further work is needed to tackle the information problems [37]. In another Canadian study, Braun et al [41] argue that the information supplied by oncologists at a regional cancer centre to family physicians caring for palliative cancer patients is often insufficient.

In Latina, Italy a 20 month survey that involved 60 GPs and a District Hospital oncology team (four oncologists and two nurses) revealed that 30% of the GPs experienced major problems in communication with the hospital team, mainly due to the lack of detailed information in the discharge letters and difficulties in telephone correspondence [57].

In Sweden a study involving twenty GPs aimed at exploring what information they wanted in contrast to what they received indicated that the information received from the specialist cancer clinic is insufficient [94]. It recommended an extended information routine was required to facilitate the expanding role of GPs in cancer care.

In the UK, the National Service Framework Work Assessments NO.1: 'NHS Cancer Care in England and Wales' warns:

> "GPs' ability to discuss the diagnosis and prognosis with patients is often hampered by lack of information from consultants ......GPs could sometimes lose track of patients during the treatment period, due to lack of information from consultants" [12].

In Wales, the Cancer Services Coordinating Group (CSCG) that operates at an all Wales level published the Cancer information Framework (CIF) [81] in year 2000 to address information requirements of different care teams. This framework focused on the information requirements of the secondary and tertiary care sectors as an immediate priority. Although the information requirements of primary care were referred to as an important parameter (section 42 of the framework), it was not addressed in the framework due to time and resource constraints.

As yet there is no Primary Care Cancer Dataset in Wales. It is envisaged that its development will take some time [Personal Communication 7, 8]. Adapting the English Primary Care Cancer Dataset [10] was not feasible, as England and Wales are taking different approaches to the collection and provision of the required cancer information. The English approach includes a comprehensive range of the clinical information items, the collection of any of them is not mandatory. Moreover, there is no one recommended system for the information collection. Whereas the Welsh approach is to define a minimal amount of information that must be collected and provide a recommended IT system to ensure consistency. It is felt that the English Dataset is so comprehensive that a full set of data is unlikely to be collected [Personal Communication 24].

2.9. Tackling communication gaps in healthcare

The last section highlighted many of the limitations in current communication between GPs and other members of cancer care teams. This section reviews several projects aimed at tackling these communication problems between different healthcare providers, in order to identify an appropriate way to tackle communication problems between GPs and other cancer care team members in Wales.

2.9.1 Reducing the delay in information transfer

Oral communications and outreach clinics (i.e. consultants seeing patients in a general practice setting) are used in many small scale projects [36, 141]. However in our situation although this approach can improve the timeliness of the information flow, the availability of GPs and other secondary/tertiary care team members at the same time is hard to ensure. Additionally, using outreach clinics on a regular basis has not proved to be a practical solution [40] due to the high costs of outreach in comparison with outpatients' clinics, when a patient is seen in a secondary/tertiary care hospital.

Telephoning systems [114], alphanumeric pagers [133], emails [67, 105], faxes [116], whiteboard [72] and teleconferences [84, 91, 92] are also advocated as technologies which can provide solutions. However with respect to the situation under investigation:

- They only offer a partial solution as we will still need a database system to document and store the communicated information.
- They do not always ensure the consistency of the communicated information because they do not mandate a standardised formula to collect information, and there is no method for enforcing the quality and content of the message.

Sharing an Electronic Patient Record System (EPRS) is used in many projects [43, 46, 56, 64, 68, 115, 118, 169] to facilitate communication between different healthcare providers. The use of shared EPRSs is usually preferred in large scale projects as it improves the speed of information flow as well as providing a database system to record and maintain the communicated information.

2.9.2 Identifying and standardising required information

Many projects have been aimed at identifying and standardising the required information to ensure consistency in collecting, recording or maintaining clinical information. This can be done in different ways and at many scales, as in the following examples:

- The English Dataset Project [2] has defined lists of individual data items - each with a clear label, definition and set of permissible values - to support many types of treatment journey including: Cancer Datasets, Child Health Dataset, Child and Adolescent Mental Health Services Dataset, Coronary Heart Disease Datasets, Diabetes Datasets, Maternity Dataset and Mental Health Minimum Dataset.

- A minimum HIV data set defined to support the management and monitoring of patients with HIV and their care programs in developing countries to enhance the accuracy, efficiency, and availability of information [164].
- A terminology management system to formally represent items of a basic data set for paediatric oncology to facilitate data sharing for nationwide clinical research in a multi-hospital environment [104].
- A standardised template to guide oncologists at a regional cancer centre dictating letters to family physicians for a cancer patient's follow-up visits [41]. Using this template resulted in an improvement in the relevance, timeliness, format and amount of information shared.

In our situation, identifying the required information will offer a partial solution to the problem as we will still need to ensure the provision of this information where and when it is required.

2.9.3 Focusing on certain treatment stages

Nowadays, with the move to multidisciplinary care teams, many healthcare providers are involved in the treatment of a patient for the same disease. Tackling the communication between all members of this team is not an easy task. Therefore, many projects have chosen to focus on selected treatment stages instead of looking at the whole treatment pathway. For example [46, 88], focused on improving the access to pathology and laboratory test results. While [144] focused on improving the communication between GPs and hospitals when patients are discharged from hospitals to their GPs. The Informing HealthCare project [125] is another example of a project which looked at the referral and discharge stages only.

In the situation we are investigating (cancer care in Wales), GPs are involved throughout the treatment journey (see Table 2.2). Therefore focusing on a certain treatment stage will provide a limited solution to the communication problems between GPs and other care team members. If the focus is purely on the transfer stage when a patient is discharged from hospital to GP then it will make it difficult for a GP to undertake some of the roles due to lack of information.

2.10 Overcoming communication gaps in Wales

In this project, the development of a shared EPRS to link GPs to other cancer care team members appeared to be the best available solution to tackle the identified communication problems in Wales, see section 2.8. This section explains why an EPRS is an appropriate solution and discusses how this system will be developed.

2.10.1 A shared Electronic Patient Record System

After investigating different ways of facilitating communication between healthcare providers, we decided that a shared EPRS between GPs and other cancer care team members is the most appropriate solution to our situation, as it will tackle the identified communication problems in Wales by providing a long term solution which:

- Reduces the delay in the information flow.
- Ensures a standardised way of collecting and recording the information.
- Provides a shared system to provide the required information to clinicians working at the primary, secondary and tertiary sectors.
- Defines the information communicated between the GPs and other care team members in an agreed format.

2.10.2 Evolutionary versus revolutionary development

In developing our system we have two options:

A. To create a radically new EPRS *(revolutionary development)*, or

B. To extend the existing ISCO/CaNISC system to primary care *(evolutionary development).*

Both choices are compared, with respect to our situation, using the following criteria:

- **Resources**

As Jones [95] indicated, the NHS management faces many competing demands on its limited resources, consequently tradeoffs between expectations and what can be delivered within the available resources would seem inevitable. Moreover, it would appear from his review, that IT investments are not necessarily perceived as a prime management aim:

> "Some of the best rated hospitals –as measured by NHS star rating- have few or no significant hospital-wide electronic records system, while some of the leaders in electronic records implementation have achieved lower star rating" [95].

In our situation, the creation of a new system to link GPs to the wide range of organisations involved in the care process (see Figure 2.1) requires a vast amount of resources. On the other hand, as the ISCO/CaNISC system is already in use by most of these organisations, expanding this system to primary care will require fewer resources.

- **User training and support of work practices**

The ability of technology to support work practices and the provision of adequate user training are recognised as key determinants for the successful introduction of a new EPRS [93, 102, 151].

The evolutionary development will allow time to enable the technologies to be incorporated in current work practice and aligned with clinical agendas while staff are trained to use them. Furthermore evolving the current system will benefit from using the ISCO/CaNISC training material already in place which will only need modification to cover new aspects. While in a radical development approach both hospital specialists and GPs will be unfamiliar with the new technology and will need some training. Additionally the current system has already addressed many of the information needs of hospital specialists, evolving this system would improve the information available to different care team members without causing information overload and unnecessary extra work.

- **Cultural and organisational challenges**

Despite the growing recognition of GPs role in cancer care, the clinical discipline Primary Care Oncology (PCO) is still facing many cultural and organisational challenges [18]. For example:

- GPs are isolated, poorly informed and rarely attend MDT meetings nor do they usually get involved in determining the treatment plan [Personal Communication 8, 18].

- GPs see a small number of cancer patients at any time whereas hospital specialists are encouraged to specialise and see larger numbers of site specific cancers.
- Clinical trials are essential for informing and updating a clinician's knowledge; however GPs currently have little or no involvement in cancer clinical trials, whereas hospital specialists have a whole network support mechanism through the Wales Cancer Trials Network (WCTN).

The evolutionary approach would help in addressing these challenges, as Gowing et al point out:

> "An EHR is not only an electronic record. It can be a political catalyst for change that can unlock hidden tension" [76].

In contrast, introducing a radically new system in this environment may add to the complexity of the situation and increase tension as the hospital staff may feel that introducing the new system to enable GPs involvement has caused an increase in their workload as they had to learn about the new system and possibly change tried and tested working practices.

- **Capability of current system to evolve**

The ISCO/CaNISC system has shown its ability to evolve as it has expanded over 15 years from a system initially developed to meet the information needs of a single department – the oncology department at Velindre hospital - to a Wales-wide cancer information system in use successfully by every cancer unit in Wales [97, 98]. Moreover, it has demonstrated its ability to accommodate different diseases in addition to cancer e.g. movement disorders.

As it already serves as an integrated care record with no identified problems - through a common 'front-end' that provides timely information to different users on a strictly need to know basis [19] - we envisage the same will happen when the system is extended to primary care.

All these factors encouraged us to adopt an evolutionary development approach and expand the ISCO/CaNISC system to primary care as our chosen methodology.

2.11 Conclusions

The NHS modernisation in the last decade has resulted in the delivery of healthcare services through multidisciplinary teams working across a wide spectrum of the care skills available through the NHS. This is known as an integrated care approach. This thesis focuses on the cancer domain as an example of the integrated care approach in our investigation into how information systems can be defined to support this changing delivery.

This chapter discussed the emerging role of GPs in the cancer care process and highlighted the need for timely and effective communication links between them and other care team members in order to enable continuity of cancer care.
It revealed many limitations in the communication between the members of care teams in the UK and in other countries, and addressed in more detail the limitations in Wales.
It then investigated how other projects have tackled communication problems in the healthcare domain, and argued that evolving the current ISCO/CaNISC system to primary care will provide the best available solution to overcome these limitations in the Welsh context.

Chapter Three

A Traditional Approach to Requirements Analysis

3.1 Introduction

While developing the required system, we have been aware of the complex nature of our project, which is caused by a number of factors:

- The complex structure of the NHS[1].
- The involvement of multiple users who have diverse skills and work in different healthcare sectors.
- The difficulty of identifying the new system requirements; as the GPs role in the care team is still in an emerging and evolving stage.

We also recognised the complementary nature of different information system analysis approaches [134, 152], and the need to use a combination of more than one approach in the same project to incorporate the strengths of each of them and to overcome weaknesses [61, 134, 152].

Therefore different approaches were investigated and a traditional approach, based upon a combination of the waterfall and the evolutionary models, was utilised in the investigation.

Despite the advantages of this approach, barriers and constraints still appeared to have limited our requirements' analysis[2] and risked reducing the acceptability of the proposed system by some users. This meant that we had to revisit the analysis approaches to get a fuller picture of the requirements.

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[1] It is not a single organisation but a loose confederation of different autonomous units e.g. thousands of independent GP surgeries, pharmacies, hospitals and clinics.

[2] The reasons for this are discussed in section 3.4.

This chapter explains our initial approach to conducting the requirements analysis and discusses its strengths and limitations. It also demonstrates the need for a holistic analysis approach that addresses both human (soft) and hard (technical) aspects of the proposed system while investigating the whole cancer care pathway in Wales.

3.2 Approaches to requirements analysis

The term 'requirements analysis' has a number of definitions in the software engineering literature [42, 134, 152]. In this thesis we consider analysis as the process of investigating the problem domain, identifying the problems that require solution in this domain and specifying a solution system to tackle the identified problems.

A review of the literature identified different approaches to requirements analysis [27, 29, 134, 152]. This section discusses the potential strengths and limitations of the use of some of these approaches in our project.

3.2.1 Ad hoc approach

An ad hoc approach does not use an explicit methodological procedure, but depends on the system developers to do what they assume will create a suitable design. It relies on their knowledge, skills and past experience to inform the determination of the requirements and the specification of the solution system. It was widely used in the pre-methodology era of system design when information system development was a technically oriented process, i.e. the main emphasis was towards programming and less emphasis directed to users and organisation needs [27, 167].

Nowadays, it is still in use for various reasons. It is mainly used in small, simple and widely familiar problem situations [42, 120]. However, it is not considered in our project because it does not provide a structured way to control the development process. Nor does it ensure an unbiased determination of the proposed system requirements. A structured approach is needed in this investigation as it will help us to manage the process. Because of the political sensitivity in the domain it is important to have no bias in the developed system.

3.2.2 Waterfall approach

This approach [134, 152] divides the development process into separate stages. Each stage results in the production of one or more documents describing the current state of the development which are approved, 'signed off', by the users before moving on to the next stage.
It provides a structured sequential framework that facilitates the development process, but is criticised for being relatively inflexible as it calls for freezing of the requirements specifications at an early stage, and it is difficult to return to stages once they have been 'frozen' [69].

In our situation, using this approach would have provided an organised way to handle the complexity of this project. However, it would have not been able to deal with evolving and/or ambiguous requirements and their resolution. It was clear that this would be an important issue our process would have to address.

3.2.3 Evolutionary (prototyping) approach

An evolutionary approach is based on the idea of constructing quick and incomplete working models of the proposed system (prototypes) and exposing them to user evaluation [50, 167]. This prototype can then be used in two ways:

- As a nucleus or basis which evolves to a final system by passing through many iterations until an adequate system has been developed. This is known as *exploratory development* [152].
- As a temporary tool to learn about certain aspects of the required system and/or its potential solution [31]. This is known as *throw-away prototyping* [152].

An evolutionary approach may achieve a high level of user satisfaction by reducing the development time and addressing the problem of changing requirements. There remains, however, the possibility of producing less efficient systems due to the tendency in this approach to accept a sub-optimal early version as the final product [16, 44]. There is a pressure from users to do this after they have seen and used the prototype system.

In our project, this approach would have given us an ability to deal with the requirements uncertainty, but it would not have offered the means for accommodating the wide range of our users and their diversity of skills and requirements, as Burns and Dennis state:

> "prototyping for one user is not difficult; prototyping for many is" [44].

3.2.4 Formal systems approach

In a formal approach, the development process is based on a mathematical transformation of the specifications to an executable program [155]. This methodological approach is likely to minimise defects in the delivered systems [154]. However, in our situation expressing requirement specifications in a mathematical notation was not appropriate or achievable because the mathematical notation does not address the human aspects of the requirements. Additionally the author and most of the users had limited mathematical skills and so would not be able to take full advantages of this approach.

3.2.5 Reuse-oriented approach

A reuse-oriented approach is based on reducing the development cost and delivery time by reusing existing software components. The development process focuses on integrating these components into a new system rather than developing them from scratch [152].

In our situation, despite the availability of many software components within the ISCO/CaNISC system which might have the required functionality, they were all designed and developed to support the secondary and tertiary care sectors. Considering their reuse for primary care requirements is not suitable as they will not meet the needs of this sector due to the considerable difference between of the clinicians' role and working patterns in each care sector (see Table 2.3).

3.2.6 Fourth generation techniques

When using fourth generation techniques, certain aspects of the new system are specified at a high level, and then software tools are used to automatically generate the source code according to this specification [134]. The use of these tools can reduce the development time, however they are still limited to very specific application domains which are suited to this approach, such as business information systems applications [134].

The complex nature of our system constrained the use of these tools, as they are inadequate without a comprehensive requirements analysis. The complexity of the situation being addressed would make it difficult to achieve this detailed requirement analysis.

3.2.7 Contingency approach

The proponents of a contingency approach argue that the inflexible use of other approaches leads to rigid adoption of methodologies (method-ism [89]). It is claimed that this does not help in understanding and managing the complexity and uncertainty of the development process. Hence the advocates do not argue for a particular approach, but recommend tailoring different approaches according to the characteristics of a given situation as the development proceeds [28, 30, 44, 173]. To some extent, this can be viewed as an exploratory framework, rather than a systematic guide to the development process [174]. While this approach has some appeal and we considered following it at the start, we found that it had no clear structure but relied on the designers to choose the best way forward at each stage. It was clear that our situation needed a clear structure. So this approach was not used in the end.

Table 3.1 summarises our review of different analysis approaches, and highlights the potential strengths and limitations of using each of these approaches in our project.

Approach	Potential strengths of using it	Potential limitations of using it
Ad hoc	- Provides a quicker solution to a particular problem.	- Usually provides short term solutions. - Has no structured way to control the development process. - Cannot ensure an unbiased determination of the requirements.
Waterfall	- Provides a structured systematic approach to the development process. - Deliverables of each stage are clearly defined; which can be useful in assessing progress.	- May lead to premature freezing of the requirements; this can cause problems with respect to uncertain and/or changing requirements. - Assumption of a linear development model; many practical situations have a development process involving iterations.
Evolutionary (prototyping)	- Usually meets the immediate needs of users. - Likelihood of change is catered for, rather than being seen as a problem.	- Can lead to a poorly structured, immature system.
Formal systems	- Offers methodical means to the development process.	- Requires specialist expertise. - Expressing requirements specifications in a mathematical notation is not always appropriate and/or achievable.
Reuse-oriented development	- Can reduce development cost and lead to faster delivery.	- Availability of reusable components is not always guaranteed.
Forth generation techniques	- May reduce the development time.	- Use is limited to very specific application domains. - May not be efficient for large systems.
Contingency	- Provides flexibility to understand and manage the complexity and uncertainty of the development process.	- Does not offer a systematic guide to the development process.

Table 3.1: Strengths and limitations of using different analysis approaches in our project

3.3 A traditional approach to analysis

As discussed in section 3.2, each approach is focused on a particular aspect of the analysis process [59], therefore a combination of different approaches is often used to augment the benefits and overcome the limitations of individual approaches [134, 152], particularly if the benefits of different approaches are needed in the current project.

This project is no exception; a traditional approach based upon a combination of the waterfall and the evolutionary models was identified as suitable approach. This was achieved by adapting the Structured System Analysis and Design Methodology (SSADM[1]) [26], in a combination with the prototyping approach. Our aims in adopting this combined analysis approach were to:

- Gain the following benefits:
  - Organising the project development process to prevent redundant or counteracting activities.
  - Maximising the users' participation in the analysis process.
  - Handling changing and/or uncertain requirements.
  - Developing the system gradually and incrementally to overcome cultural and organisational barriers.
- And overcome the following limitations:
  - Handling the freezing of the requirements at early stages of the development process which limits the ability to change them.
  - Delivering an immature system.
  - A potential risk of system rejection if clinicians working practices are not supported.

By employing this approach, we identified two groups of potential user community namely GPs and cancer specialists. Hence ten GPs, with a variety of clinical and research interests, [Personal Communication 9 to 18] and three cancer specialists

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[1] Our investigations show that this methodology has been successfully used for more than two decades in a similar environment e.g. civil service applications [27].

with different clinical specialisms [Personal Communication 3 to 5] were consulted with the aim of involving a representative sample of the two groups[1]..
This section explains how this approach was used in our project.

3.3.1 Assessing the technical feasibility

As shown in Table 2.3 an EPRS in primary care is different from an EPRS in secondary and tertiary care. Consequently, expanding the current ISCO/CaNISC system, as it stands, to primary care will not meet GPs need. Also, the alternative of introducing a new separate system for cancer patients in primary care raises other concerns because:

- GP Practices have already made significant investment in their EPRSs, adding a new system is another burden with respect to training and finance.
- Considering the short GP consultation time with a patient [73], it is not feasible to ask a GP to enter his/her cancer patient information twice (to the existing GP system and the new system) as this would add an extra load on already hard pressed workers.

Hence, to avoid financial constraints and to keep dual data entry to a minimum the ideal proposed system must interface with existing GP systems. However, this was not technically possible, so the development process began with a feasibility study [20, 24] to:

- Assess the technical practicability of expanding the ISCO/CaNISC system to primary care in such a way that it minimised the impact on GPs.
- Ensure that the benefits of the proposed system would outweigh the cost.

A pilot interface, developed by the author in a previous project [17], was connected to a GP surgery[1] via the NHS Network in Wales. Eight GPs [Personal

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[1] It is extremely difficult to ensure that the volunteers are truly representative and cover all view points.

communication 9 to 16] practiced retrieving their cancer patients' information from the ISCO/CaNISC system in an almost real time situation via this interface. Figure 3.1 outlines how this interface was used by GPs.

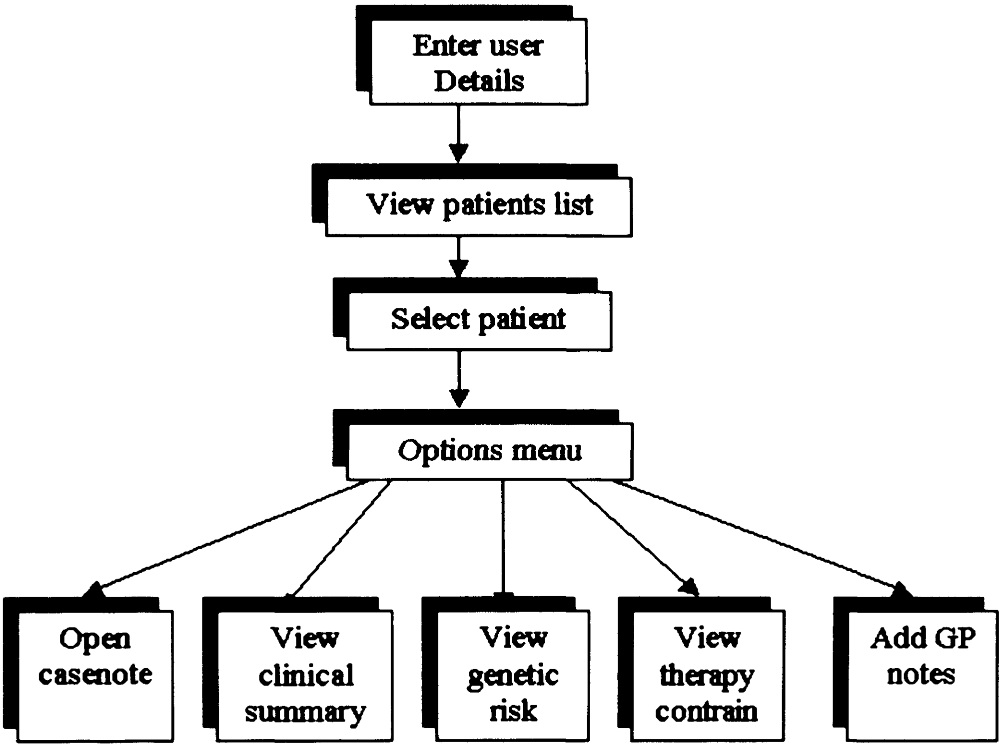

Figure 3.1: The pilot interface for GPs [17]

This experiment demonstrated the technical feasibility of the pilot system[2]. The eight GPs answered a questionnaire, designed by the author, to evaluate the interface (a copy of the questionnaire is included in Appendix B).

They all preferred using this system to communicate with other care team members. Most of them (71%) thought this interface was a useful tool in searching for a particular patient's record, see Figures B.3 (a, b). The provided functions were

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[1] Ely Bridge Surgery (http://www.elybridge.co.uk/index.htm)

[2] All GP systems in Wales are currently connected to the NHS network, so our system can interface with them via this network as demonstrated in the feasibility study.

generally agreed (57%), see Figures B.5 (a, b). Their feedback showed a wide acceptance of the proposed system and reflected their awareness of the need to improve current communications with other care team members [20, 24].

3.3.2 Domain investigations

The author has an understanding of the medical domain gained by her previous experience as a hospital doctor for seven years. Additionally, she carried out an ethnographic study[1] [152] in which she spent several weeks observing the care process at the Velindre NHS Trust (the South East Wales cancer centre[2]), the Ely Bridge Practice in Cardiff and the Holme Towers palliative care centre in Penarth. This helped her gain knowledge and insight of different aspects of the cancer care domain in Wales. Different features of this domain were noted, including:

- Cancer is not a single disease or a discrete speciality like surgery or gynaecology [81]. It is a group of diseases; each of which is often treated by a team of more than one healthcare professional. In this situation, timely communication between care team members is important to maintain the continuity of care.
- Because GPs are in overall charge of their patients, cancer patients and their families frequently seek advice from their GPs. However, in reality GPs are often poorly informed about the care provided for their patients in the secondary/tertiary sectors.
- GPs see a small number of cancer patients and are expected to detect and deal with cancer amongst a sea of general problems and conditions. A robust communication with other care team members is essential to widen their experience in cancer care.

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[1] An observational technique used to understand social and organisational requirements

[2] This hospital is currently the centre for radiotherapy and chemotherapy in South Wales. In addition to providing oncology services it is also the centre for Breast Test Wales, Cervical Screening Wales, the Welsh Blood Service and the Welsh Cancer Intelligence and Surveillance Unit.

A Data Flow Diagram (DFD) was constructed to help the author gain a better understanding of the common clinical activities and their information inputs and outputs, see Figure 3.2.

This diagram was corroborated by eight GPs [Personal Communication 9 to 16] and three hospital specialists [Personal Communication 3 to 5] to ensure an accurate perception of the current system had been achieved.

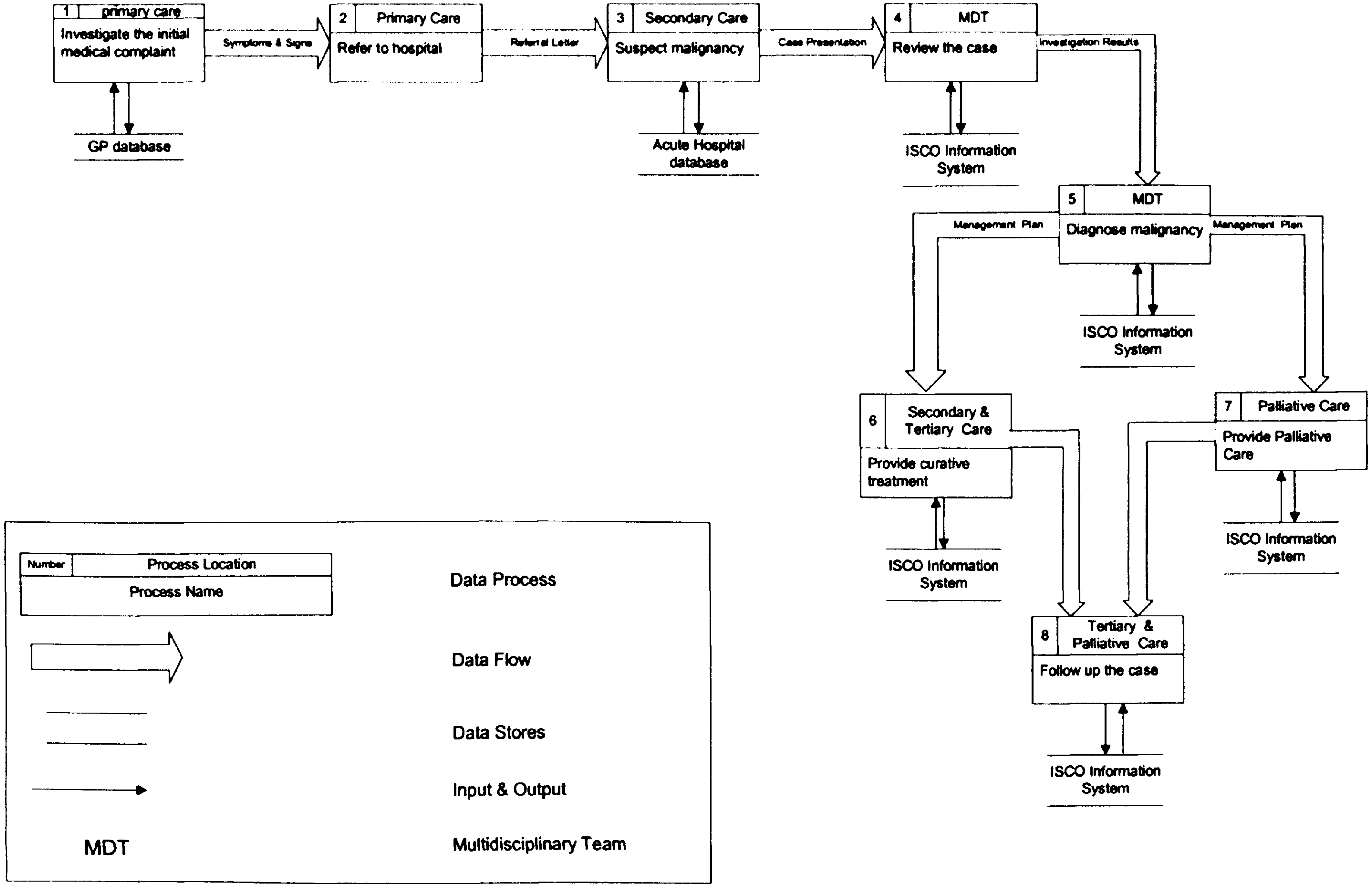

Figure 3.2: A Data Flow Diagram (DFD) to show the common cancer care process in Wales [23]

It was concluded that:

- **Before referral**: a full set of a patient's medical information is locked away in the Practice EPRS. This usually includes information about the current medical problems as well as past medical history.

- **At referral**:

  - A GP sends a referral letter by post, sometimes by fax, to request further investigation from the secondary care sector. It is up to GPs to decide what information should be included in this letter.

  - At secondary care, detailed investigations are conducted to arrive at the diagnosis. The information of the investigation conducted and/or the care provided at secondary care is hidden in the secondary care EPRS.

  - If the possibility of malignancy is high, the patient is transferred to an MDT who is also provided with the information the secondary care specialists believe is relevant. Sometimes GPs are also updated with this information.

- **Diagnosis, treatment and follow up**

  - If the diagnosis of a malignancy is established, the patient is registered in the ISCO/CaNISC system and from this point his/her information can be shared with other care team members, apart from the GP. Currently GPs receive confirmation of the diagnosis by letters, which is contradictory to the national targets[1] of a maximum delay of 24 hours for this communication [58].

  - All through the treatment and follow up journey the communication between GPs and other care team members is maintained by letter and occasionally by fax- a less than ideal situation because of the time delays inherent in this method of communication.

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[1] The cancer standards [58] advises that the GP must be informed of the diagnosis within 24 hours of the patient being informed, this is not achievable in a communication by letter.

3.3.3 Requirements elicitation and analysis

In our project, elicitation and analysis proceeded in parallel and a feedback loop between them was extended until the later stages of the requirements analysis, as gathering information introduced further understanding and analysis which guided further elicitation.

The elicitation activities were undertaken to capture as much information as possible to help us answer three questions:

- What information should be communicated between GPs and other care team members?
- What functions the proposed system should provide?
- What are the constraints that limit our development process?

And the analysis activities used this information to:

- Achieve an understanding of the nature of the cancer care domain in Wales and identify how this affects our project.
- Investigate the communication problems (which the new system will try to solve).
- Determine the information requirements in order to inform the subsequent specification of the new system.

Many techniques were used in this process, including: ethnography, background reading [47, 48, 63, 81], documents inspection [99] and semi-structured interviews with ten GPs [Personal Communication 9 to 18] and three hospital specialists [Personal Communication 3 to 5].

The functional requirements identified by this activity were presented to the members of the two groups individually [Personal Communication 3 to 5, 9 to 18] using the UML use case diagrams. The individuals were asked to comment on the accuracy and completeness of the diagrams, which led to the final set of use cases shown in Appendix B.

The main findings of this process can be summarised as:

- The interviewees preferred a system that enabled them to communicate at each stage of the treatment pathway, rather than an improvement which focused on improving communication at certain stages only.
- Improving the speed of the information flow between the two groups was the most frequently mentioned requirement.
- GPs required the new system to handle their cancer patients' information as well as to give them access to cancer documents electronically (e.g. a palliative care handbook).
- All interviewees expressed concern about getting unnecessary information that may lead to information overload. They all required the provision of the essential information only.
- None of the interviewees were able to define precisely what information is required by/from GPs at each stage of the care process at this point in time.

3.4 Traditional versus Problem oriented analysis

Despite the recognition of many communication problems at this stage, it was realised that the recognised problems were open ended and ill defined. For instance, the clinicians [Personal Communication 3 to 5, 9 to 18] complain about the communication speed when a GP refers a cancer patient to the specialist. This is because the time delay between the GP sending the referral note and its receipt by the hospital is too long. Nevertheless, this is only the recognised symptom of a wider problem, as GPs are often not aware of the proper referral destination, i.e. to whom the patient should be referred [136], also there is no agreement on what information should be included in the referral note.

Additionally, A number of conflicting requirements were identified, for instance, one specialist insisted that the proposed system must have a mechanism to alert specialists as soon as they receive a GP correspondence. Another specialist viewed this as information overload and confirmed that a GP correspondence should wait until the next patient consultation.

The resolution of many of these conflicting requirements was not possible due to inconsistent perspectives among the interviewees of what information the system must, and must not, provide [21, 22].

Hence, a challenge with an associated trade-off was faced, namely either to:

- Specify the new system according to the findings at this stage, or
- Spend more time gaining a deeper understanding of the problem so that a fuller system could be specified.

The first option offers a shorter delivery time and *initial* user satisfaction by providing them with working software sooner. However there is a risk of perpetuating the problems inherent in the current ways of communication, due to an incomplete understanding of these problems. The second option on the other hand lengthens the development time and provides a more complete system as it is based on a deeper understanding of the problem domain.

In this project the second option was chosen, and a fuller analysis was undertaken in order to identify and address the fundamental causes of the existing problems, and hence to gain a fuller understanding of the requirements, as pointed out by Wilson:

> "Both the problems are not understood or not identified, and therefore the information requirements which are supposed to address these problems are inappropriate or at worse not known" [171].

This choice meant that we could take a fuller look at the situation and try to gain a fuller understanding of the problem under investigation.

3.5 Need for a holistic analysis

The initial analysis strategy proved to be inadequate in our situation because:

- It did not provide the means to simultaneously investigate communication problems throughout the whole treatment pathway; instead each problem was tackled in isolation with an assumption that solutions to sub-problems would give a solution to the whole problem. However, tackling each problem separately led to unresolved conflicts in the requirements.

- It was not capable of accommodating different view points or resolving conflicting requirements. The diversity in the requirements was mainly due to different clinical needs and working practices in each care sector. Failing to address these different perspectives would be a major obstacle as our new system would span the three healthcare sectors and involve different user groups.

Hence, a holistic analysis approach that investigates the whole treatment pathway, and considers both human and technical aspects of the requirements is essential as it will provide a more complete understanding of the requirements. As explained above, not taking a holistic approach will lead to an incomplete understanding of the requirements. Consequently, heightening the risk of designing an inappropriate system:

> "If we do not have better understanding of the richness and complexity in the practical accomplishment of the work, then we will not be able to coevolve the design of systems that will fit in with work and the design of new working practices that will take advantages of technology" [70]

The importance of the requirements analysis stage is highlighted in the literature, see e.g. [42, 113], and is re-emphasised by Taylor's study [160] that classifies unclear requirements as the most common cause of IT projects failure[1], see Figure 3.3. This figure shows the number of times each cause was mentioned and the score given to each one in the study.

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[1] Success was defined as delivering to the sponsor everything specified to the quality agreed upon, within the time and cost laid out at the start.

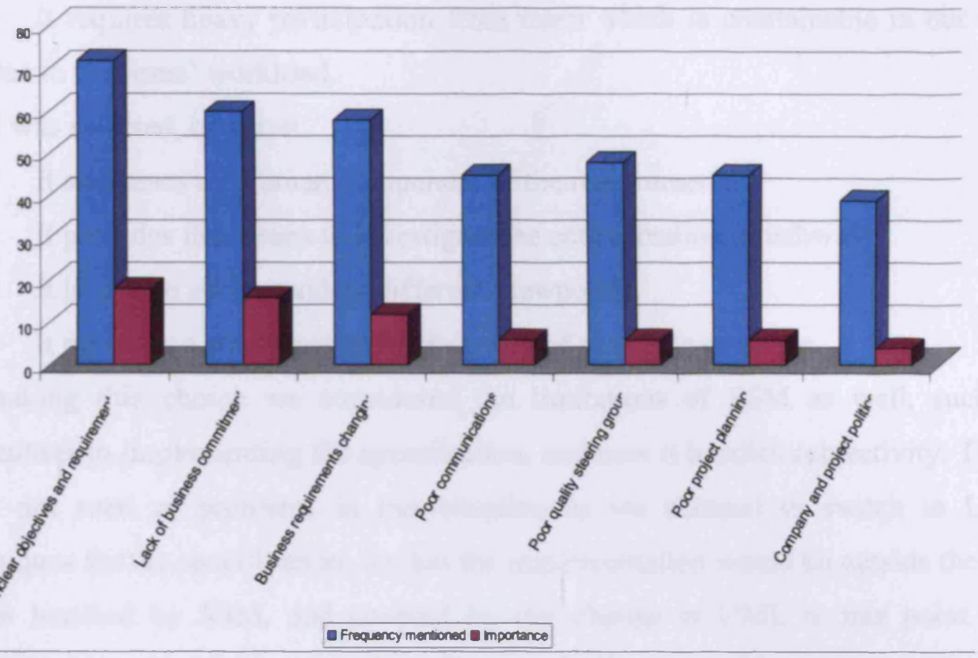

Figure 3.3: Cause of IT projects failure [160]

Hence, a review of the literature was conducted with the aim of selecting a methodology (or a combination of methodologies) that allowed:

- Investigation of the whole treatment pathway,
- The soft (human) aspects of the requirements to be addressed, and
- A consensus view of the problem under investigation to be identified.

Three methodologies: Information Systems work and Analysis of Changes (ISAC) [27, 60, 100], Effective Technical and Human Implementation of Computer Based Systems (ETHICS) [27, 119] and Soft Systems Methodology (SSM) [52-54, 171] were considered, due to their capabilities for addressing soft aspects of the requirements and handling ill defined problem situations [27].

The three methodologies were reviewed in more detail to determine which should be used.

In this process, ISAC was excluded because:

- It does not allow investigation of the whole cancer care process as it concentrates on sub-processes [27].
- It relies on users to perform the analysis themselves which is not practical in our situation because of users' workload and lack of analysis skills.

ETHICS was also excluded, because:

- It requires heavy participation from users which is unattainable in our case due to the users' workload.

SSM was selected, because:

- It addresses the human component of the requirements.
- It provides the means to investigate the entire treatment pathway.
- It is able to accommodate different viewpoints.
- It provides a structured defensible way of resolving conflicts.

In making this choice we considered the limitations of SSM as well, such as difficulties in implementing the specification, and how it handles subjectivity. These were not seen as problems in our situation as we planned to switch to UML techniques for the specification. So that the implementation would be outside the soft stages handled by SSM, and covered by our change to UML at this point. We accepted that subjectivity could also affect our findings with SSM but hoped to limit this effect due to our awareness that it might be present.

Thus the following development stages were undertaken using SSM to give a fuller appreciation of the requirements.

3.6 Conclusions

This chapter explained how an incremental analysis approach, based upon a combination of the traditional and the evolutionary approaches, was initially applied in this project. It demonstrated its benefits and highlighted its limitations, with respect to our project. These limitations led to us considering what approach was needed to overcome the limitations. It then argued that addressing the soft (human) aspects of the requirements is essential to achieve a better understanding of the problems. This view is also supported by Kay, who states:

> "It is not only software and hardware but 'people-ware' too" [101].

We concluded that a holistic analysis approach which investigates the whole cancer treatment journey and considers both soft (human) and hard (technical) aspects of the requirements will achieves a consensus view of the problem under investigation and will provide a more complete set of requirements. Hence, we decided to adopt this holistic approach in our project.

Chapter Four

The Holistic Approach

4.1 Introduction

At the start of the project, technical obstacles appeared to be the prime cause of the communication gaps between GPs and other cancer care team members in Wales. Hence, the first stage of the development process focussed on investigating the technical feasibility of interfacing our system with GP systems, see section 3.3.1.

Further investigations (see section 2.8) revealed that the communication gaps are mainly due to information problems, not technology problems. This led to the analysis being re-focused on addressing the information problems.

Initially a traditional analysis approach was adopted (see section 3.3), however this proved to be inadequate mainly because it did not offer the means to investigate the whole cancer treatment journey in its entirety, and was not able to handle the conflicting requirements or to accommodate various stakeholders' different viewpoints. Hence a holistic approach that investigated the entire treatment pathway while considering both the (human) (soft) and the technical (hard) aspects was needed to overcome these limitations.

Chapters four and five describe how the holistic approach was used in our project. This chapter focuses on using SSM tools and techniques to:

- Determine the information requirements.
- Investigate the problems that hinder the provision of this information to appropriate people.

4.2 Using SSM

SSM [27, 54, 171] is a practical methodology that helps analysts gain an understanding of, and investigate, real world problems that are not well defined and ill structured. It applies *system theory*[1] by addressing both the human (soft) and the technical (hard) aspects of the problem.

SSM acknowledges that various stakeholders view the same problem from different viewpoints according to their backgrounds, roles and objectives. It, therefore, focuses on achieving an agreement of what the problem(s) under investigation is (are) [21, 22, 27, 29, 52, 54, 171]. This can be achieved through employing the different tools and techniques involved in this methodology.

SSM was used in this project to frame the scope of the problem under investigations in order to determine the key information that must be communicated between GPs and other members of cancer care teams.

This was done through many stages (see Figure 4.1) and involved a series of individual interviews with thirty five stakeholders who undertake various roles in the cancer care domain in Wales (GPs, cancer specialists, practising and research nurses, managers and IT professionals) [Personal Communication 1 to 35]. This was done with the aim of reaching an agreement (or a common view) of the problem(s) under investigations and the key information that must be communicated between GPs and other care team members.

These stages were:

- Gaining a deeper understanding of the cancer care domain.
  - Exploring the problem situation.
  - Expressing the author's understanding of the current situation.

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[1] A theory that recognises that the whole is greater than the sum of the parts; and considers the problem situation in its wider context [52].

- Investigating the whole treatment pathway.
    - Searching for different views (beliefs) of what would be an ideal situation through many debates with the thirty five stakeholders.
    - Creating Root Definitions (RDs) to describe these views. A RD is a conceptual statement, that does not exist in reality, its equivalent in real world terminology might be a business objective or mission statement [171]. It is a concise, tightly constructed statement that describes what the system under investigation is [52]
    - Combining these views in a single RD to present a consensus view of the core purpose of the whole cancer care process.
    - Developing an explicit Conceptual Model (CM) that demonstrates the activities that must take place to achieve what is described in this RD.
    - Developing a wider conceptual model known as the Consensus Primary Task Model (CPTM). The CPTM contains a full set of activities agreed by all interviewees as the key activities of the whole cancer care process.
- Identifying the GPs key clinical activities, by extracting the activities directly related to GPs from the CPTM as agreed with all the interviewees.
- Determining the information requirements by identifying the information inputs and outputs of these activities.
- Investigating the problems hindering the provision of the required information to the appropriate people by comparing the current information provision against the required information provision.

These stages are an adaptation of the framework provided by SSM [54, 171]. It was adapted to suit our situation, as the rest of this chapter will discuss.

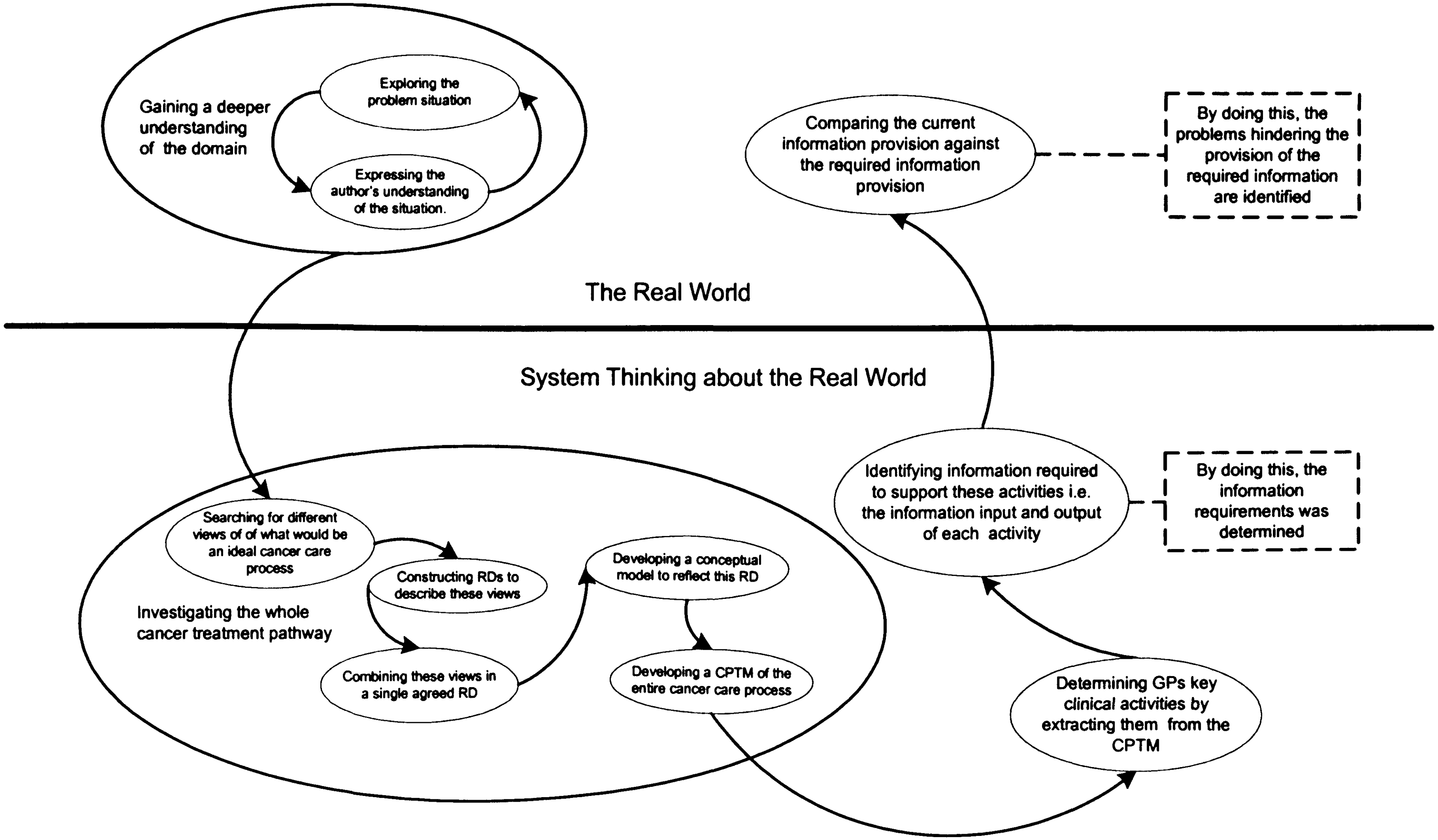


Figure 4.1: Adaptation of SSM for this project

4.3 Deeper understanding of the problem situation

As discussed in section 3.4 a fuller understanding of the problem domain was required to determine the exact nature and scope of the problem under investigation. A rich picture was used as an exploratory technique in this stage. A rich picture is a pictorial representation of what the situation under investigation is taken to be [171]. It is commonly used within the healthcare domain to explore difficult situations, roles of apparent significance, issues and areas of conflict. For example:

- Checkland [52] used rich pictures to investigate mergers between district health authorities. He also used them to illustrate the perception of healthcare professionals and health service managers of the White Paper 'The New NHS' [52].
- Bailey and Urquhart [34] used rich pictures to explore the information needs of clinical cancer trials.

Semi-structured interviews were held with thirty five stakeholders including GPs, cancer specialists, practising and research nurses, managers and IT professionals [Personal Communication 1 to 35] to gain more knowledge of the cancer care domain in Wales. The interviews were centred around discussing two rich pictures[1] constructed by the author to demonstrate her perception of the current situation in Wales.

These pictures were used as an exploratory tool to gain a fuller understanding of the problem under investigation. This was done by presenting the pictures to the interviewees during individual meetings to initiate discussions about, and gain further clarification, of the situation. The author asked all the interviewees: *'this is my understanding of the situation, have I got it right from your prospective?'*

---

[1] The rich picture is literally "a picture of what the situation is taken to be". It is not a direct translation of the reality but a perception of this reality [171]

Some of them agreed with the pictures as they were, while others suggested changes. This led to more iteration requiring further interviews until all interviewees agreed with the pictures (up to three interviews were required with each interviewee).

The interviewees' feedback was part of an iterative process which improved the pictures and led to a clearer understanding of the many political and organisational issues affecting the care process. For instance:

> "We need the link with them to know exactly what they do, and they say to our patients" [Personal Communication]
>
> "They have to realise that the patient is mine, they only borrow him/her for a limited period of time" [Personal Communication]

These discussions also helped to identify many areas of conflict that did not initially appear, when traditional analysis tools and techniques were used such as the controversial views held by the interviewees regarding our new system. For example, one cancer specialist recommended that GPs should have full access to their cancer patients' information, yet another hospital specialist recommended limited access to certain information only.

The final pictures from this part of the analysis are shown in Figures 4.2 and 4.3 respectively. Figure 4.2 reflects the perception of three core strategies of cancer services; the Calman Hine report [47], the Cameron report [48] and the Cancer Information Framework (CIF) [81]. Figure 4.3 reflects the author's understanding of the current information flows in Wales. It also shows the controversial views held among the interviewees regarding the proposed system.

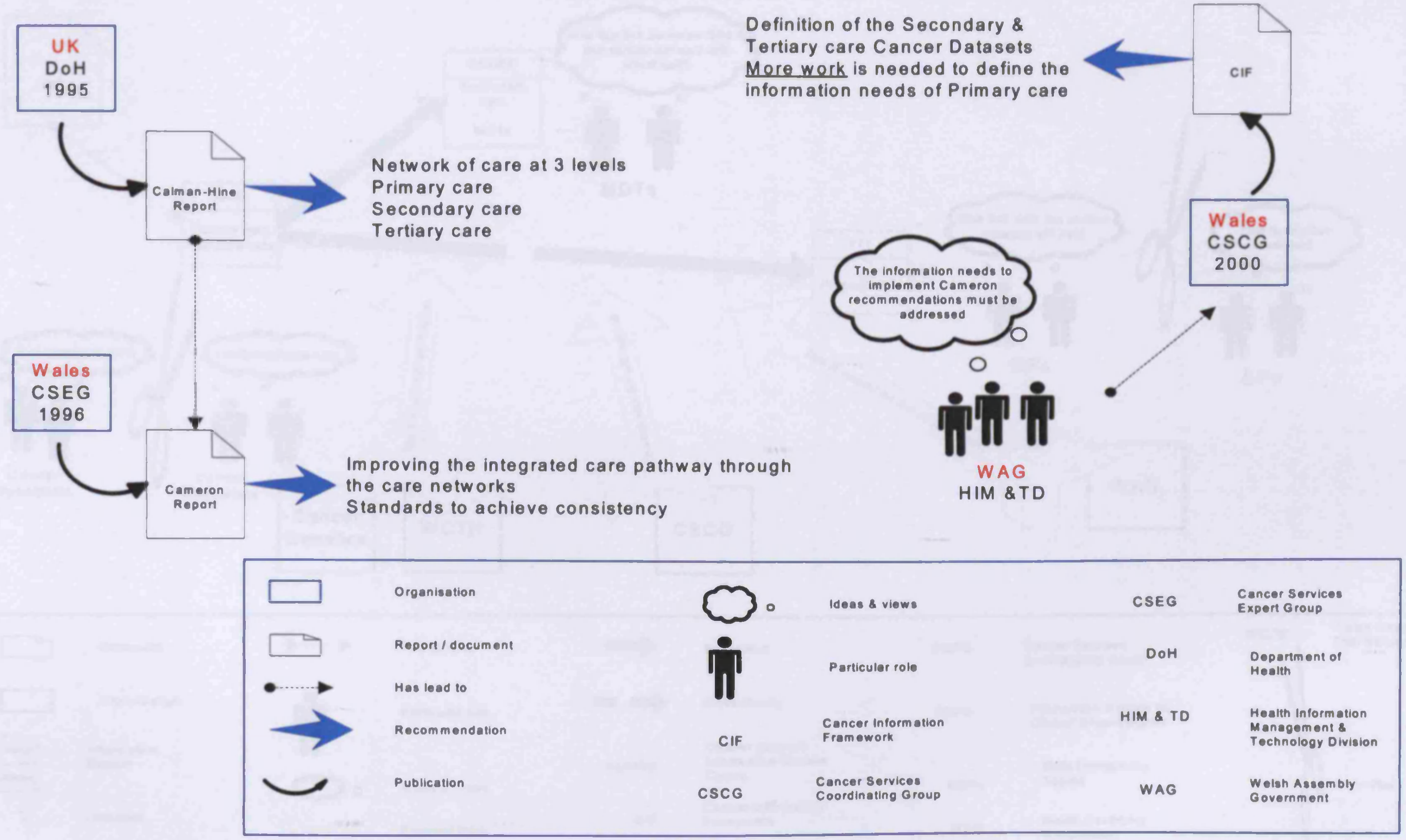


Figure 4.2: Rich picture reflecting the authors' perception of the strategies of cancer services in the UK [25]

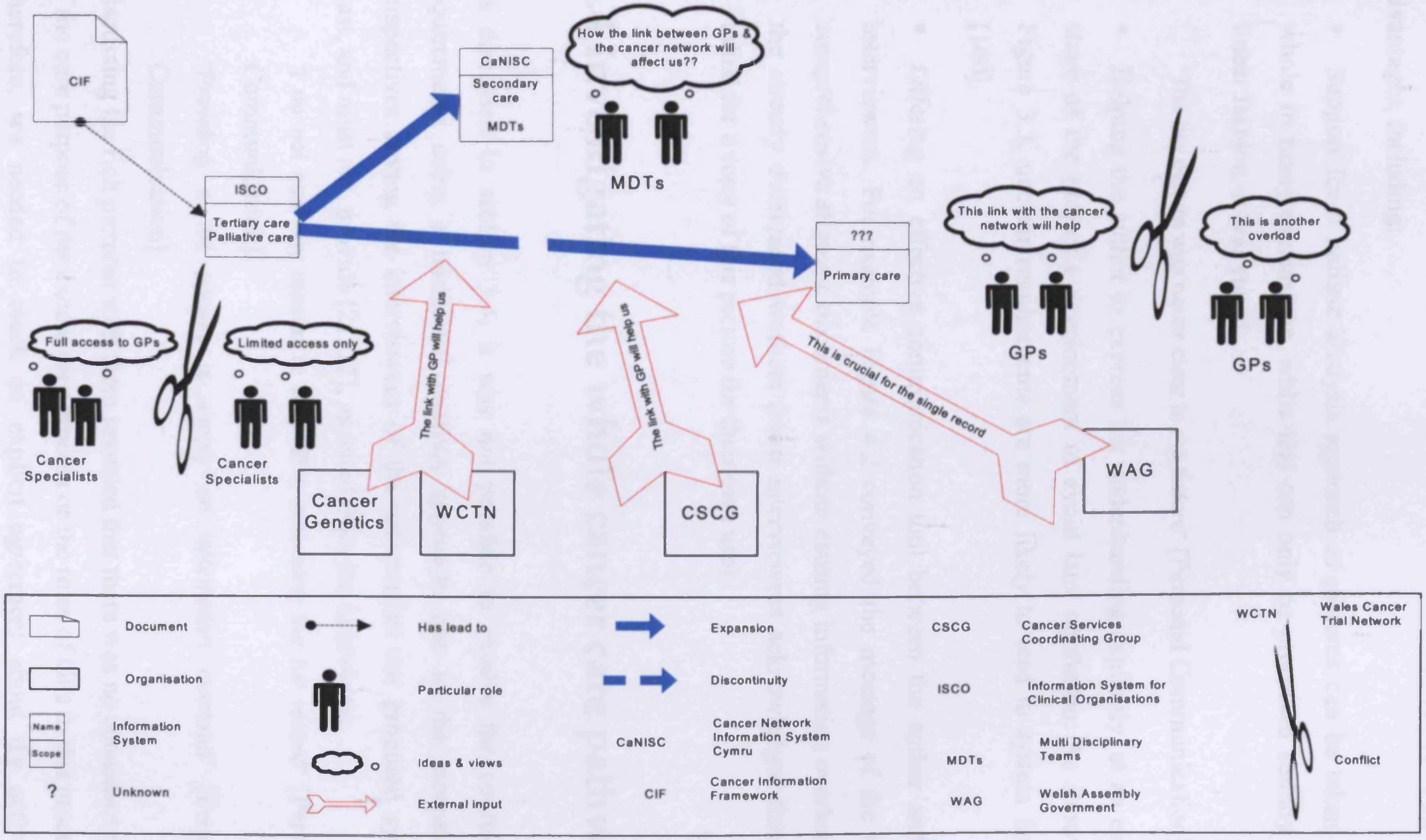


Figure 4.3: Rich picture reflecting the authors' perception of the current information flows in Wales [25]

In the context of this project, this pictorial representation provided many advantages, including:

- Support for a holistic analysis approach as pictures can be taken as a whole in many dimensions, while text can only be processed serially in a linear fashion. It was stated:

  "The big picture was never clear to me before" [Personal Communication]

- Helping the author to express her understanding explicitly, at an earlier stage of the project's development to avoid later confusion. As shown in Figure 3.3, unclear requirements are more likely to lead to system failure [160].

- Offering an effective communication tool between the author and the interviewees. For example Figure 4.2 conveyed the message of the three comprehensive strategic documents without causing information overload on the already overloaded workers (most interviewees acknowledged this and asked for a copy of this picture for their own use).

4.4 Investigating the whole cancer care pathway

As discussed in section 3.4, it was not possible to resolve the conflicting requirements using a traditional analysis approach, due to the inconsistent perspectives among the interviewees of the information our proposed system must, and must not, provide [21, 22], as noted from the interviews:

> "I do not see any reason to stop GPs accessing the full record" [Personal Communication].
>
> "Providing a full access is simply an information overload" [Personal Communication].

Discussing the rich pictures with them revealed that there was no consensus view of the core purpose of the cancer care process or the roles of GPs in this process. Therefore, we needed to reach an explicit agreement about the activities comprising the whole cancer care pathway in order to be able to extract the activities relevant to the GPs role at each stage of this pathway. This was attained through the following stages:

- All interviewees were asked *what do you take the core purpose of the whole cancer care process to be either now and/or in the future?* Each interviewee provided one statement, resulting in a total of thirty five individual statements as follows:

1. A system to help us answering patients' questions.

2. A system to support the provision of a good 'end of life' care.

3. A system to allow GPs to communicate effectively with palliative care teams.

4. A system to improve the care of cancer patients in our Practice.

5. A system to improve diagnosing and treating cancer

6. A system to support cancer audit by collecting, recording and maintaining relevant information.

7. A system to establish a robust information network.

8. A system to implement 'Agenda for Change'.

9. A system to inform the clinical decision making.

10. A system to take account of patient privacy and data protection issues.

11. A system that closes the open loop between GPs and other care team members.

12. A system to support the discipline 'Primary Care Oncology'.

13. A system that improves cancer outcome within the available resources.

14. A system that allows me to access my cancer patients' information effectively.

15. A system to ensure coordination and collaboration between different team members.

16. A system to ensure compliance with the national guidelines.

17. A system that makes the best use of technology within the limits of other constraints.

18. A system that provides an improved services.

19. A system that uses recent IT to help cancer patients.

20. A system that ensure the provision of information in the right time at the right place.

21. A system that links GPs with the cancer network.

22. A system that makes the best use of the available resources.

23. A system to report to me the information provided to patients and families.

24. A system that ensures the evaluation of the care provision.

25. A system that provides referral and other clinical guideline clearly.

26. A system to help the performance of GPs in cancer.

27. A system that ensures information sharing between all members of the care team.

28. A system to provide relevant information at the right time.

29. A system to establish a good link between all professionals involved in the care process.

30. A system to support the implementation of the 'Cancer Information Framework'.

31. A system to ensure the compliance with the national standards.

32. A system that provide high quality services.

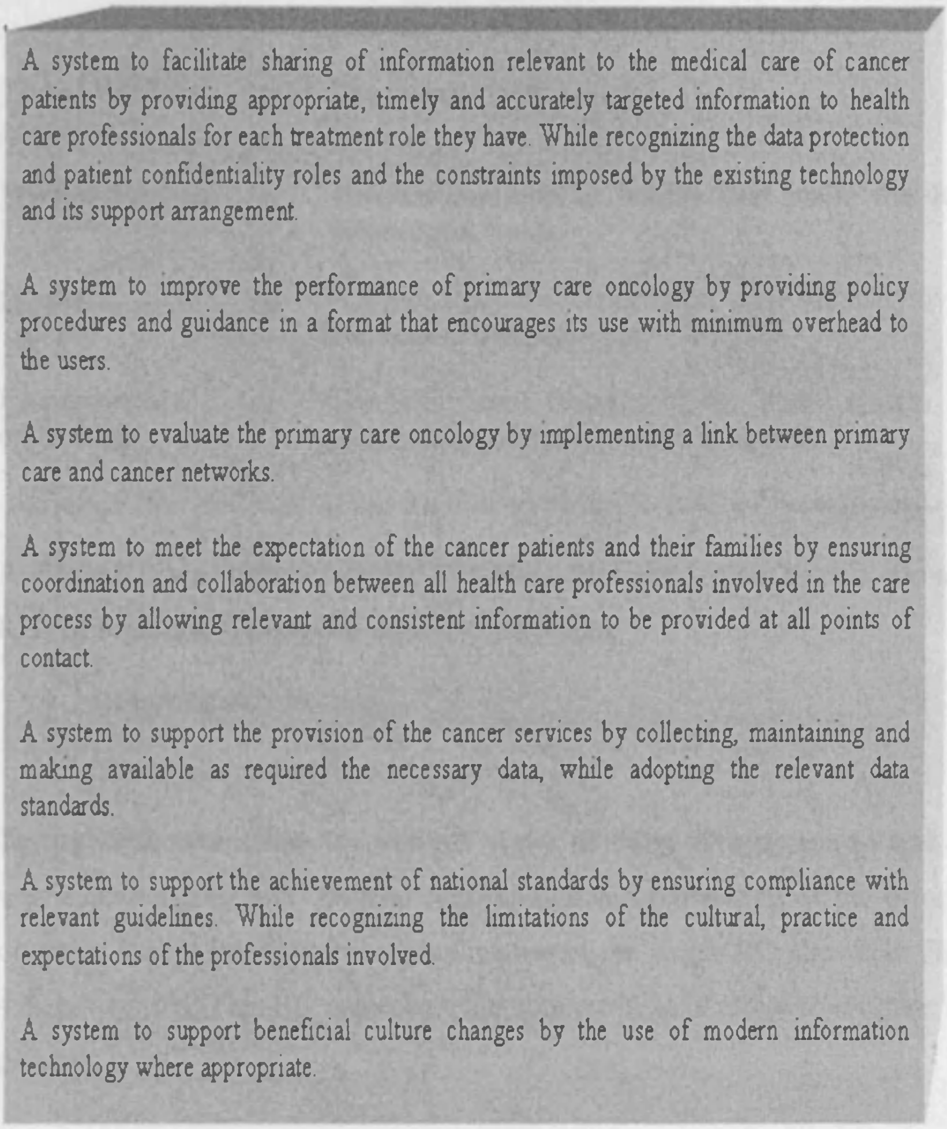
33. A system that achieves relevant standards.

34. A system to facilitate cancer services.

35. A system to improve the patients' quality of life.

- Many of the interviewees' thirty five statements reflected similar views. The author was able to determine seven distinct views of the whole cancer care process by analysing and synthesising these statements.

- These views were used to construct seven Root Definitions (RDs) reflecting these seven views. Each RD reflects a single view point. Figure 4.4 shows the seven RDs constructed at this stage.



A system to facilitate sharing of information relevant to the medical care of cancer patients by providing appropriate, timely and accurately targeted information to health care professionals for each treatment role they have. While recognizing the data protection and patient confidentiality roles and the constraints imposed by the existing technology and its support arrangement.

A system to improve the performance of primary care oncology by providing policy procedures and guidance in a format that encourages its use with minimum overhead to the users.

A system to evaluate the primary care oncology by implementing a link between primary care and cancer networks.

A system to meet the expectation of the cancer patients and their families by ensuring coordination and collaboration between all health care professionals involved in the care process by allowing relevant and consistent information to be provided at all points of contact.

A system to support the provision of the cancer services by collecting, maintaining and making available as required the necessary data, while adopting the relevant data standards.

A system to support the achievement of national standards by ensuring compliance with relevant guidelines. While recognizing the limitations of the cultural, practice and expectations of the professionals involved.

A system to support beneficial culture changes by the use of modern information technology where appropriate.

Figure 4.4: Seven RDs reflecting the interviewees' views of the whole cancer care process

- The structure of the seven RDs was validated to ensure that they were well formed and the words used were precisely defined. This was done by checking each RD against six elements, represented by the CATWOE mnemonic, this is the validation approach recommended by Wilson as he states:

> "CATWOE must be a test of the structure and words chosen in the RD " [171]

The **CATWOE** acronym stands for [54, 171]:

Customer	The beneficiary or victim affected by the activities.
Actor	The agent who carries out the transformation process.
Transformation process	The change taking place.
Weltanschauung[1]	The assumptions or beliefs that make the RD meaningful.
Owner	A wider system decision taker with authority over the system defined.
Environmental constraints	The significant features of the wider system of which the problem situation is a part.

- A single RD was then developed by asking the interviewees to rank the seven RDs in Figure 4.4, using the following criteria:
  - Its importance to them,
  - The likelihood of its occurrence.

Trying to accommodate the various views of thirty five people in one RD, was a challenging task. Several regroupings and reordering of the priorities occurred before the final conceptualisation of the single RD shown in Figure 4.5 was agreed. This RD represents the core purpose of the whole cancer care process.

A system to provide care to cancer patients, according to the individual care pathway, by making available treatment in terms of equipments, drug applications and surgical procedures as appropriate, but acting within constraints arising from a resource's availability and patient condition

Figure 4.5: A core RD representing the core purpose of the whole cancer care process

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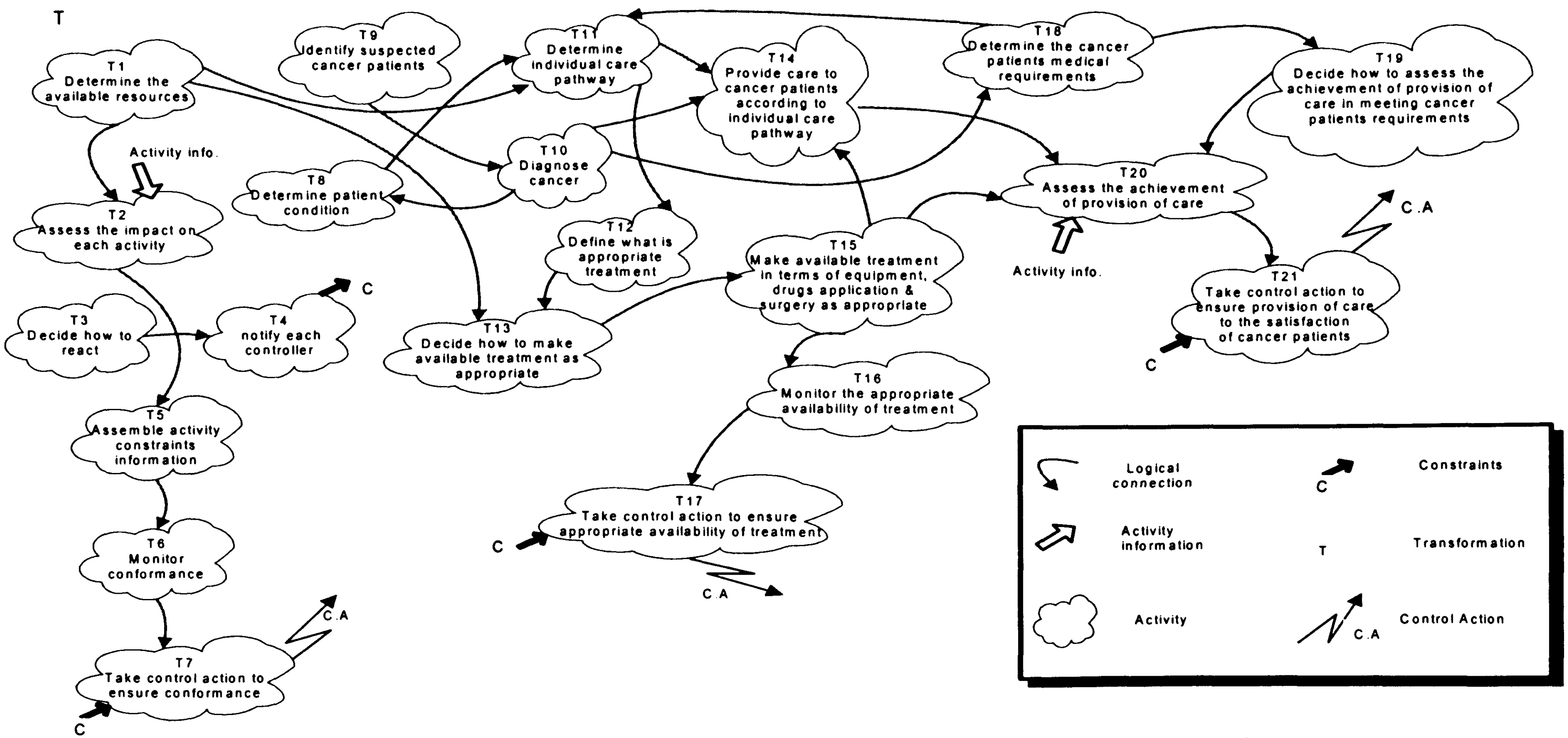
[1] This is a German term, the English equivalent is 'world view'

The results of this stage were shown to Dr Brian Wilson, an experienced SSM practitioner and one of the co-inventors of the methodology, who agreed with the findings.

- This core RD was used to develop a conceptual model that included the activities that must take place to achieve what is described in this RD, and showed the logical connection between these activities.

> "The RD tells us what the system is; the CM tells us what the system must do to be the one defined [171]

Figure 4.6 illustrates this model. This model was presented to the thirty five interviewees [Personal Communication 1 to 35], and discussed iteratively with all of them making appropriate changes until they all agreed with it.



A system to provide care to cancer patients, according to the individual care pathway, by making available treatments in terms of equipment, drug application and surgical procedures as appropriate but acting upon constraints arising from the resource's availability and the patient condition.

Figure 4.6: A conceptual model representing the core purpose of the cancer care process

- We continued the process of interviewing the same thirty five stakeholders [Personal Communication 1 to 35] with the aim of developing and agreeing a fuller model to represent the consensus view of the key activities occurring in the whole cancer care pathway and the logical connections between theses activities.

This model is known as a Consensus Primary Task Model (CPTM). Wilson [171] suggested four different methods to construct the CPTM in order to cope with varied situations in which it can be applied. These methods are known as the:

- Mission-statement based.
- W-decomposition.
- Wider system extraction.
- Enterprise Model assembly.

The mission-statement based method was excluded because *a single statement that represents the mission of the cancer care process in Wales* does not exist. The W-decomposition and the wider system extraction methods were also excluded as they required an unrealistic investment of time by the interviewees.

Hence, the Enterprise Model assembly method was chosen, because it supported our holistic approach by ensuring that the total range of activities required would be considered and included in the model. This method requires four types of activities to be included in the model [171]:

Transformation activities (T)	Activities representing the core purpose of the enterprise (its main transformation).
Support activities (S)	Activities representing the facilities required to support the transformation process.
Linking activities (L)	Activities representing the link with the external environment
Planning, Monitoring and Control activities (PMC)	Activities representing the management aspects required

The four types of activity were identified and included in our CPTM as follows:

- The transformation activities that represent the core purpose of the cancer care process had already been identified and included in the conceptual model (see Figure 4.6) developed from the core RD (see Figure 4.5).
- Two RDs representing the facilities required to support the transformation process were constructed and agreed by all the interviewees, see Figures 4.7a and 4.7b. Examples of the statements used to construct these RDs were:

  > "We will achieve nothing without having the appropriate staff" [Personal Communication].
  >
  > "Establishing a good knowledgebase is fundamental" [Personal Communication].

  These RDs were used to develop the two Support CMs shown in Appendix C, Figures C1 and C2 respectively.

A system to ensure the availability of skilled personnel and physical resources to ensure the execution and control of all activities while exploiting opportunities arising from developments in technology and best practice but recognising constraints due to legislation, local policy, standards and cultural constraints

Figure 4.7a: Support$_1$ RD

A system to Support all activities by maintaining and developing a knowledge base which recognises the need to share knowledge and learning amongst relevant professionals and other authorised users while acting within the constraints arising from data protection and all aspects of patients' confidentiality together with relevant standards related to currency storage

Figure 4.7b: Support$_2$ RD

- Two RDs representing the link with the external environment were constructed and agreed by all the interviewees, see Figures 4.8a and 4.8b. Examples of the statements used to construct these RDs were:

  > “The core is to satisfy the patients” [Personal Communication].
  >
  > “We have to reassure them that we liaise with each other” [Personal Communication].

These RDs were used to develop the two Linking CMs shown in Appendix C, Figures C3 and C4 respectively.

A system to meet the expectations of cancer patients and their families by ensuring coordination and collaboration between all care professionals and others involved in the care process while making available and sharing relevant and consistent information

Figure 4.8a: Link_1 RD

A system to assemble intelligence related to the needs of cancer patients and health risks within a particular community as a means of supporting appropriate care within that community

Figure 4.8b: Link_2 RD

- Two RDs representing the management aspects were constructed and agreed by all the interviewees, see Figures 4.9a and 4.9b. Examples of the statements used to construct these RDs were:

  > “You have to be aware of different strategies and plans” [Personal Communication]
  >
  > “Cancer Research Wales owns the project because they fund it” [Personal Communication]

These RDs were used to develop the two Planning, Monitoring and Control CMs shown in Appendix C, Figures C5 and C6 respectively.

A local area health board owned by Cancer Research Wales (CRW), to formulate plans for the development of health care facilities in terms of both physical and human resources capabilities to meet the current and projected health care needs of the defined community and to execute such plans in accordance with agreed priorities, finance availability, national targets and existing development plans.

Figure 4.9a: PMC$_1$ RD

A system to ensure the execution and control of all activities by ensuring the availability of skilled personnel and physical resources while exploiting opportunities arising from developments in technology and best practice but recognising constraints due to legislation, local policy, standards and cultural constraints.

Figure 4.9b: PMC$_2$ RD

- The structure of the CPTM was then validated against the Formal System Model (FSM) criteria as recommended by Checkland [52] and Wilson [171]. These criteria are:

Purpose:	Does the model derived achieve the purpose defined? This question determines the degree of defensibility of the model.
Connectivity:	The model must represent a system, not just an aggregate of the activities needed. Hence it must show logical connection of the activities.
Hierarchy:	This system is located at some position within a systems hierarchy extending from wider systems to subsystems of the organisation. Is this considered?
Measures of performance	Does every subsystem include monitoring and control activities?

Decision-taking process (controller)	Does the control subsystem ensure that if this set of activities exist in the real world, then they would work together to achieve the defined purpose?
Resources:	Does the implied authority of the controller cover the total resources available to the activities?
Boundary	Does the represented authority operate within the system boundary?

- This validation showed that our model fulfilled these criteria. The final model was presented to all interviewees, who all agreed with it.

4.5 Determining the GPs key clinical activities

Despite the growing participation of GPs in the cancer care process, their role is not yet clearly defined. Different, sometimes conflicting, views were given by clinicians in the interviews [Personal Communication 1 to 5, 9 to 18, 27, 28, 34]. For example, some assumed that the GPs must be involved in setting up the treatment plan, while others believed that this is purely a specialist's decision and that the GPs role was to support the decision and assist in its implementation.
Hence, determining the GPs key activities in the care process was essential, in order to identify the information required to support these activities, as Wilson indicates:

> "Information requirements analysis is seeking to identify the information needed by an organisation, or a part of an organisation, and hence a statement of what the information is to support by ways of the activities undertaken is an essential part of the analysis" [171].

As all the interviewees agreed that the CPTM included the key activities of the whole cancer care treatment pathway, the GPs clinical activities were determined by extracting the activities directly related to GPs from the CPTM. This set of activities was derived through consultation with the interviewees. This consultation involved the following stages:

- The CPTM included one hundred and ninety seven activities, handling this number of activities all at once, was very difficult for both the author and the interviewees. Additionally interviewees showed an interest only in the activities directly related to their roles (e.g. managers showed interest in the management activities not the clinical activities). Therefore the model was divided, in a full consultation with the interviewees, into sixteen sets of related activities as shown in Figure 4.10.

- Cancer screening activities
- Diagnosing activities
- Medical assessment activities
- Treatment activities
- Information management activities
- Knowledge base management activities
- Patient expectation management activities
- Care provision activities
- Constraints management activities
- Human resource management activities
- Physical resource management activities
- Technology management activities
- Planning management activities
- Intelligence assembly activities
- National targets management activities
- Overall performance management activities

Figure 4.10: CPTM activity sets

Each set included a group of related activities representing an aspect of the care process, see Table C.1 in Appendix C.

- The activity sets were presented to the interviewees according to their roles. Table 4.1 shows the activity sets and who they were presented to.

The interviewees in the presentation groups were asked to label each activity with one of the following labels:

Internal activity: GPs play a key role in this activity.

Border activity: GPs may/may not participate in this activity.

External activity: GPs are not involved in this activity.

They all agreed on fourteen internal activities, forty nine border activities and one hundred and thirty four external activities identified in Table C.1, Appendix C.

This classification process resulted in all interviewees agreeing on the fourteen key clinical activities in which GPs play a significant role within the entire cancer care process.

Activity set	**Presented to**
Screening subsystem	Clinicians: Personal Communication [1 to 5, 9 to 18, 25 to 28, 34]
Diagnosing subsystem	Clinicians: Personal Communication [1 to 5, 9 to 18, 25 to 28, 34]
Medical assessment subsystem	Clinicians: Personal Communication [1 to 5, 9 to 18, 25 to 28, 34]
Treatment subsystem	Clinicians: Personal Communication [1 to 5, 9 to 18, 25 to 28, 34]
Information management subsystem	Clinicians, IT professionals and Managers: Personal Communication [3 to 18, 20 to 24, 25 to 28, 34]
Knowledge base management subsystem	Clinicians, IT professionals and Managers: Personal Communication [1 to 5, 9 to18, 25 to 28, 33 to 34]
Patient expectation management subsystem	Clinicians and Managers: Personal Communication [1 to 19, 25 to 35]
Care provision subsystem	Clinicians: Personal Communication [1 to 5, 9 to 18, 25 to 28, 34]
Constraints management subsystem	IT professionals and Managers: Personal Communication [6 to 8, 19 to 24, 29 to 35]
Human resource management subsystem	IT professionals and Managers: Personal Communication [6 to 8, 19 to 24, 29 to 35]

Physical resource management subsystem	IT professionals and Managers: Personal Communication [6 to 8, 19 to 24, 29 to 35]
Technology management subsystem	IT professionals and Managers: Personal Communication [6 to 8, 19 to 24, 29 to 35]
Planning management subsystem	Managers: Personal Communication [6 to 8, 19 to 21, 29, 32 to 35]
Intelligence assembly subsystem	Managers: Personal Communication [6 to 8, 19 to 21, 29, 32 to 35]
National targets management subsystem	Managers: Personal Communication [6 to 8, 19 to 21, 29, 32 to 35]
Overall performance management	Managers: Personal Communication [6 to 8, 19 to 21, 29, 32 to 35]

Table 4.1: Activity sets with associated interviewee groups

4.6 Identifying information requirements

The information requirements were identified by determining the information required to perform each of the fourteen key GP clinical activities (the information inputs) and determining the information produced by each of these activities (the information outputs) as illustrated in Figure 4.11.

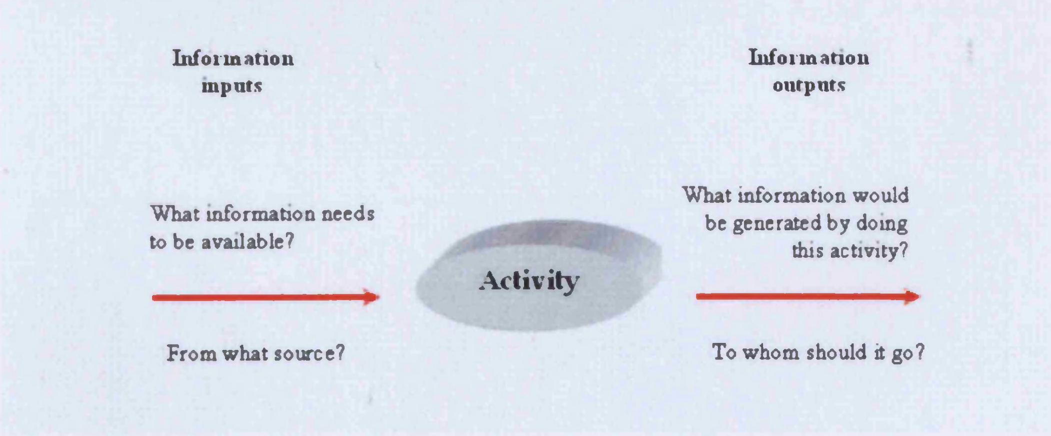


Figure 4.11: Identifying the information required to support each activity

This was achieved by undertaking the following stages:

- We continued the interviews with the clinicians[1] [Personal Communication 1 to 5, 9 to 18, 25 to 28, 33 to 34]. The fourteen clinical activities were presented to all of them; they were asked two questions *'What information is required by each of these activities?'* and *'what information would be generated by doing each of these activities?*
- The author then determined the source and the destination of the required information (i.e. where the information is currently available and to whom this information should go) relying on her medical experience and her understanding of the cancer care domain in this task.
- These results were presented to the thirty five interviewees for approval. Table 4.2 presents the information required by each activity, its source and destination.

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[1] This was purely a clinical task; hence we only involved the clinicians at this stage.

Information Input	**From**	**To**	**Activity**	**Information Output**	**From**	**To**
-Patient's medical complaint -Family history -Cancer referral guidelines -Cancer diagnosis staging -Contacts of the available MDT's -Genetic risk factors -Cancer genetics contact	-The patient -MDT -Cancer Genetics	-Primary care	**T9 Identify suspected cancer patients**	-Referral criteria for malignancy suspicion -Referral to cancer genetic	-Primary care	-MDT -2nd care -Cancer Genetics
See T9	See T9	See T9	**L112 Identify cancer patients and their families**	See T9	See T9	See T9
See T9	See T9	See T9	**L25 Identify cancer patients within that community**	See T9	See T9	See T9

-Referral criteria for malignancy suspicion -Investigations results	-Primary care -Primary care -2nd care -MDT	-MDT -2nd care -MDT	**T10 Diagnose cancer**	-Cancer diagnosis staging -Confirmation or rejection of cancer	-MDT	-1ry care -2nd care -3rd care
-Past medical history and case mix -Investigations results	- Primary care -Primary care -2nd care -3rd care	-MDT	**T8 Determine patient condition**	-Medical assessments notes	-MDT	-1ry care- 2nd care 3rd care
-Family history -Past medical history and case mix -Cancer diagnosis staging -Medical assessments notes -Investigations results	-Primary care -MDT	-MDT -Primary care -2nd care -3rd care	**T18 Determine the cancer patients medical requirements**	-The patient' medical requirement	-MDT	-Primary care -2nd care -3rd care

-Past medical history and case mix -Cancer diagnosis staging -Investigations results -Available treatment options -Medical assessments notes	-Primary care -MDT	-Primary care -2nd care -3rd care	**T11 Determine individual care pathway**	-Treatment plan	-MDT	-Primary care -2nd care -3rd care
See T11	See T11	See T11	**T12 Define what is appropriate treatment**	See T11	See T11	See T11
-Investigations results -Medical assessments notes -Treatment plan -Follow-up notes	-MDT -1ry care -2nd care 3rd care	-1ry care -2nd care 3rd care	**T14 Provide care to cancer patients according to individual care pathway**	-Assessed treatment details	-1ry care -2nd care -3rd care	-1ry care -2nd care -3rd care

See T14	See T14	See T14	**T15 Make available treatment in terms of equipment, drugs application and surgery as appropriate**	See T14	See T14	See T14
-Information required by the GPs -Information required by 2nd, 3rd and Palliative care teams	-1ry care -2nd care 3rd care	-1ry care -2nd care 3rd care	**L114 Identify what information the healthcare professionals need**	-Identification of the information relevant to patient's care	-1ry care -2nd care -3rd care	-1ry care -2nd care -3rd care
See L114	See L114	See L114	**L117 Define information relevant to patient care**	See L114	See L114	See L114
-Identification of the information relevant to patient's care	-1ry care -2nd care -3rd care	-1ry care -2nd care -3rd care	**L120 Determine where they need to be available**	-Relevant information destination	-1ry care -2nd care -3rd care	-1ry care -2nd care -3rd care
See L114 and L120	See L114 and L120	See L114 and L120	**S220 Determine how to Share this knowledge and learning**	See L114 and L120	See L114 and L120	See L114 and L120

T: Transformation activity
S: Support activity
L: Link activity
PMC: Planning, Monitoring and control activity

Table 4.2: Information requirements of the key activities, with source and destination

4.7 Problems in provision of information

The problems hindering the provision of the required information, throughout the entire treatment journey, were investigated by comparing the current information provision against the required information provision. This was achieved through the following stages:

- As explained in section 4.6 the essential information categories were agreed by all the thirty five interviewees [Personal Communication 1 to 35] as the required information provision.
- The current information provision was then identified as follows:
    - The fourteen conceptual activities derived from the CPTM were presented to the thirty five interviewees [Personal Communication 1 to 35], who were asked to determine the equivalent activities that currently take place in the real world. They determined five clinical activities, namely: cancer screening, cancer referral, cancer diagnosis, cancer treatment and follow-up and cancer information coordination.
    - The information inputs and outputs of these five real world activities were identified as previously explained in section 4.6, see Figure 4.11.
- The comparison between the current and the required information provision was conducted using the Maltese cross tool [170].
  The Maltese cross is a four-part matrix. Its north axis shows the conceptual activities while the south axis shows the equivalent current activities. The east and west axes are identical, with the west axis representing the information inputs and the east axis the information outputs, see Figure 4.12.

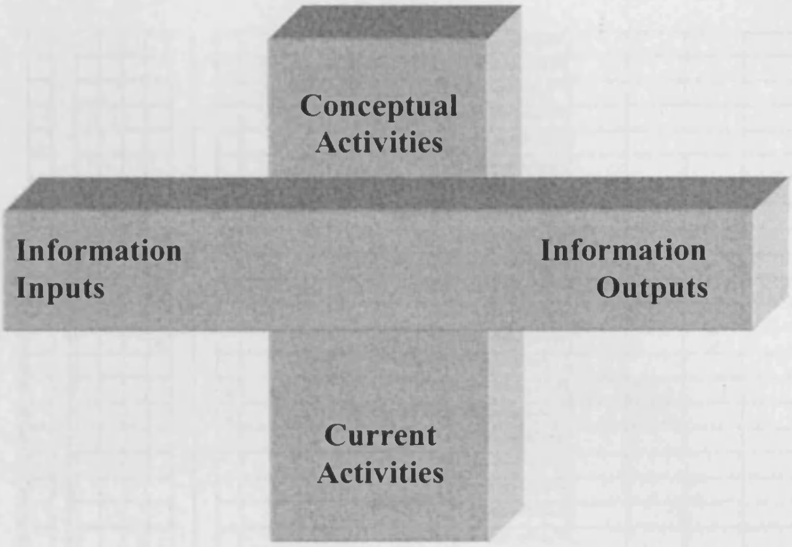


Figure 4.12: The Maltese cross structure

- The conceptual activities, their information inputs and outputs were placed in the upper half of the cross while the real activities, their information inputs and outputs were placed in its lower half as shown in Figure 4.13.

Activities
N

W
Input

E
Output

S
IPPs

Activities / IPPs	I_{24}Relevant information destination	I_{23}Identification of the information relevant to patient's care	I_{22}Information required by 2nd, 3rd & Palliative care teams	I_{21}Contact of all professionals involved in the care process	I_{20}Assessed treatment details	I_{19}Follow-up notes	I_{18}Treatment plan	I_{17}The patient' medical requirement	I_{16}Medical assessments notes	I_{15}Past medical history& case mix	I_{14}Available treatment options	I_{13}Investigations results	I_{12}Confirmation or rejection of cancer	I_{11}Contacts of the MDT in charge	I_{10}Referral to cancer genetic	I_{9}Referral criteria for malignancy suspicion	I_{8}Information required by the GPs	I_{7}Cancer genetics contact	I_{6}Genetic risk factors	I_{5}Family history	I_{4}Contacts of the available MDT's	I_{3}Cancer diagnosis staging	I_{2}Cancer referral guidelines	I_{1}Patient's medical complaint
14) Determine how to Share knowledge & learning	See activities 13, 15 for the information aspects (the management aspects are outide the scope)																							
13) Determine where they need to be available		X																						
12) Define information relevent to patient's care	See activity 13																							
11) Identify what information the healthcare proffesionals involved in the care process need			X														X							
10) Make available treatment in terms of equipment, drugs application & surgery as appropriate	see activity 10 for the information aspects (the management aspects outside the scope)																							
9) Provide care according to individual care pathway						X	X		X			X												
8) Define what is appropriate treatment	see activity 7 for the information aspects (the management aspects outside the scope)																							
7) Determine individual care pathway									X	X	X	X										X		
6) Determine the cancer patients medical requirements									X	X		X								X		X		
5) Determine patient condition										X		X												
4) Diagnose cancer												X				X								
3) Identify cancer patients within that community	See activity 1																							
2) Identify cancer patients & their families	See activity 1																							
1) Identify suspected cancer patients																		X	X	X	X	X	X	X
Cancer screening										2, 5									1	2, 5				
Cancer referral																		2	2	2, 3, 4, 5, 6, 7, 8	2	2	2	2, 3, 4, 5, 6, 7, 8
Cancer diagnosis												8				2, 3, 4, 5, 6, 7, 8								
Cancer treatment & follow up					2	2, 4, 5	2, 5	4	2	2, 3, 4, 5, 6, 7, 8	2, 5	5, 6, 8					6, 9			2, 3, 4, 5, 6, 7, 8		2, 5, 6		
Cancer information coordination			2, 4	4, 9													9							

Activities / IPPs	I_{1}Patient's medical complaint	I_{2}Cancer referral guidelines	I3Cancer diagnosis staging	I_{4}Contacts of the available MDT's	I_{5}Family history	I_{6}Genetic risk factors	I_{7}Cancer genetics contact	I_{8}Information required by the GPs	I_{9}Referral criteria for malignancy suspicion	I_{10}Referral to cancer genetic	I_{11}Contacts of the MDT in charge	I_{12}Confirmation or rejection of cancer	I_{13}Investigations results	I_{14}Available treatment options	I_{15}Past medical history& case mix	I_{16}Medical assessments notes	I_{17}The patient' medical requirement	I_{18}Treatment plan	I_{19}Follow-up notes	I_{20}Assessed treatment details	I_{21}Contact of all professionals involved in the care process	I_{22}Information required by 2nd, 3rd & Palliative care teams	I_{23}Identification of the information relevant to patient's care	I_{24}Relevant information destination
14) Determine how to Share knowledge & learning	See activities 11, 13 for the information aspects (the management aspects are outide the scope)																							
13) Determine where they need to be available																								X
12) Define information relevent to patient's care	See activity 11																							
11) Identify what information the healthcare proffesionals involved in the care process need																							X	
10) Make available treatment in terms of equipment, drugs application & surgery as appropriate	See activity 9 for the the information aspects (the management aspects outside the scope)																							
9) Provide care according to individual care pathway																				X				
8) Define what is appropriate treatment	See activity 7 for the information aspects (the management aspects outside the scope)																							
7) Determine individual care pathway																		X						
6) Determine the cancer patients medical requirements																	X							
5) Determine patient condition																X								
4) Diagnose cancer			X									X												
3) Identify cancer patients within that community	See activity 1																							
2) Identify cancer patients & their families	See activity 1																							
1) Identify suspected cancer patients									X	X														
Cancer screening																								
Cancer referral									2, 3, 4, 5, 6, 7, 8	2, 3, 4, 5, 6, 7, 8														
Cancer diagnosis			5, 6									5, 6												
Cancer treatment & follow up																								
Cancer information coordination																							4, 9	4, 9

Figure: 4.13 The Maltese Cross Comparison

- As a result of this comparison seven types of information problem in the current information provision were determined, see Figure 4.14.

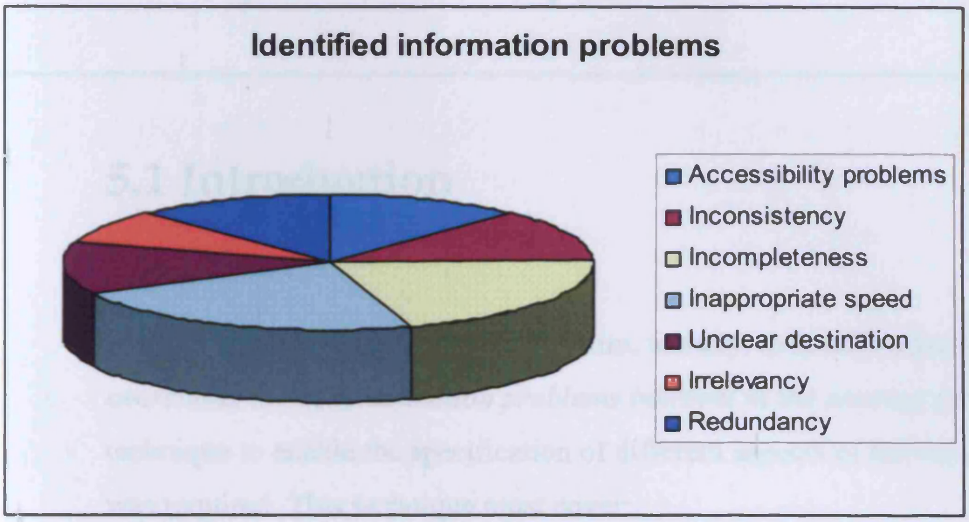


Figure 4.14: The identified information problems [25]

Inappropriate speed i.e. the timeliness of the information was the most frequent (23% of the identified problems), followed by incompleteness of the information (21% of the identified problems). Inconsistency, accessibility and redundancy of the information problems were at the same level (each accounting for 12%), as did unclear destination also 12%. The irrelevancy of the information was the least frequent problem (8% of the identified problems).

4.8 Conclusions

In this chapter, we have described the adaptation of SSM to create a holistic analysis approach. This holistic approach was used to investigate the cancer care domain. This identified the information requirements. Thus fulfilling the first two research aims, namely:

- To use a holistic analysis approach to investigate the whole cancer treatment journey in Wales.
- To determine the key information that must be communicated between GPs and other members of cancer care teams in Wales.

Chapter Five

Requirements Specification for PEPRS

5.1 Introduction

In order to achieve the third research aim, namely: *to specify a system which overcomes the communication problems inherent in the existing system*, a technique to enable the specification of different aspects of the solution system was required. This technique must cover:

- **Functional requirements:** what functions should the system provide to GPs and other care team members?
- **Behavioural requirements**: how will these functions be co-coordinated?
- **Structure requirements**: what data will be used to perform the functional requirements?

This chapter describes how our holistic approach was extended with specification features which were used to specify the requirements of the whole cancer treatment journey. The final specification resulting from using this approach are presented. This specification is named the Proposed EPRS (PEPRS). This acronym is used to refer to this specification in this thesis.

5.2 Potential specification techniques

In order to identify an appropriate technique to accomplish the specification task, a review of software engineering literature was conducted [27, 39, 42, 134, 147, 152, 153, 157, 172]. This review showed the availability of many techniques. It also showed that some techniques were more frequently used than others.

Each technique was investigated with respect to our project. The results of this investigation are summarised in Table 5.1.

This review showed that each technique supports some of the specification aspects required but not all of them (i.e. no best technique for all situations). Consequently, available techniques were evaluated and Unified Modelling Language (UML): use cases, activity and class diagrams were chosen to specify the functional, behaviour and structural requirements respectively as discussed in more details in sections 5.3, 5.4 and 5.5.

Specification technique	**Functional specifications**	**Behavioural specifications**	**Structural specification**	**Potential strengths for using it**	**Potential limitations for using it**
Text-based specification [172]	√	√	√	- It provides flexible and powerful way to expressing the requirements.	-It results in a very large quantity of text, this can be a barrier to the users reviewing the specification properly, e.g. failure to mention an important dataflow or an incorrect statement about the direction of flow may not be noticed in a long written specification. -It is usually vague and ambiguous, particularly with behavioural and structure specification. -The above limitations make it difficult to validate the specified requirements.
Pseudo-code [27, 147]	√	√		- It minimises ambiguity and misunderstanding.	- Our users are not familiar with the pseudo-code conventions, and would find validating the specified requirements difficult.
Formal (mathematically-based techniques)	√	√		- It can provide precise and unambiguous specification.	- It requires mathematical experience; the author and most of the users have limited mathematical skills.

[27, 42, 134]				-It can prove that the solution system meets the specified requirements.	Functions that provide human interaction are difficult to express mathematically.
Flow chart [27, 134, 147]		√		- It clearly shows the flow of control.	- It does not show who is responsible for each activity. - It does not show concurrent activities.
DFD diagramming [134, 172]	√			- It enables the communication with the users. - It provides the flexibility to abstract to any level of detail as required.	- It does not clearly determine when to stop decomposing processes. This may drag the specification to immature design as it answers "how" instead of "what" questions.
Entity Relationship modelling [27]			√	- It is widely used and straightforward to implement. - It separates the data from the processes that must be applied to transform this data.	- It often needs a supplementary data dictionary because it lacks detailed description of the entities, relationship and attributes included in the model.
Throw-away prototyping [27, 134, 152]	√			- It approximates the final system to the users and allows them to validate the requirements specification before progressing to the design and implementation stages.	- It can raise false expectation of the delivery time.

Unified Modelling Language (UML[39, 152, 157]):				-It provides a widely range of diagram types, this offers a clear separation of different specification aspects.	- Lots of diagrams can be confusing to users.
Use case diagram	√			- It provides an effective way to capture and validate the functional requirements as they are easy to understand by users.	
Activity diagram		√		- It shows who is responsible for each activity. It also shows concurrent activities.	
Class diagrams			√	- It clearly identifies the classes that should exist in the system and the relationships between them.	

√ Frequently used

√ Occasionally used

Table 5.1: Strengths and limitations of using different specification tools in our project

5.3 Specifying and validating functional requirements

5.3.1 Selecting the technique

The first stage of the specification process was to determine what functions the PEPRS should provide in order to support the identified key activities of GPs in the cancer care process.

The following techniques were considered:
- Throw-away prototyping.
- Text-based specification.
- DFD diagramming.
- UML use case diagrams.

The throw-away prototyping was excluded to avoid raising a false expectation among the users of an earlier delivery time of the system than could be achieved.

Initially a combination of the text-based specification and DFD were used. However this was not appropriate as the users were not familiar with the diagram notation and they found reviewing and validating the functional requirements an exhaustive and time consuming process. Consequently other techniques were investigated and UML use case diagrams were then chosen, because:
- They are easy to understand by users; hence they can be used for gathering, specifying and validating the requirements.
- They link each function to the user asking for it. This will be important in extending the system in the future as the specified requirements will be easily traceable.

- The literature shows that use cases can be used as an extension to SSM, as Bustard et al recommends:

  > "SSM is a broader form of analysis than use-case modelling. SSM leads directly to the development of coherent business models and use-case modelling helps to identify particular functions of this business" [45]

5.3.2 Moving from SSM to UML use cases

As discussed in section 4.5, the SSM analysis resulted in determining fourteen clinical activities that mainly involve GPs and also involve other care team members.

Hence, to identify what functions the PEPRS should provide to support these clinical activities, clinicians involved in each activity were interviewed as shown in Table 5.2. The interviewees were asked: '*In order to perform this clinical activity, what function would you like our system to provide?*'

Treatment stage	Activity	Interviewees
Referral	- T9 Identify suspected cancer patients. - L112 Identify cancer patients and their families. - L25 Identify cancer patients within that community. - T8 Determine patient condition.	GPs, cancer genetics and cancer specialists [Personal Communication 1 to 5, 9 to 18].
Diagnosis	- T10 Diagnose cancer.	GPs and cancer specialists [Personal Communication 3 to 5, 9 to 18].
Treatment	- T18 Determine the cancer patients medical requirements. - T11 Determine individual care pathway. - T12 Define what is appropriate treatment. - T14 Provide care to cancer patients according to individual care pathway. -T15 Make available treatment in terms of equipment, drugs application and surgery as appropriate.	GPs, cancer specialists and palliative care [Personal Communication 3 to 5, 9 to 18, 27 to 28].
Follow-up	- L114 Identify what information the patients need. - L117 Define information relevant to patient care. - L120 Determine where they need to be available. - S220 Determine how to Share this knowledge and learning.	GPs, cancer specialists, WCTN and palliative care [Personal Communication 3 to 5, 9 to 18, 27, 28, 33, 34].

Table 5.2: Care team members interviewed for each activity

This resulted in the capture and specification of many required functionalities by various clinicians. These functions were categorised into five sets of use cases[1] to reflect the requirements of the five clinician groups interviewed, namely: GPs, cancer specialists, cancer geneticist, WCTN and palliative care clinicians. Each set was presented to the clinicians concerned for further validation and agreement on the final version.

The constructed diagrams followed UML version 1.5 Notation Guide [132, 142], see Table 5.3:

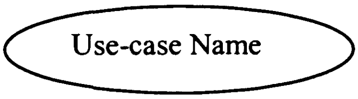
Diagram element	Notation
The system's boundaries. Only represented on the top level diagram	 System Name
A use case is a coherent unit of functionality provided by a system	 Use-case Name
An actor is a role played by an external user when communicating with a particular use case. An actor could be a person or an external system	 Actor Name
Relationships: The participation of an actor in a use case A sub-case of the use case An additional behaviour if a certain exception is met Inheritance between a generalised and specialised use case	——————— <<include>> - - - - - - - - ▶ <<extend>> - - - - - - - - ▶ ——————▷

Table 5.3: The use case diagram notations

The top level use case diagrams are shown in Figures 5.1, 5.2 and 5.3. The complete sets of the use cases are in Appendix D.

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[1] Each use case represented a single function.

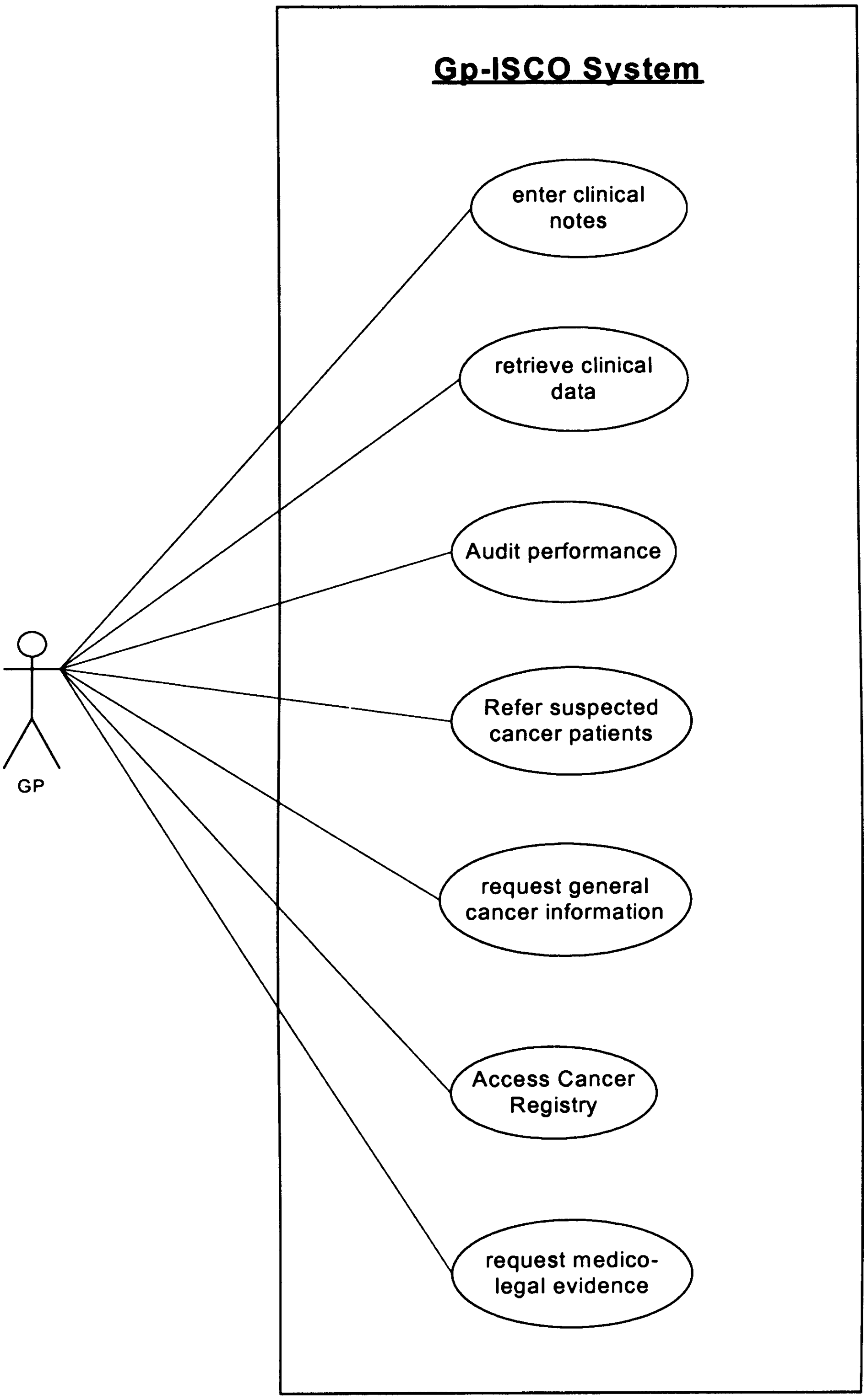


Figure 5.1: GP top level use cases

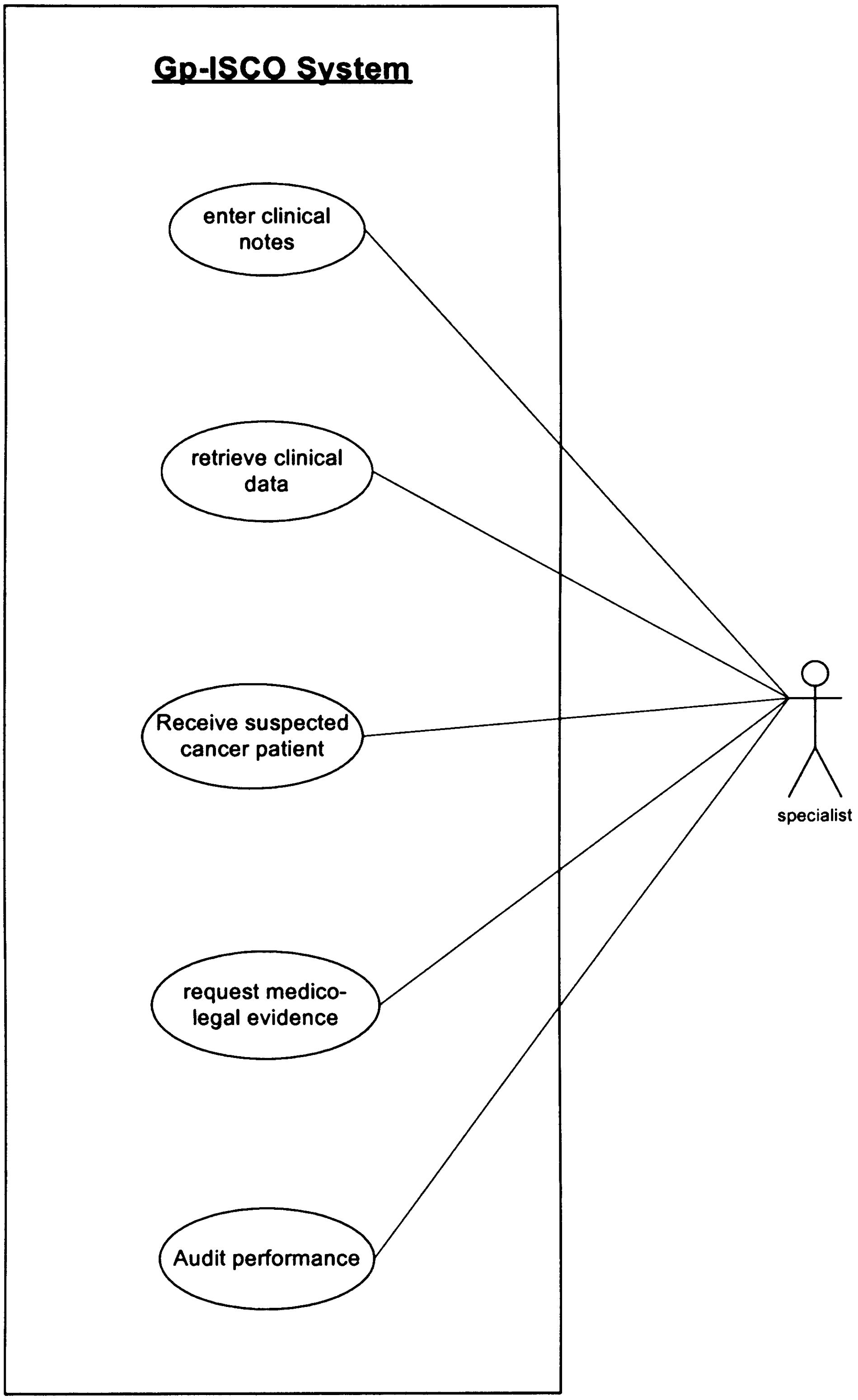


Figure 5.2: Cancer specialist top level use cases

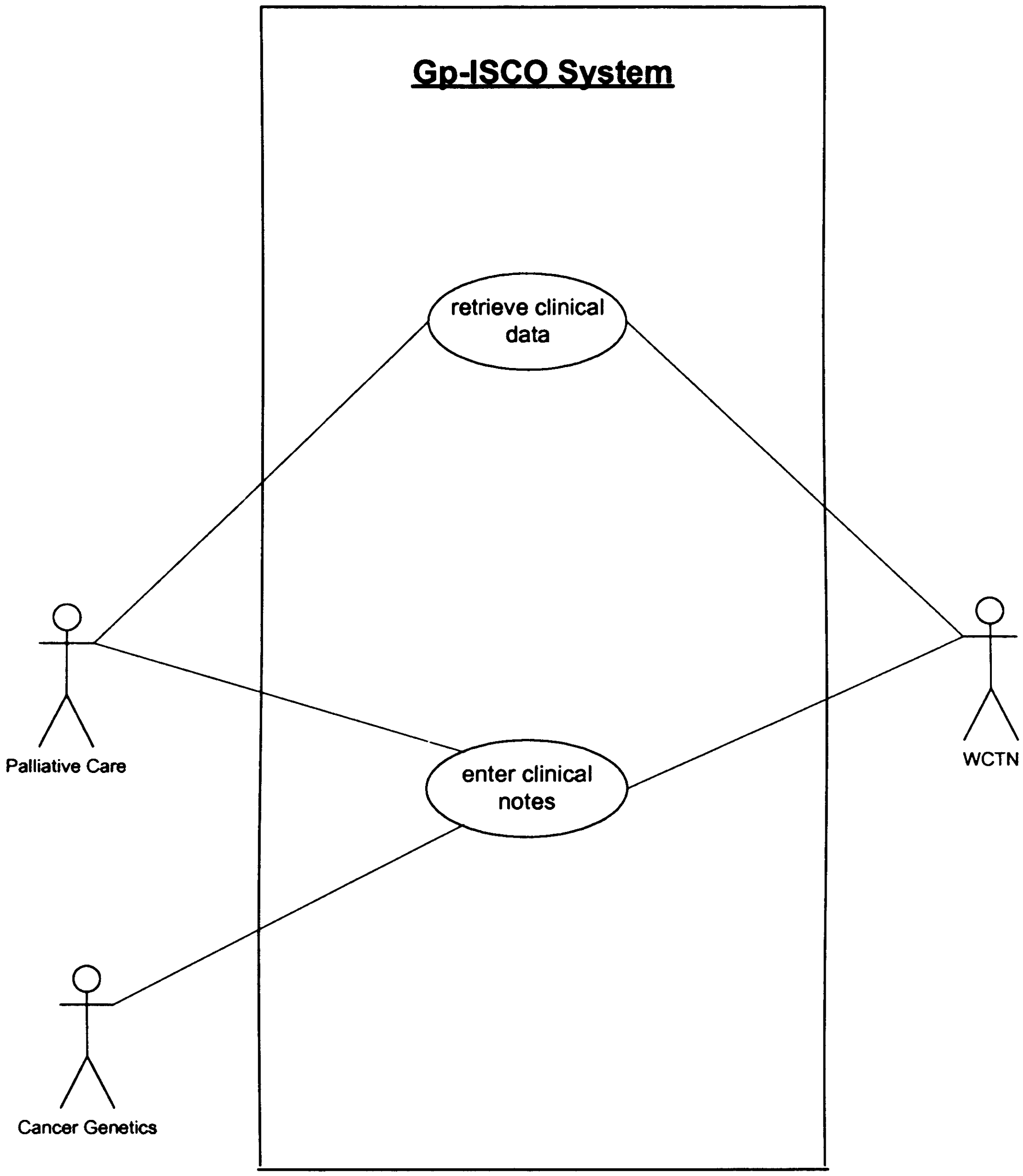


Figure 5.3: Palliative care, cancer genetics and WCTN top level use cases

5.4 Behavioural specification

The aim of this process was to specify how the functional requirements, specified in the use cases, will be coordinated. Many techniques were available, including:

- Text-based specification.
- Pseudo-code technique.
- Formal (mathematically based specification).

- Flow chart diagram.
- UML activity diagram.

From the outset: text based, pseudo-code and mathematically based techniques were excluded. The text specification was excluded because it is usually vague. Pseudo-code and mathematical techniques were excluded because our users are not familiar with them and do not have the necessary expertise to deal with them. The flow chart and UML activity diagrams were investigated in more depth, and the activity diagram was chosen because:

- It clearly shows who is responsible for each activity.
- It can model concurrent activities.
- An activity diagram can extend SSM by mapping the conceptual activities to real activities in the solution system, as Tawileh et al states:

> "The combination of SSM and UML -activity diagram- proved to be highly beneficial. While SSM aided the identification of required system activities, UML provided the means to link those activities to the final information system and communicate the system design in an elegant, standardised notation that is widely understood by software developer" [159].

Three activity diagrams representing the whole treatment pathway were designed, namely:

- Diagnosis cancer activity diagram (see Figure 5.4).
- Treat cancer activity diagram (see Figure 5. 5).
- Follow-up cancer activity diagram (see Figure 5. 6).

Each of these diagrams shows the sequence of activities conducted at this stage and who is responsible for each activity. It also shows concurrent activities that will take place in parallel. The diagrams follow the UML version 1.5 Notation Guide [132, 142], as shown in Table 5.4:

Diagram element	Notation
Initial state	●
Final state	◉
Action state is a shorthand for a state with an internal action and at least one outgoing transition	⬭
Transition	→
Decision to indicate different possible transitions	◇
Synchronization bars to show concurrent activities	▬
Swimlanes to show who is resposible for each activity.	| | |
Notes	🗎

Table 5.4: The activity diagram notations

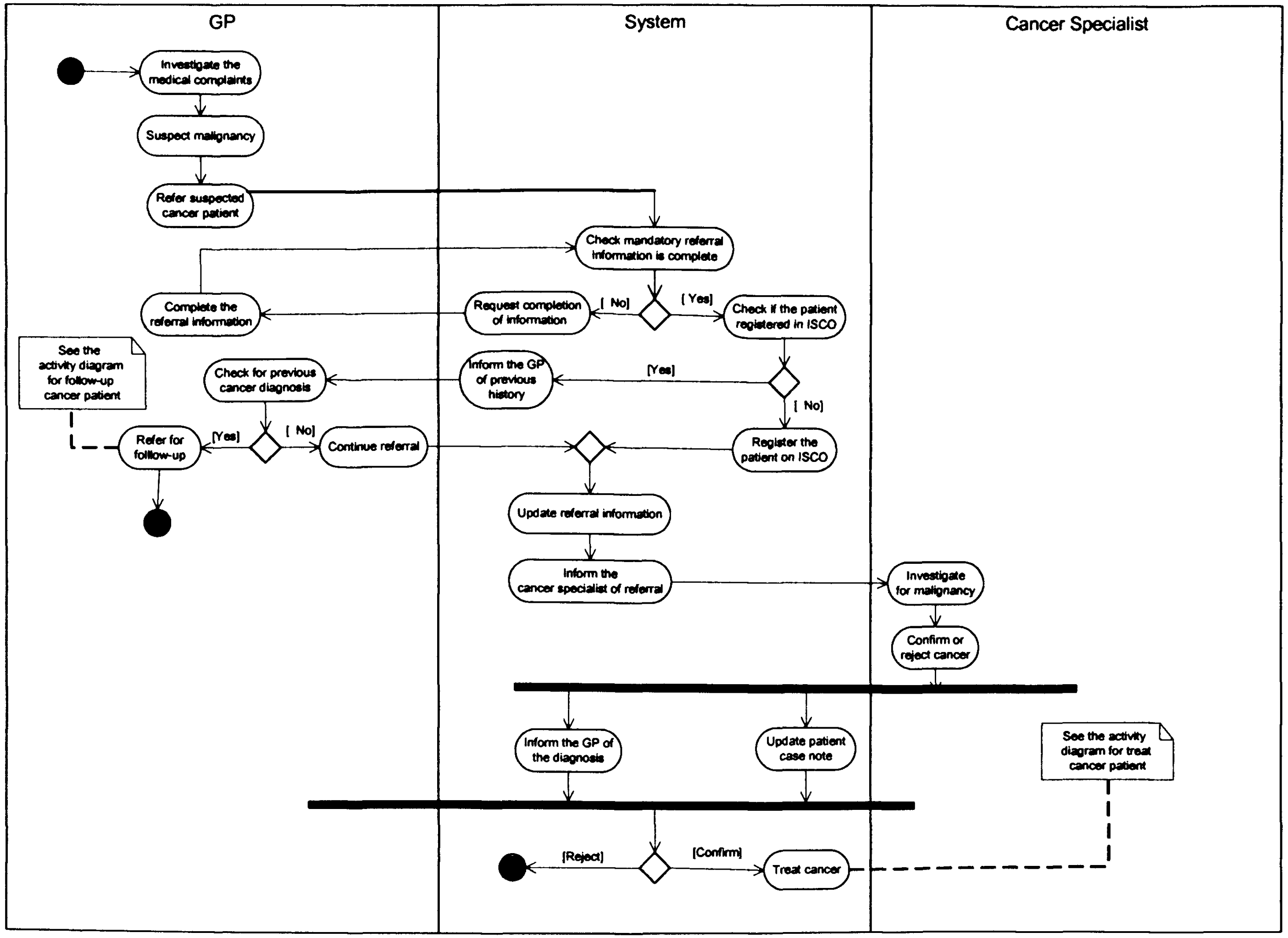


Figure 5.4: Diagnose cancer activity diagram [90]

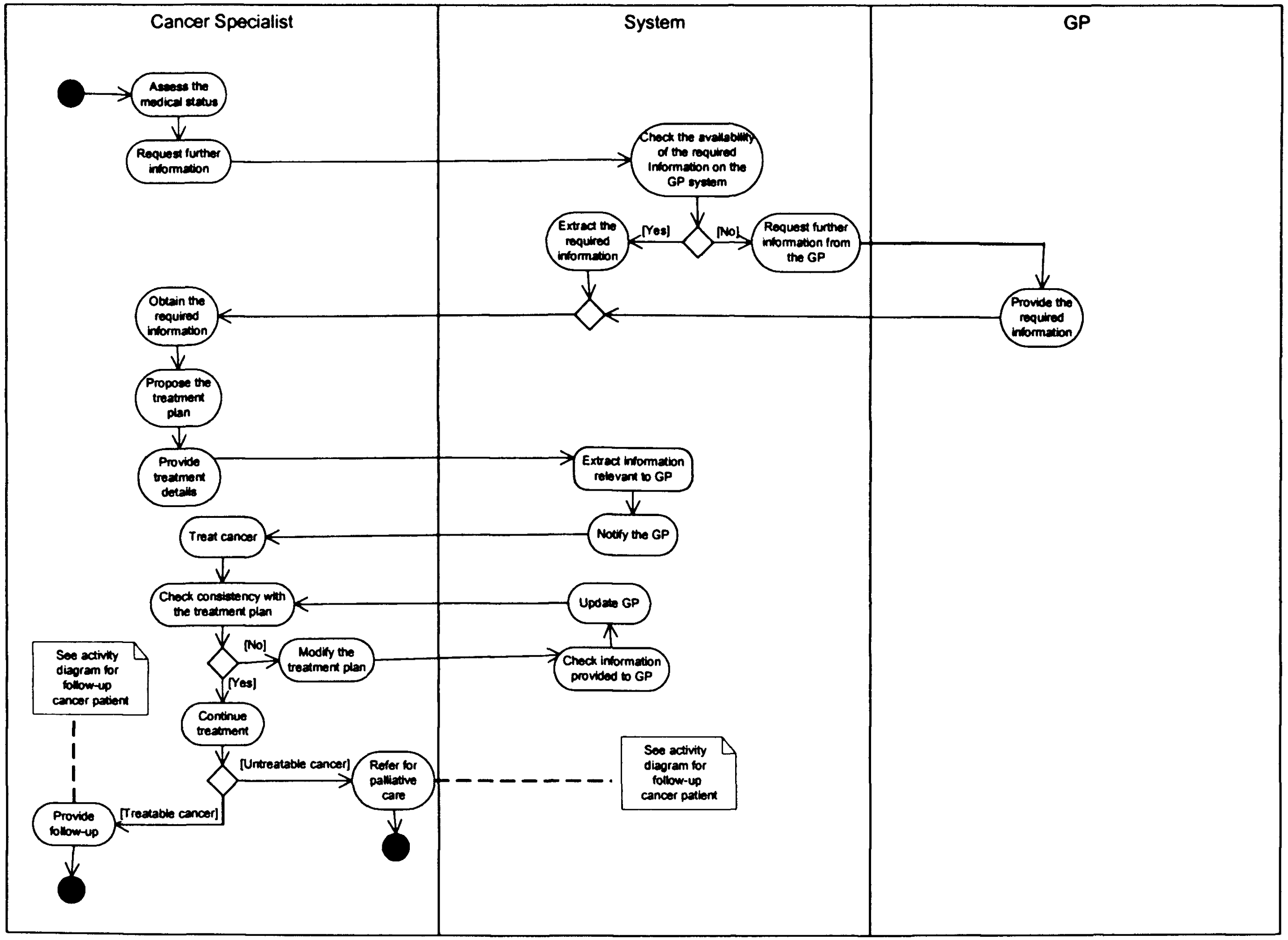


Figure 5.5: Treat cancer activity diagram

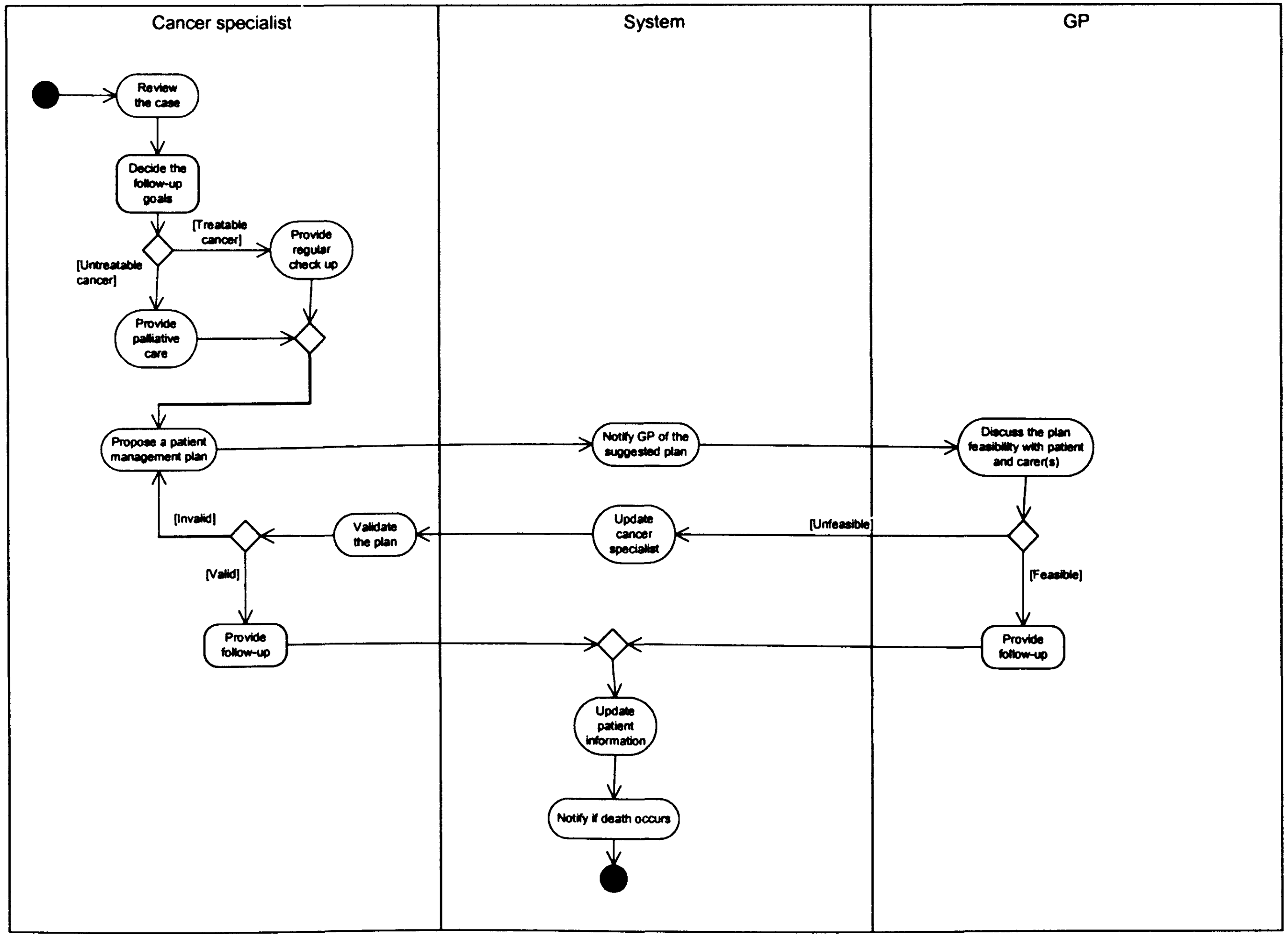


Figure 5.6: Follow-up cancer activity diagram

5.5 Structural specification

The structural specification focussed on understanding and documenting the data structure of the solution system, two techniques were considered for this stage namely:

- Entity Relationship modelling.
- UML class diagram.

Both techniques appeared to be offering the same advantages, however the class diagram was chosen as it gave continuity of using the UML notation in all specification stages.

The aim of this process was to specify the data structure of the PEPRS. This was achieved by developing a class diagram including the classes that should exist in this system and their relationships (see Figure 5.7).

It indicates the data that is already stored either in the current ISCO/CaNISC system or a GPs EPRSs. This will be used in future work to design the PEPRS by extending the current ISCO/CaNISC data structure to include all the specified data.
The diagrams followed the UML version 1.5 Notation Guide [132, 142], as shown in Table 5.5.

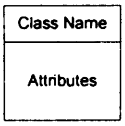
Diagram element	**Notation**
A class is the descriptor for a set of objects with similar structure, behaviour, and relationships.	
Relationships:	
Generalization: inheritance between a parent super-class and a child sub-class.	————▷
Association: a description of a connection among instances of classes.	————

Table 5.5: The class diagram notations

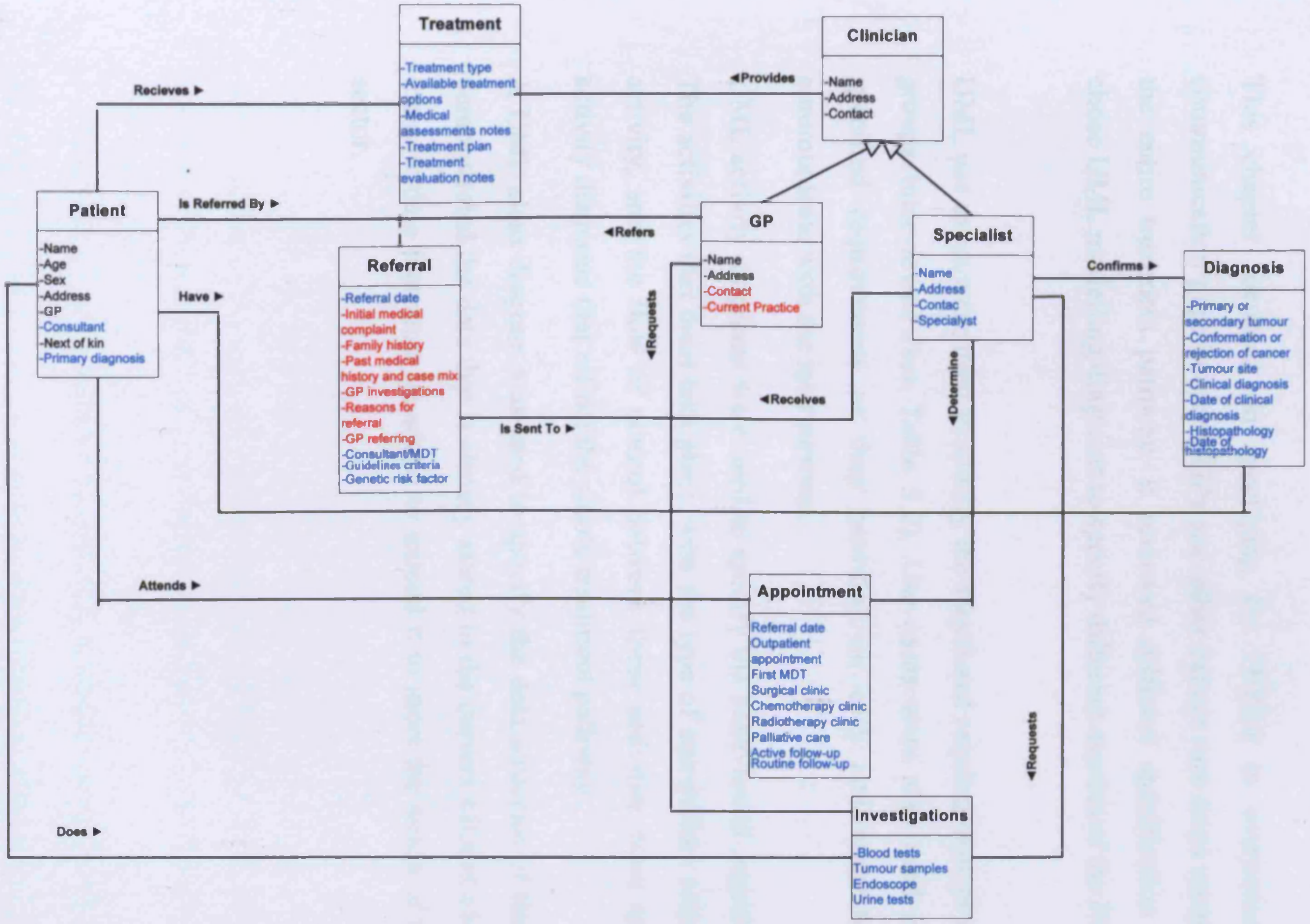


Figure 5.7 UML class diagram of data structure of the PEPRS

Currently Stored in ISCO/CaNISC
Currently Stored in GPs EPRS
Currently Stored in both

5.6 Conclusions

This chapter focussed on specifying the PEPRS to overcome the identified communication gaps between GPs and other cancer care team members throughout the entire treatment pathway. It reviewed different specification techniques and chose UML modelling diagrams to specify different aspects of the PEPRS.

UML use cases were used to specify the functional requirements of the five clinician groups interviewed (see Table 5.2). Use cases were also used in validating the specified requirements as they provided an easy and understandable tool to communicate with the interviewees.

UML activity diagrams were used to specify the behavioural aspects of the PEPRS. The activities that must take place, with the type of stakeholder responsible for each activity, and the flow of control between these activities were specified in three activity diagrams that reflect the whole treatment pathway.

A UML class diagram was used to specify the data structure of the PEPRS. It also demonstrated the data that is already stored in the current ISCO/CaNISC system and the new data that must be added to extend it to meet the needs of the primary care sector.

Chapter Six

Evaluation

6.1 Introduction

The work presented in this thesis is based on the following hypothesis:
"'A holistic analysis approach that investigates the whole cancer treatment journey in Wales and addresses both human (soft) and technical (hard) aspects of the requirements will identify a more complete set of requirements in comparison to the traditional analysis approach that investigates certain treatment stages and addresses the technical aspects of the requirements only'

In order to prove this hypothesis, the following statements have to be demonstrated:

- A traditional analysis approach was undertaken.
- A holistic analysis approach was undertaken.
- The use of the holistic analysis approach provided a more complete set of requirements than traditional approaches.

This chapter will evaluate the work presented in this thesis by assessing the achievements of the research against this research hypothesis. It will also discuss the limitations of the work and introduce research projects spawned by our work. It is structured as follows:

- Section 6.2 shows that a traditional analysis approach was used in this project.
- Section 6.3 shows that a holistic analysis approach was used in this project.
- Section 6.4 assesses whether a more complete set of requirements has been obtained by the holistic analysis.

- Section 6.5 discusses the limitations of this research.
- Section 6.6 identifies related projects in Cardiff initiated and influenced by our project to show the impact of the work.
- Section 6.7 draws conclusions for this chapter.

6.2 Undertaking a traditional analysis approach

Section 3.3 provided evidence to show that a traditional approach, that adapted SSADM, was employed at the start of the project.

At that stage:

- We focused mainly on the technical aspects of the requirements, see section 3.3.1.
- Identified two potential user groups namely GPs and cancer specialists, see section 3.3.2, 3.3.3.
- Specified the functional requirements of the two groups using UML use case diagrams, see Appendix B.

6.3 Undertaking a holistic analysis approach

The research hypothesis indicated that a holistic approach must consider three dimensions namely:

- Investigating the whole cancer treatment pathway
- Addressing human (soft) aspects of the requirements.
- Addressing technical (hard) aspects of the requirements.

Our analysis:

- Investigated the whole cancer treatment journey in Wales (as detailed in section 4.4)
- It addressed human (soft) aspects of the requirements by:

  - Involving a wide variety of the stakeholders including GPs, cancer specialists, practising and research nurses, managers and IT professionals [Personal Communication 1 to 35] in the analysis activities through full consultations and continued feed back from these stakeholders.
  - Identifying many cultural and organisational issues as the rich pictures in Figures 4.2 and 4.3 illustrated.
- It addressed technical (hard) aspects of the requirements by:
  - Assessing the technical feasibility of interfacing the ISCO/CaNISC system with GP systems, as explained in section 3.3.1.
  - Determining the clinical processes which the PEPRS will support (i.e. the fourteen key clinical activities to be undertaken by GPs. These were agreed by all the interviewees), see section 4.5.
  - Identifying the information that must be communicated between GPs and other members of the cancer care teams in Wales, as explained in section 4.6.
  - Identifying seven information problems that hinder the provision of the required information, as discussed in section 4.7.
  - Specifying functional, behavioural and structural aspects of the PEPRS, see sections 5.3, 5.4 and 5.5.

6.4 Provision of a more complete set of requirements

The hypothesis argues that the use of the holistic approach **will provide a more complete set of requirements**. In this section we assess the results achieved when the holistic approach was adopted against the results we would have achieved if we had ignored the holistic view and continued with a traditional approach.

6.4.1 Involvement of more user groups

As discussed in section 3.3 when the traditional analysis was initially used, we focused on investigating the requirements of the GPs and cancer specialists only. Whereas the use of the holistic approach allowed us to investigate the requirements of other types of clinicians involved in the care process. This included staff involved in cancer genetics, palliative care and WCTN requirements. This occurred because the approach made the analyst more aware of the wider context and this encouraged the involvement of more stakeholders.

Table 6.1 compares the clinicians involved at each treatment stage when using each analysis approach in this project.

Treatment Stage	Clinicians involved when the holistic approach was used	Clinicians involved when the traditional approach was used
Referral	▪ GPs ▪ Cancer specialists ▪ Cancer genetics	▪ GPs ▪ Cancer specialists
Diagnosis	▪ GPs ▪ Cancer specialists	▪ GPs ▪ Cancer specialists
Treatment	▪ GPs ▪ Cancer specialists ▪ Palliative care	▪ GPs ▪ Cancer specialists
Follow-up	▪ GPs ▪ Cancer specialists ▪ WCTN ▪ Palliative care	▪ GPs ▪ Cancer specialists

Table 6.1: Comparison of clinician groups involved in the analysis approaches

6.4.2 Identification of more functional requirements

In this section we assess whether the holistic approach has led to specifying more functional requirements by comparing the use cases identified by the traditional approach against the use cases identified by the holistic approach.

As discussed in section 6.4.1, the holistic approach identified use cases for five clinician groups. Each use case group included three levels of use cases (main use cases, first level of sub-cases and second level of sub-cases) as shown in Appendix D. For each use case, or sub-case, we compared whether it was fully, partially or not identified by the traditional and the holistic approaches. This comparison is detailed in Table 6.2.

Use case name	**Traditional**	**Holistic**
GPs use cases		
▪ Enter clinical notes	o	●
▪ Provide contact details	●	●
▪ Provide contact during the working hours	●	●
▪ Provide contact out of hours	●	●
▪ Enter past medical history details	●	●
▪ Provide family dynamics information	X	●
▪ Enter co-morbidity details	X	●
▪ Document information provided to patient	X	●
▪ Enter death details	●	●
▪ Enter death time	●	●
▪ Enter death reasons	●	●
▪ Retrieve clinical data	o	●
▪ Retrieve case note summary	o	●

▪ Retrieve first visit details	X	●
▪ Retrieve the overview of the treatment plan	X	●
▪ Check the expected side effects	X	●
▪ Retrieve discharge summary	●	●
▪ Identify own patients on clinical trials	X	●
▪ Identify own patients having genetic risk	X	●
▪ Obtain other professionals contact details	●	●
▪ Obtain contact during the working hours	●	●
▪ Obtain contact out of hours	●	●
▪ Audit performance	X	●
▪ Refer suspected cancer patient	O	●
▪ Retrieve the referral guidelines	X	●
▪ Obtain specialist contact details	●	●
▪ Enter referral criteria	●	●
▪ Request general cancer information	X	●
▪ Request the referral guidelines	X	●
▪ Request the MDTs contact	X	●
▪ Access the diagnosis staging criteria	X	●
▪ Identify general genetics risk information	X	●
▪ Access general clinical trials information and answers to patients FAQs	X	●
▪ Access the palliative care handbook	X	●

▪ Access the hospital information leaflets	X	●
▪ Access cancer registry	X	●
▪ Require medico legal evidences	X	●
Cancer specialists use cases		
▪ Enter clinical notes	0	●
▪ Enter case note summary	0	●
▪ Enter first visit details	X	●
▪ Enter overview of the treatment plan	X	●
▪ Highlight the expected side effects	X	●
▪ Enter discharge summary	●	●
▪ Provide contact details	●	●
▪ Provide contact during the working hours	●	●
▪ Provide contact out of hours	●	●
▪ Retrieve clinical data	0	●
▪ Request GP contact details	●	●
▪ Request contact during the working hours	●	●
▪ Request contact out of hours	●	●
▪ Retrieve past medical history details	●	●
▪ Retrieve family dynamics information	X	●
▪ Retrieve co morbidity details	X	●
▪ Retrieve the information provided to the patient	X	●

▪ Retrieve death details	●	●
▪ Retrieve death reasons	●	●
▪ Retrieve death time	●	●
▪ Receive suspected cancer patient	●	●
▪ Request medico legal evidences	X	●
▪ Audit performance	X	●
Palliative care use cases		
▪ Retrieve clinical data	X	●
▪ Retrieve family dynamics information	X	●
▪ Retrieve death details	X	●
▪ Retrieve death time	X	●
▪ Retrieve death reasons	X	●
Cancer genetics use cases		
▪ Enter clinical notes	X	●
▪ Notify GP when the patient has a genetic risk	X	●
▪ Provide individual risk information	X	●
▪ Prevent access	X	●
WCTN use cases		
▪ Retrieve clinical data	X	●
▪ Enter clinical notes	X	●
▪ Enter case note summary	X	●
▪ Highlight the expected side effect	X	●

▪ Notify the GP when the patient is recruited to trials	X	●
▪ Provide contact details	X	●
▪ Provide contact during the working hours	X	●
▪ Provide contact out of hours	X	●

● Fully identified
O Partially identified
X Not identified

Table 6.2: Comparison of use cases identified by the traditional and holistic approaches

GP use cases:

The holistic approach identified thirty seven GP use cases in total. Seven of these are main use cases, eighteen first level sub-cases and twelve second level sub-cases, as detailed in Table 6.2.

- At the main level of use cases, the traditional approach partially identified three out of the seven and did not identify the other four, see Figure 6.1.
- At the first level of sub-cases, the traditional approach identified six out of the eighteen, partially identified one and did not identify the other eleven, see Figure 6.1.
- At the second level of sub-cases, the traditional approach identified seven out of the twelve and did not identify the other five, see Figure 6.1.

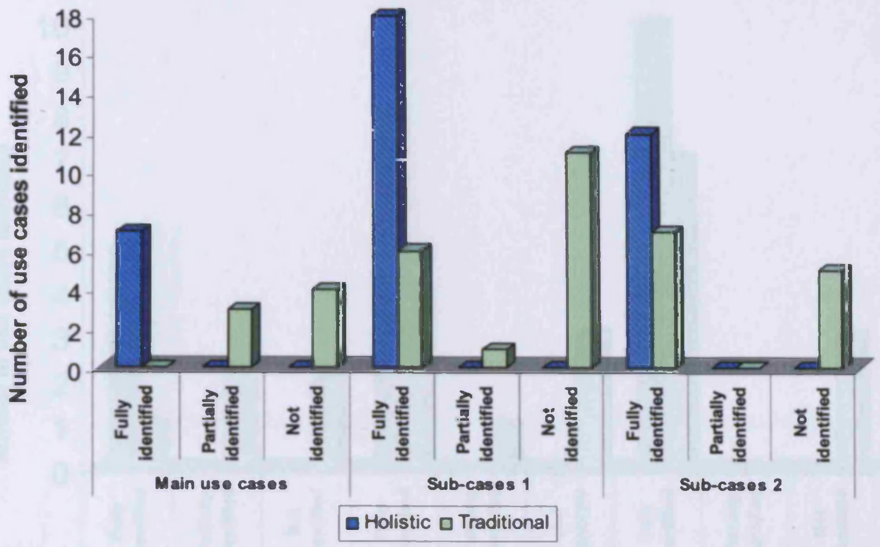


Figure 6.1: Comparison of identifying GP use cases by the approaches

Cancer specialist use cases:

The holistic approach identified twenty three cancer specialist use cases in total. Five of them are main use cases, eight first level sub-cases and ten second level sub-cases, see Table 6.2.

- At the main level of use cases, the traditional approach identified one out of the five, partially identified two and did not identify the other two, see Figure 6.2.
- At the first level of sub-cases, the traditional approach identified four out of the eight, partially identified one and did not identify the other three, see Figure 6.2.
- At the second level of sub-cases, the traditional approach identified seven out of the ten and did not identify the other three, see Figure 6.2.

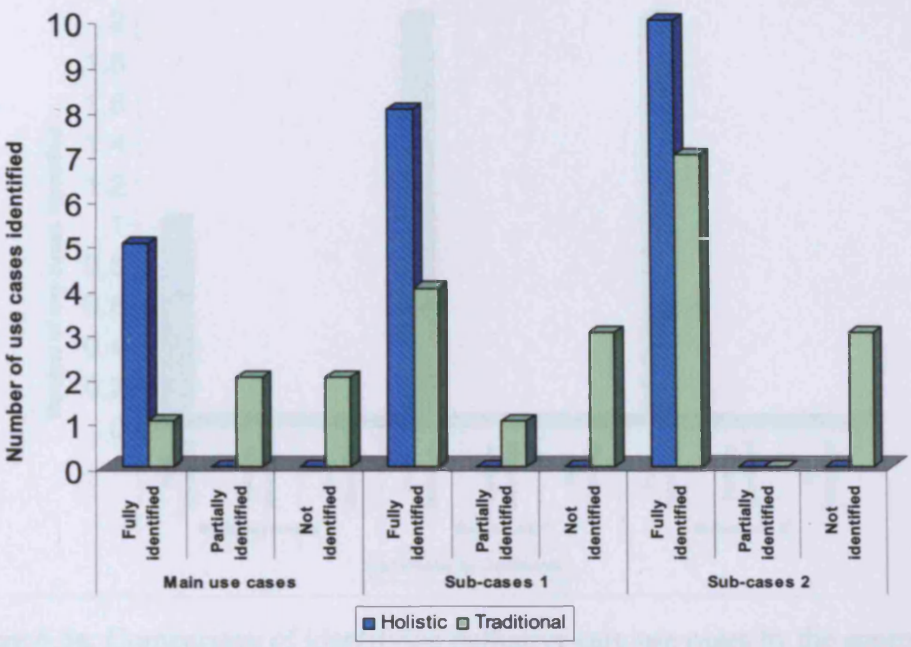


Figure 6.2: Comparison of identifying cancer specialist use cases by the approaches

Palliative care, cancer genetics and WCTN use cases:

As detailed in Table 6.2, the holistic approach identified five palliative care use cases, one main use case, two first level sub-cases and two second level sub-cases, (see Figures 6.3a). It also identified four cancer genetics use cases, one main use case, two first level sub-cases and one second level sub-case (see Figures 6.3b). In addition, it identified eight WCTN use cases, two main use cases, two first level sub-cases and four second level sub-cases (see Figures 6.3c).

Whereas the traditional approach was limited to the analysis of GPs and cancer specialists' requirements only, hence it did not investigate the requirements of palliative care, cancer genetics or WCTN and did not identify any use cases for them.

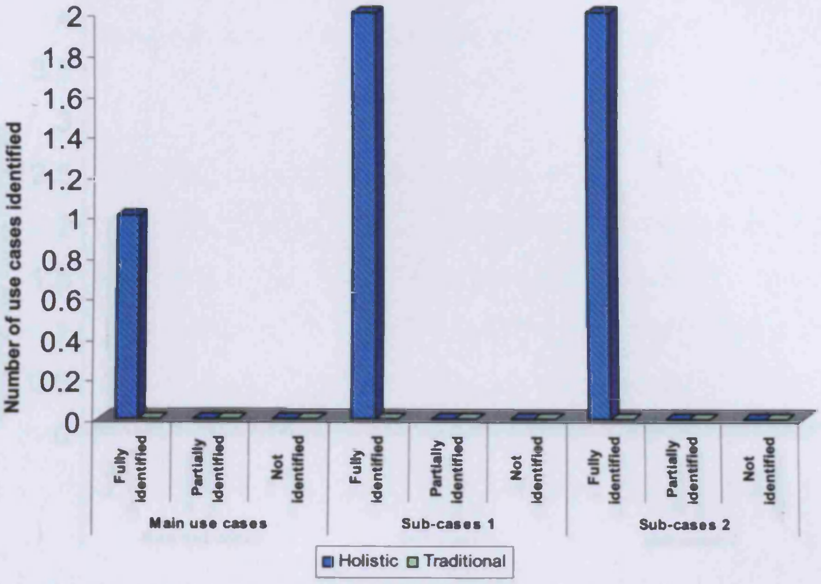


Figure 6.3a: Comparison of identifying palliative care use cases by the approaches

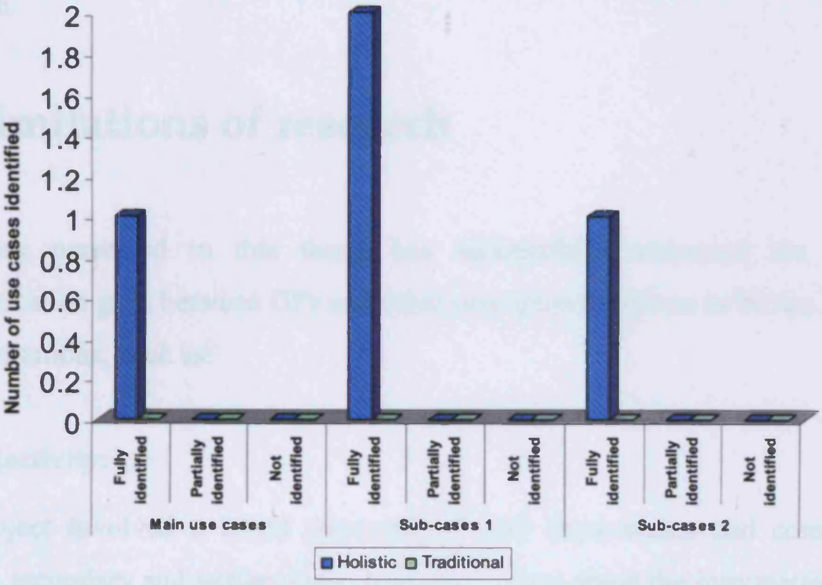


Figure 6.3b: Comparison of identifying cancer genetics use cases by the approaches

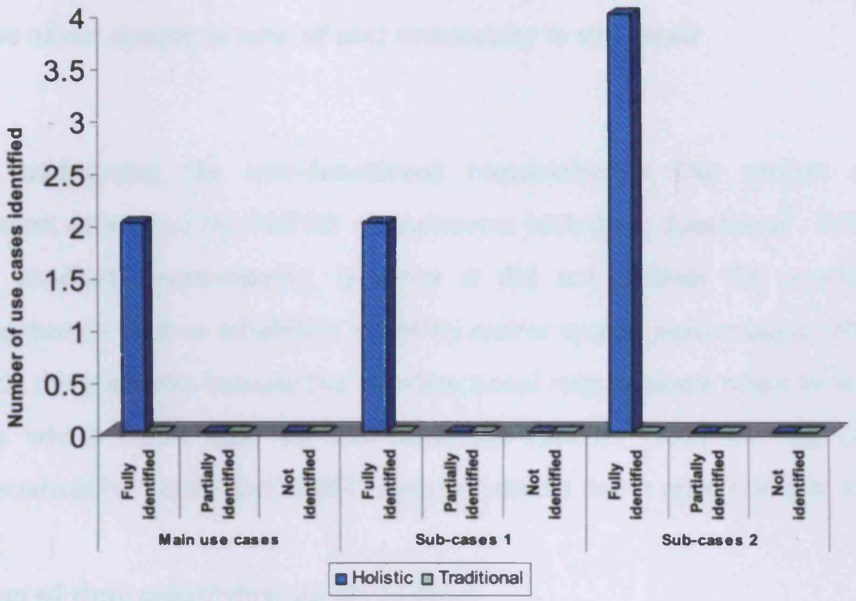


Figure 6.3c: Comparison of identifying WCTN use cases by the approaches

This comparison clearly shows the identification of more use cases by the holistic approach.

6.5 Limitations of research

The work presented in this thesis has successfully addressed the identified communication gaps between GPs and other care team members in Wales. However, it has limitations, such as:

- **Subjectivity:**

This project involved a broad spectrum of user departments and combined the primary, secondary and tertiary care clinicians' views about the information needing to be shared. Hence, we interviewed a wide range of stakeholders including GPs, cancer specialists, practising and research nurses, managers and IT professionals [Personal Communication 1 to 35] with a comprehensive correspondence with each interviewee to avoid subjectivity and bias. However, it has to be mentioned here that the scope of our sample in term of user community is still small

- **Not addressing the non-functional requirements**: Our project specified different aspects of the PEPRS requirements including: functional[1], behavioural and structural requirements; however it did not address the non-functional requirements such as reliability, usability and/or system performance. We did not tackle these aspects because the non-functional requirements relate to the system as a whole rather than its individual sub-systems [152] i.e. our system is constrained by the ISCO/CaNISC system features that it must conform to.

- **Effect of time constraints on the project**

Time and resource constraints did not allow us to deliver what we initially planned, e.g. although the soft system approach offered the means to conduct a detailed problem analysis, the long time we spent on the pre-requirement stage prevented us from implementing a proof of concept prototype that would have been developed if the project time limits had allowed.

6.6 Local impact of research

This project has acted as a catalyst in that it has spawned many other MSc and PhD projects at Cardiff, such as:

- An MSc project in 2003 [107], that designed and implemented a prototype system to support the information needs of a cancer hospice in Wales. This project was underpinned by our concept of addressing the information need of various healthcare professionals throughout the entire cancer treatment journey.
- An MSc project in 2004 [149], that designed and implemented a prototype system to extend the ISCO/CaNISC system to provide personalised information to cancer patients. This project was stimulated by our concept of tailoring the

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[1] The functions delivered by the system to its users.

current ISCO/CaNISC design to meet different needs. This project successfully displayed personalised information to cancer patients.

- An MSc project in 2005 [15, 90], this project was based on the care pathway defined by our activity diagrams (see Figures 5.3, 5.4 and 5.5). The project investigated how these activities could be implemented as a workflow.
- A current PhD project, started in 2003, this project is extending our patient centric approach by enabling a cancer patient to use his/her diagnosis and treatment information held in the ISCO/CaNISC system to link to web site holding related information. At the moment an anonymised version of the system is used for ethical reasons [14].
- A current PhD project, started in 2004, this project is implementing a prototype system, by using wireless technology, to provide information to different members of the cancer care teams in Wales. This came as a result of our approach to support continuity of care by providing information across the three healthcare sectors (primary, secondary and tertiary). It utilises the concept of a virtual organisation to create a patient centred system to support the work of an integrated care team. This is based on the PEPRS specified in this research.

6.7 Conclusions

This chapter assessed the achievement of the research against the research hypothesis. This was done in a number of ways including: assessing the use of both traditional and holistic analysis approaches. And assessing the attainment of a more complete set of requirements.

As shown in section 6.4 the use of the holistic approach led to a more complete set of requirements, in that it identified the requirements of three clinician groups (palliative care, cancer genetics and WCTN) whose information requirements were not identified by the traditional approach.

Furthermore it compared the number of use cases identified by both approaches. This comparison revealed that the holistic approach identified sixteen main use cases in total, while the traditional approach fully identified one of them (6.25%), partially identified five (31.25%) and did not identify the other ten (62.5%). At the first level of sub-cases, the comparison showed that the holistic approach identified thirty two sub-cases, while the traditional approach fully identified ten of them (31.25%),partially identified two (6.25) and did not identify the other twenty (62.5%). At the second level of use cases, the holistic approach identified twenty nine sub-cases, while the traditional approach fully identified fourteen (48.3%) and did not identify the other fifteen (51.7%). This demonstrates that the holistic approach specified more functional requirements by involving more clinician groups and tackling both soft and hard aspects of the requirements.

The chapter also highlighted the limitations of the research and introduced the other research projects at Cardiff catalysed by this project. The next chapter will highlight possible areas for future work and draw the thesis conclusions.

Chapter Seven

Conclusions and Future Work

7.1 Synopsis

In this thesis we have described the growing role of GPs in the cancer care process and emphasised the need for timely and effective communication between them and other members of cancer care teams in order to maintain the continuity of care.
We investigated the current communication between the two groups in Wales and identified three main problems hindering this communication, namely:

- Delays in transfer of information.
- Lack of a shared system to provide the required information to the three care sectors.
- Information that must be communicated has still to be defined.

We then reviewed how other projects tackled the communication problems in the healthcare domain. As a result, we decided that developing an EPRS to be shared between GPs and other members of cancer care teams in Wales will offer the best available solution in our situation.

In developing the required system, we considered two approaches, namely:

- The revolutionary approach, that aims at developing radically new systems, or
- The evolutionary approach that enhances current systems.

Both approaches were compared with respect to our situation, and we decided to adopt the evolutionary approach and extend the current Wales-wide cancer network information system to primary care.

A review of different analysis approaches was conducted, and a traditional approach (based around a combination of the waterfall and evolutionary models) was selected

and initially used in this project. At this stage a panel of thirteen stakeholders covering GPs and cancer specialists [Personal Communication 3 to 5, 9 to 18], were involved in the process.
Despite the advantages gained by using this approach we faced barriers that limited our requirements' analysis and risked reducing the acceptability of the proposed system by some users (such as many conflicting requirements that we were not able to resolve).

Hence, a holistic analysis approach that is able to investigate the whole cancer treatment journey in Wales and provides the means to resolve conflicting requirements was essential. Hence, we revisited the analysis methodologies to identify a methodology or a combination of methodologies that can support this holistic approach. As a result of this review a combination of SSM and UML was selected to create our approach.

At that stage we needed to cover more disciplines in the stakeholders' panel. Thus thirty five stakeholders having various roles in the cancer care domain (GPs, cancer specialists, practising and research nurses, managers and IT professionals) [Personal Communication 1 to 35] were involved through a series of semi-structured interviewees.

By doing this we proposed a system (PEPRS) that can overcome the problems hindering the communication between GPs and other care team members (as identified in section 2.8). We also provided a common system that can be shared by all care team members working in the three healthcare sectors (primary, secondary and tertiary).

A slight concern is that the method of selecting the thirty five stakeholders might contain bias towards people with particular view points. We tried to limit this within a constraint that we needed to have people who had the time available to interact with us and were prepared to give us this time. We initially discussed with a number of people who we might approach to ask if they were willing to cooperate. Our aim was to have representatives of all the types of stakeholders and then within each type to select representatives sub-groups if possible. It was more important at this stage to be sure that the selected people would co-operate so that an iterative approach would works, than to avoid a bias in the view particularly if the attempt to avoid bias prevented the work been done.

7.2 Fulfilment of the research aims

The aims of this research as stated in section 1.2 were:

1. To use a holistic analysis approach to investigate the whole cancer treatment journey in Wales.
2. To determine the key information that must be communicated between GPs and other members of cancer care teams in Wales.
3. To specify a system which overcomes the communication problems inherent in the existing system.

This thesis demonstrated the achievement of the three aims as follows:

Aim one:

4. *To use a holistic analysis approach to investigate the whole cancer treatment journey in Wales, while taking account of the human and technical aspects of the requirements.*

We have clearly demonstrated that we have investigated the whole cancer treatment journey in Wales (see section 4.4). Chapter four showed that we have considered the soft (human) aspects of the requirements, and chapter five showed that we have considered the hard (technical) aspects of the requirements.

This has led to:

- Gaining a deeper understanding of the domain. Consequently, a more complete set of requirements was specified (see Section 6.4).

- Addressing the conflict in the requirements by achieving a consensus view among thirty five stakeholders with varied roles in the cancer care domain (Personal Communication 1 to 35), of what clinical activities our system must support. This was done through the following stages:
    - Identifying that this conflict arose because different stakeholders have various implicit viewpoints of the role of GPs in the cancer care process.
    - Identifying these viewpoints and presenting them in seven RDs (see Figure 4.4). Each of these RD reflected a single view point of an ideal cancer care process.
    - Incorporating these RDs into a single RD (see Figure 4.5). This RD was agreed by all the interviewees to be a description of the core purpose of the cancer care process. A CPTM that identified the activities that must take place to achieve this core purpose was then developed (see section 4.4).
    - Determining the activities that our system must support, by extracting them from the CPTM with the agreement of the stakeholders. That these were the sub-set that our new system will support (see section 4.5).
- Having the ability to investigate different treatment stages simultaneously, this contributed to avoiding bottlenecks and reducing the level of redundant activities.

Aim two:

To determine the key information that must be communicated between GPs and other members of cancer care teams in Wales.

This was achieved through the following stages:

- Determining the information required to support the GPs key clinical activities (as demonstrated in section 4.6)
- Identifying where this information is currently available and where it should be provided (as demonstrated in Table 4.2).

Aim three:

To specify a system which overcomes the communication problems inherent in the existing system.

The specified PEPRS (see sections 5.3, 5.4 and 5.5) can overcome the currently occurring problems in communication between GPs and other care team members by:

- **Reducing the delay in the information transfer**:

Currently the ISCO/CaNISC technology allows information to be available to care team members in almost real time. However they communicate with GPs via posted mail[1] which can take up to two weeks to reach its destination. During this time a clinical situation may change dramatically and the information received may be radically out of date when it arrives at the GP surgery [Personal Communication 3 to 5, 9 to 18].

The PEPRS is an extension of the ISCO/CaNISC system that will adopt its technology, hence we envisage that the information will be available to/from GPs in almost real time via the NHS Wales network technology, thus overcoming the first problem.

- **Proposing a shared system to provide the required information across the healthcare spectrum:**

Table 2.3 showed the lack of a shared system to provide the required information to primary, secondary and tertiary care sector systems. This is due to the different needs, roles, and clinician's working patterns in each sector.

The PEPRS addresses this problem by specifying a shared record that accommodates the different needs and can support the requirements of the stakeholders. For example, it provides a summary of the case notes to GPs, because they need chronological and less detailed information about the patient, while it

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[1] Occasionally they communicate via faxes or telephone depending on the two parties being available at the same time [96]

provides a more in-depth set of information of the past medical history and case mix of information to secondary/tertiary care specialists to meet their clinical needs. Thus it can support these requirements.

- **Identifying the key information that must be communicated:**

Section 2.8.3 highlighted the need to identify the information that must be communicated between GPs and other care team members, if the care team is to effectively treat the patient.

The PEPRS specification addresses this by identifying the information required to support the key clinical activities of GPs in the cancer care process, as detailed in section 4.6. It also identified the source of this information (where this information is currently available) and its destination (where should it be provided), as illustrated in Table 4.2. Furthermore our investigations addressed the problems currently hindering the provision of the required information as discussed in section 4.7. This means that the PEPRS will provide the required information.

7.3 Contribution to research

Within this thesis, we have made the following research contributions:

- The specification of PEPRS (see sections 5. 3, 5.4 and 5.5) that can overcome the limitations of the current communication between GPs and other members of cancer care teams in Wales by reducing the delay of information transfer; providing a common system that can be shared between the three care sectors and identifying the information that must be communicated between GPs and other care team members.
- The specification of a shared system that can provide the required information to cancer care team members working in the primary, secondary and tertiary sectors. This system showed that information could be provided across the healthcare spectrum according to the needs and working practices of the clinicians in each care sector. By doing this we addressed the lack of a shared

system that can span the three care sectors and created a common record structure for cancer information that is consistent with the Connecting for Health proposal [19].

- We employed soft system techniques within the cancer care domain to identify and resolve conflicting requirements. And thereby accommodated different viewpoints to achieve a consensus view among the involved stakeholders (as detailed in section 4.4).
- The identification of the key role of GPs in the cancer care process. This was achieved by determining the GPs key clinical activities at each stage of the cancer treatment pathway (see section 4.5) and identifying the information that must be provided to support these activities. This was agreed with the thirty five stakeholders having various responsibilities in the cancer care domain in Wales (GPs, cancer specialists, practising and research nurses, managers and IT professionals) [Personal Communication 1 to 35] (see section 4.6). This provides an embryonic Primary Care Cancer Dataset for Wales [18].
- The creation of a holistic analysis approach that investigates the whole cancer care pathway and considers both soft (human) and hard (technical) aspects of the requirements. This approach provided the means to tackle uncertain and/or conflicting requirements.

7.4 Wider research context

The holistic approach presented in this thesis provides a generic way to resolve conflicting information requirements. Conflict often arises when an attempt is made to integrate a number of different independent communities, who developed their own unique working practices, to work together in a single organisation. Each of these communities is likely to have different expectations from any new information system. Our approach addresses this issue by identifying these expectations explicitly and incorporating them into a consensus view of what the new system should/should not do.

Thus our approach can be used outside the cancer care domain, for example:

- In other healthcare domains such as developing an information system to support haemophilia care teams. These teams usually involve haematologists, orthopaedic surgeons, GPs and psychiatrists.
- In a university domain to develop a student record system to be shared by different university departments such as academic departments, finance and registry departments.

7.5 Research publications

Various aspects of this research have been presented at peer reviewed health informatics conferences, this includes:

- [20], this paper assessed the feasibility of developing a shared EPRS to provide information to cancer care teams working across the healthcare spectrum.
- [21], this paper demonstrated the use of SSM to gain a deeper understanding of the cancer care domain in Wales.
- [23], this paper emphasised the significance of a holistic analysis approach by demonstrating the benefits of looking at the whole cancer care pathway when developing an EPRS to support the care team.
- [19], this paper investigated the feasibility of our proposed system to collaborate with the forthcoming National Care Record System[1].
- [25], this paper highlighted the benefits gained by combing SSM and UML to investigate the cancer care domain and specify a system to overcome the limitations in the current communication between GPs and other care team members.
- [18], this paper addressed the technical, cultural and organisational challenges encountered during the project development.

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[1] A single EPRS to support every NHS patient from birth to death.

- [90], this paper investigated the use of workflow technology to coordinate the clinical activities of the cancer care pathway. It developed a prototype system that utilised WfMS to coordinate the activities presented in our activity diagram (see Figure 5.4).

Additionally, [20, 21] were selected for publication in the Health Informatics Journal [22, 24]. [18] has been invited for publication in the Informatics in Primary Care Journal.

7.6 Future work

In this thesis, we adapted and utilised information system tools and techniques to facilitate communication in the healthcare domain. This introduced many ideas/concepts that can be further extended in the future. This section highlights possible areas for future work.

7.6.1Ongoing work at Cardiff

Many concepts introduced by our work were further extended by other health informatics research projects at Cardiff, for example:

- We highlighted the need to investigate the whole cancer care treatment pathway and provide information to different care team members throughout this pathway. This was extended by two MSc projects in 2003 [107], and 2004 [149], as explained in section 6.6.
- We have identified different clinical activities throughout the care pathway, this was extended by an MSc project [15], that implemented a prototype system to coordinate these activities utilising the workflow technology [90].
- We emphasised the concept of tailoring the information provision according to individual patient's need (patient centric approach). This was extended by two ongoing PhD projects as demonstrated in section 6.6.

7.6.2 Planned work

We have been asked by the WCTN and the North Wales Department of General Practices, to investigate the possibility of proposing a system that can enable GPs to participate in the cancer clinical trials across Wales based on our PEPRS.

It is also planned to expand the identified information categories to develop a Primary Care Cancer Dataset for Wales.

7.6.3 Future developments

- Developing a prototype based on the PEPRS to enable the communication between GPs and other cancer care team members.
- To assess, through a clinical trial, if our system can impact the disease outcome
- To apply the created holistic approach in other areas of the healthcare domain (e.g. haemophilia, diabetes).

Glossary

Cancer	is the general term usually used to refer to malignant tumours. It is not a single disease but a group of diseases affecting both sexes in different age groups.
Chemotherapy	is the treatment or prevention of disease by means of chemical substances. The term is often restricted to the treatment of cancer i.e. anticancer drugs.
Colposcopy	is the method of examining the Vagina and Cervix by means of the binocular instrument known as the colposcope. It is used to screen for cancer of the cervix.
EPRS	is a clinical information system that includes information recorded and kept by health professionals about an individual's illness(es).
Ethnography	is an observational technique to understand social and organisational requirements.
Medical Record	refers to the information recorded and kept on paper or electronically by health professionals about an individual's illness(es). It is normally confidential to the patient and professionals responsible providing care to that patient.
Oncology	is the branch of medicine that deals with the malignant diseases.
Palliative care	is the active total care of patients whose disease is not responsive to curative treatment e.g. control of pain. The goal of palliative care is achievement of the best possible quality of life for patients and their families.
Primary care	is the care provided by general medical practitioners (traditionally titled the family doctor) or other health professionals who have first contact with a patient needing or wanting medical attention.
Private healthcare	is the provision of medical and dental care to patients who either pay for the care directly, through private medical insurance or through employer funded private insurance.
Radiotherapy	is the treatment of disease (mainly cancer) with penetrating radiation.
Secondary care	is the healthcare provided by medical specialists or hospital staff members for a patient whose primary care was provided by the

	general practitioner.
Stakeholder	is any person or group who will be affected by the system directly or indirectly.
Tertiary care	is the services provided by specialized hospitals equipped with diagnostic and treatment facilities not available at general hospitals, to treat unusual disorders that do not respond to therapy that is available at secondary care centres.

Appendix A

Overview of the UK Healthcare System

Healthcare in the UK is provided by two systems:

- The National Health Service (NHS) which provides a wide variety of health services free of charge to all UK residents regardless of their ability to pay. The majority of UK patients are treated and cared for by this system.
- Private healthcare services, via private health premises or within the NHS under certain circumstances.

The National Electronic Library for Health (NELH) states that:

> "The standards of clinical care are generally the same in the two systems but private patients can see the specialist of their choice at a time convenient to them" [121]

Introduction to the NHS

The NHS was established in 1948 to provide a comprehensive range of medical services to residents in the UK. The UK central government used to be responsible for managing the NHS across the UK. However the central government now is only responsible for the NHS in England, while the devolved governments of Northern Ireland, Scotland and Wales are running the NHS in their countries.

Despite the divergence in policies and initiatives of the four governments, the NHS basic structure and functions in the four countries remain nearly the same. The NHS across the UK operates through three sectors: primary care, secondary care and tertiary care.

- **Primary care** involves General Practitioners (GPs) and their teams (e.g. health visitors, district nurses, midwives and counsellors). Every UK resident has the right to register with a GP [8] who provides the first diagnosis of a non acute illness1. GPs also give advice, prescribe treatment or refer to the specialist services for secondary or tertiary care. Generally most patients are treated by their GPs and do not require any referral to secondary or tertiary care:

> "Even so, over 90% of health episodes are contained within the primary care sector and do not therefore require a GP to make a referral to the secondary sector" [121]

It was estimated in 2002 that over 37000 GPs work in the NHS across the UK (full time and part time) mostly self employed in group practices. On average about 1900 patients2 are registered with an individual GP.

- **Secondary care** refers to general hospitals that provide a wide range of clinical specialities (e.g. general medicine, paediatrics and general surgery).
- **Tertiary care** refers to hospitals and health centres that provide specialist services not available in secondary care (e.g. Cancer Centres).

GP practices are managed locally by practice managers. In addition to that, their performance is monitored by the Strategic Health Authorities (SHAs) in England and the Local Health Boards (LHBs) in Wales to ensure the provision of consistent care. GP practices provide outpatient care only.

On the other hand, each NHS hospital is run by an NHS trust and may provide inpatient, day case and outpatient care depending on available resources.
Under this system trusts act as health providers in the internal market whereas GP practises act as purchasers buying healthcare from providers within given budgets. In England this fund is allocated by the Department of Health and distributed by the SHAs [8] while in Wales it is allocated by the Welsh Assembly Government and distributed by the LHBs [123]

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1 People injured in accidents or suffering an acute illness usually go to hospital accident and emergency units across the country.
2 This Figure varies markedly between rural and city practices.

Appendix B

The Initial Analysis Approach

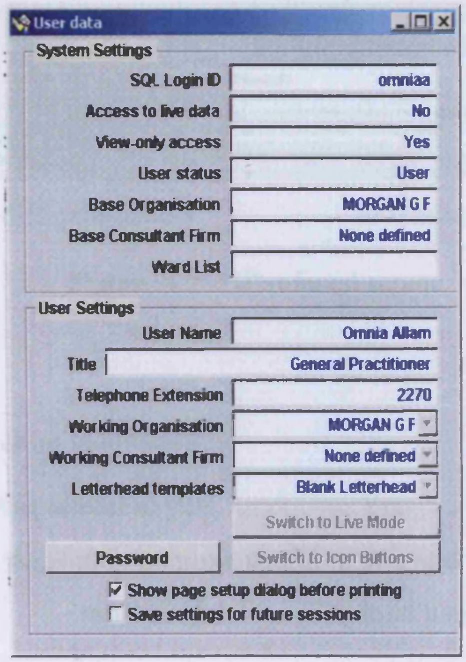
B.1 Pilot interface evaluation

This section illustrates the questionnaire used to evaluate the pilot interface and the results of this evaluation [20, 24]

The log in screen

Please enter your user name and password, click OK

The system will identify you as a GP, as shown in Figure B1.



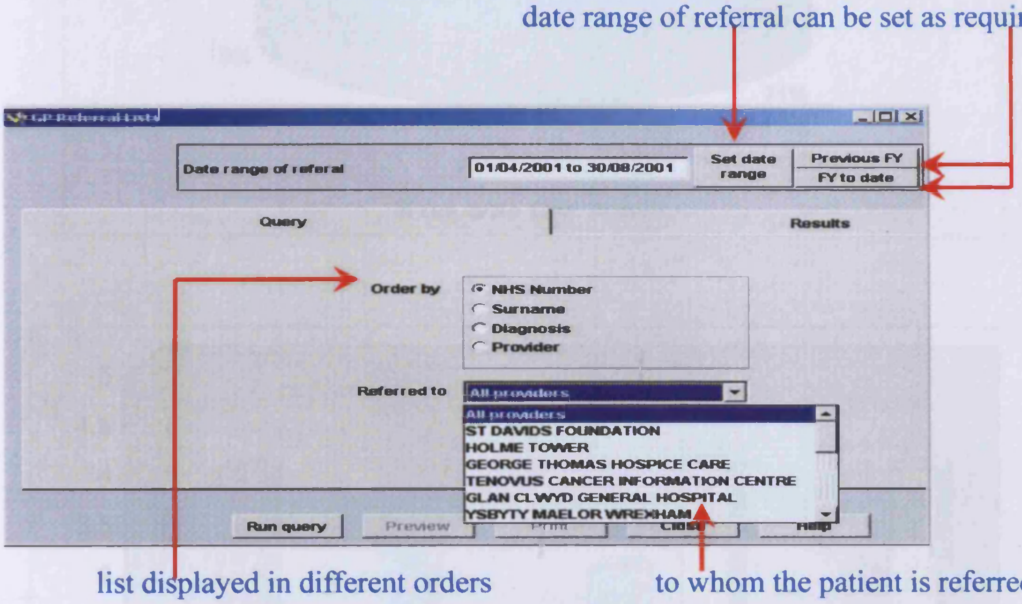
SQL Login ID: omniaa
Access to live data: No
View-only access: Yes
User status: User
Base Organisation: MORGAN G F
Base Consultant Firm: None defined
Ward List:
User Name: Omnia Allam
Title: General Practitioner
Telephone Extension: 2270
Working Organisation: MORGAN G F
Working Consultant Firm: None defined
Letterhead templates: Blank Letterhead
☑ Show page setup dialog before printing
☐ Save settings for future sessions

Figure B.1: Demonstrates the log-on screen where the system identifies the user as a GP

The referral screen

This screen (see Figure B.2) allows you to extract a list of your patients referred to secondary/ tertiary cancer specialist from the ISCO/CaNISC system.

- Clicking on the **Query** button allows you to request a list of patients referred to a specific provider within a certain date range in a chosen order
- Click on **Run-query** button to extract the required information.



date range of referral can be set as required

Date range of referral: 01/04/2001 to 30/08/2001

Order by: ● NHS Number ○ Surname ○ Diagnosis ○ Provider

Referred to: All providers

list displayed in different orders

to whom the patient is referred

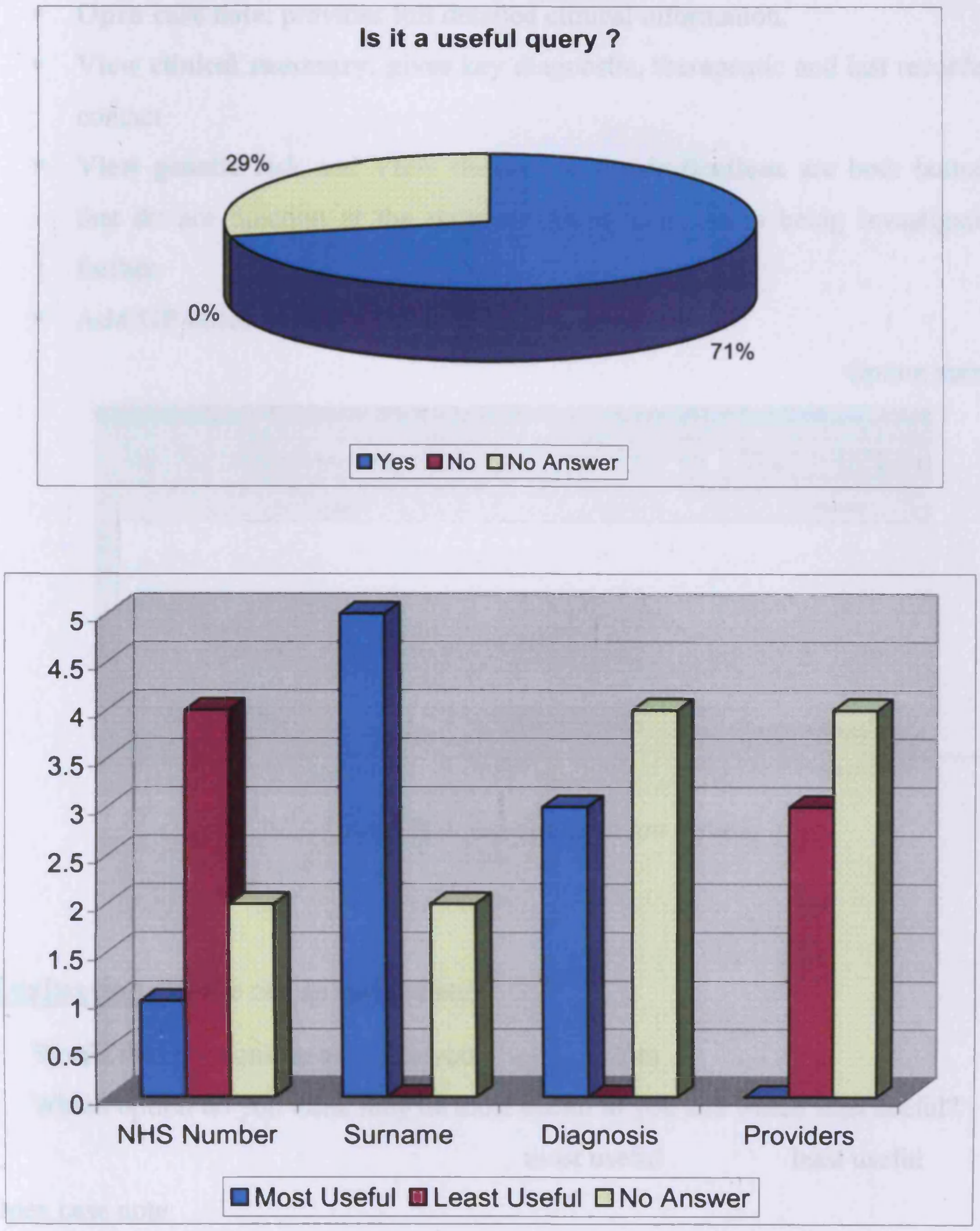
Figure B.2: GP referral screen

Evaluation (Please tick as appropriate)

- Is this type of querying useful to you Yes No
- Which filter do you think may be most useful to you and which least useful?

	most useful	least useful
NHS Number		
Surname		
Diagnosis		
Provider		

Feedback

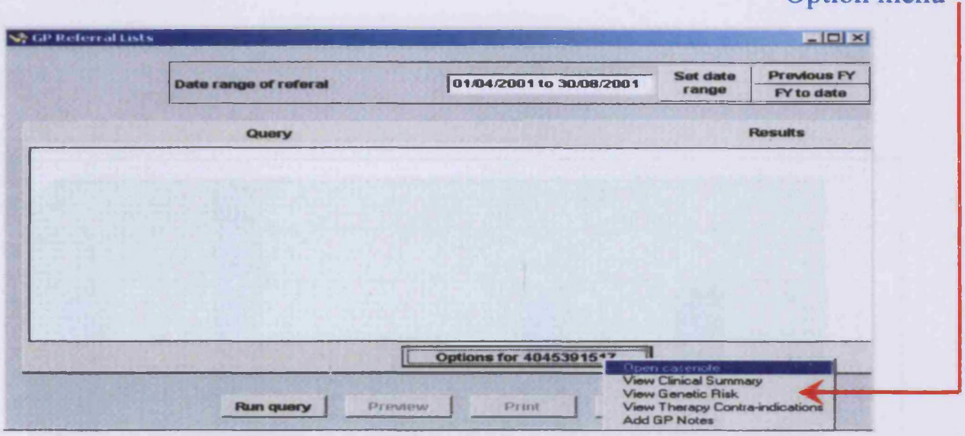


Figures B.3 (a, b): Feedback to the GP referral screen

An Option menu screen

This screen (see Figure B.4) offers different functions on the selected patient record.

- **Open case note**: provides full detailed clinical information.
- **View clinical summary**: gives key diagnostic, therapeutic and last recorded contact
- **View genetic risk** and **View therapy contraindications** are both buttons that do not function at the moment while their use is being investigated further.
- **Add GP notes:** calls the GP annotation screen.



Option menu

Date range of referal 01/04/2001 to 30/08/2001

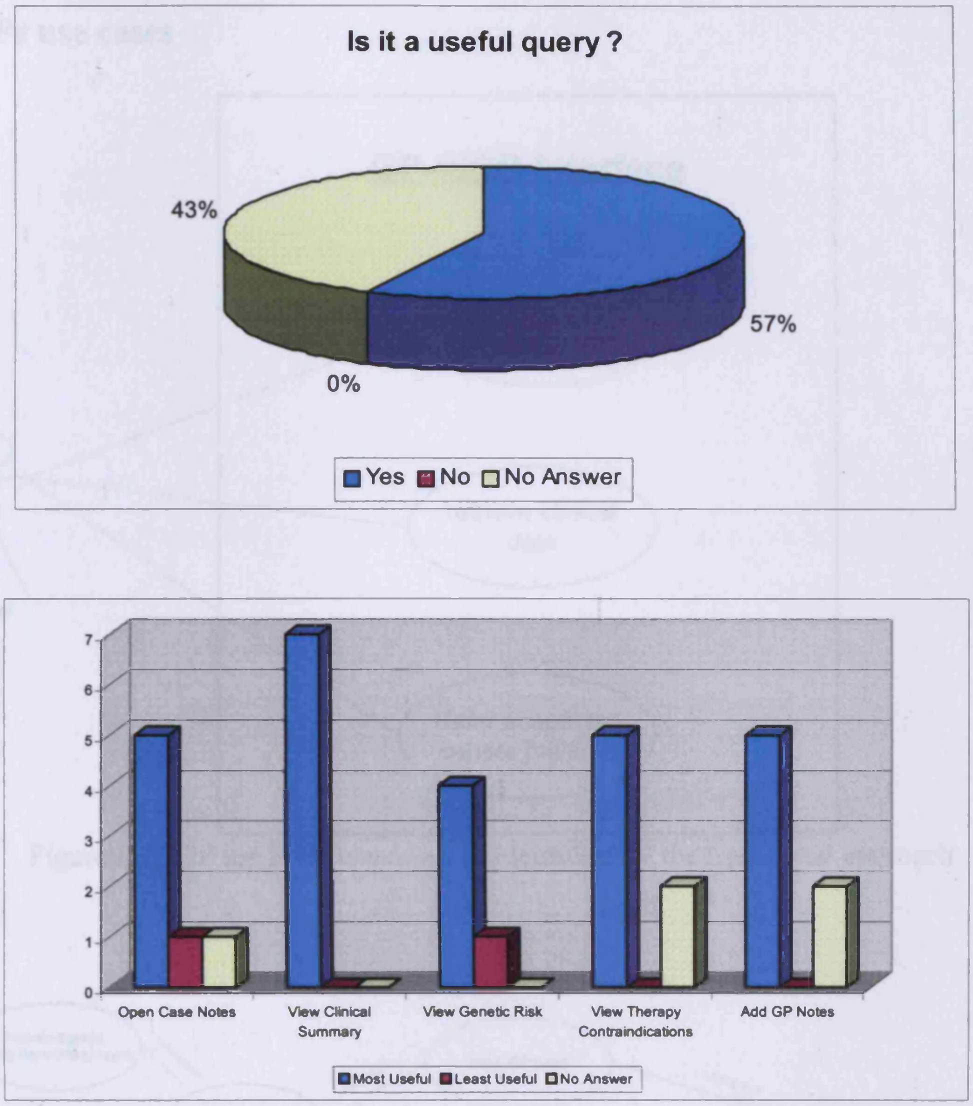
Figure B.4: An option menu screen

Evaluation (Please tick as appropriate)

- Would these options be useful to you Yes No
- Which option do you think may be most useful to you and which least useful?

	most useful	least useful
Open case note		
View clinical summary		
View genetic risk		
View therapy contraindications		
Add GP notes		

Feedback



Figures B.5 (a, b): Feedback to the option menu screen

B.2 Functional requirements

GPs use cases

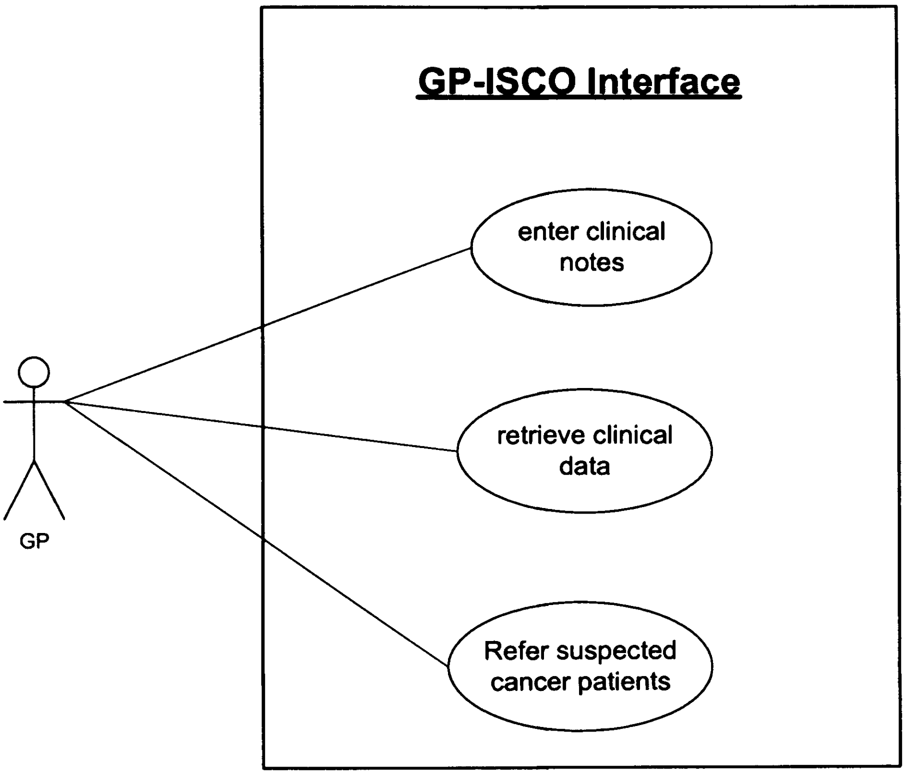


Figure B.6: GP top level use cases as identified by the traditional approach

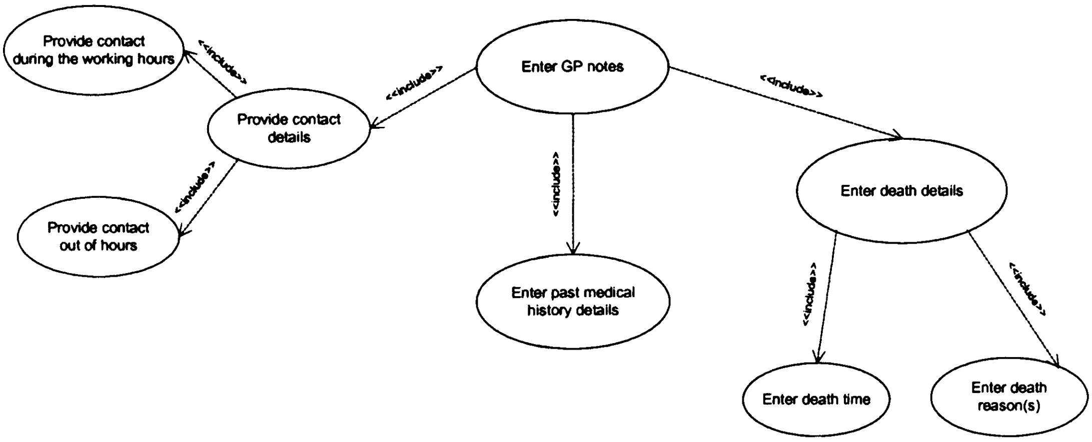


Figure B.7: GP enter clinical notes use cases as identified by the traditional approach

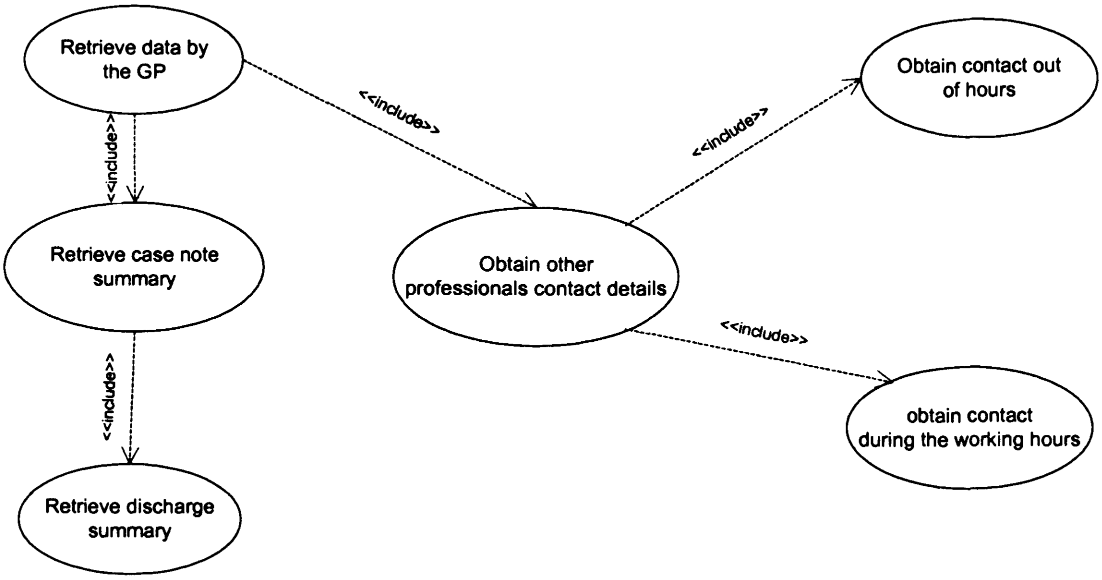


Figure B.8: GP retrieve clinical data use cases as identified by the traditional approach

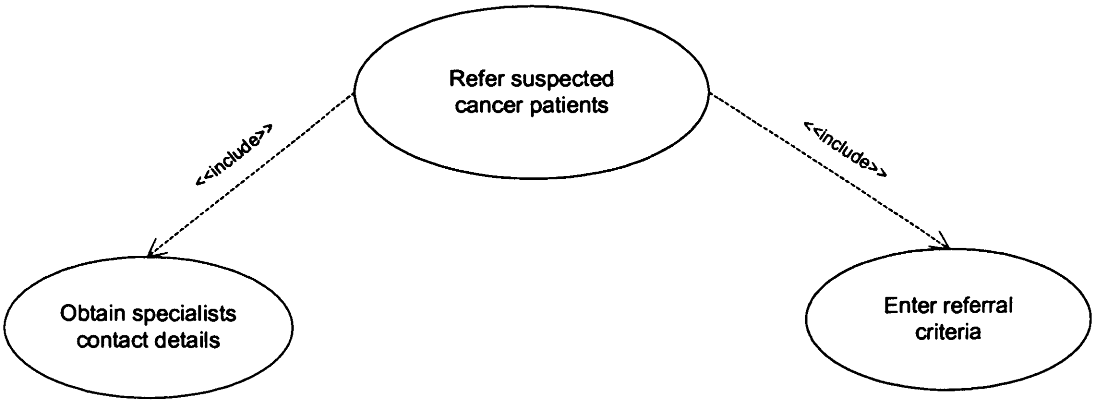


Figure B.9: GP refer suspected cancer patient use cases as identified by the traditional approach

Cancer specialists use cases

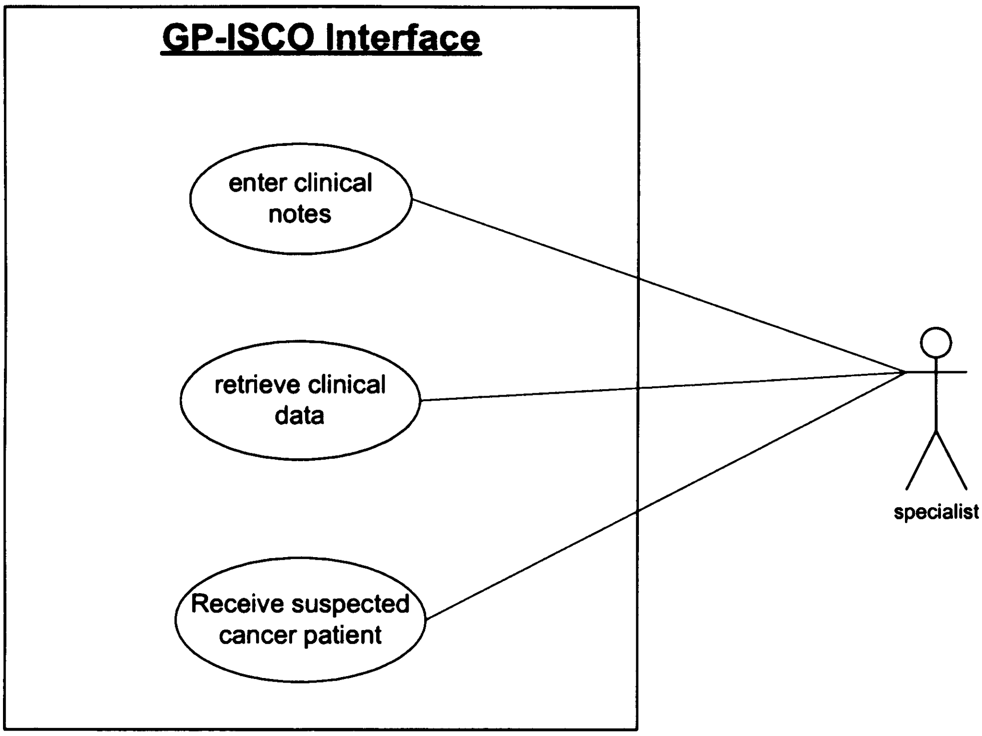


Figure B.10: Cancer specialist top level use cases as identified by the traditional approach

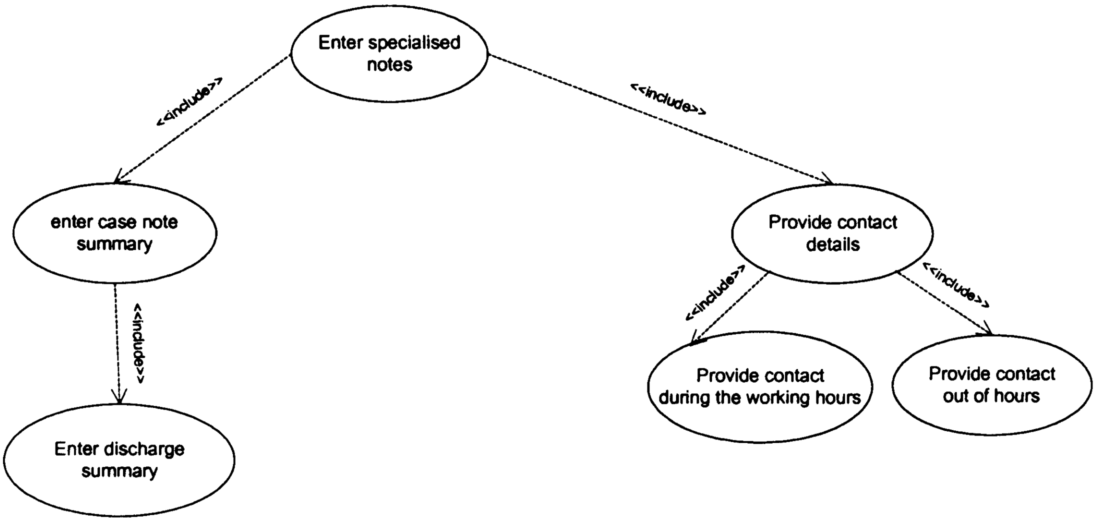


Figure B.11: Cancer specialists enter clinical notes use cases as identified by the traditional approach

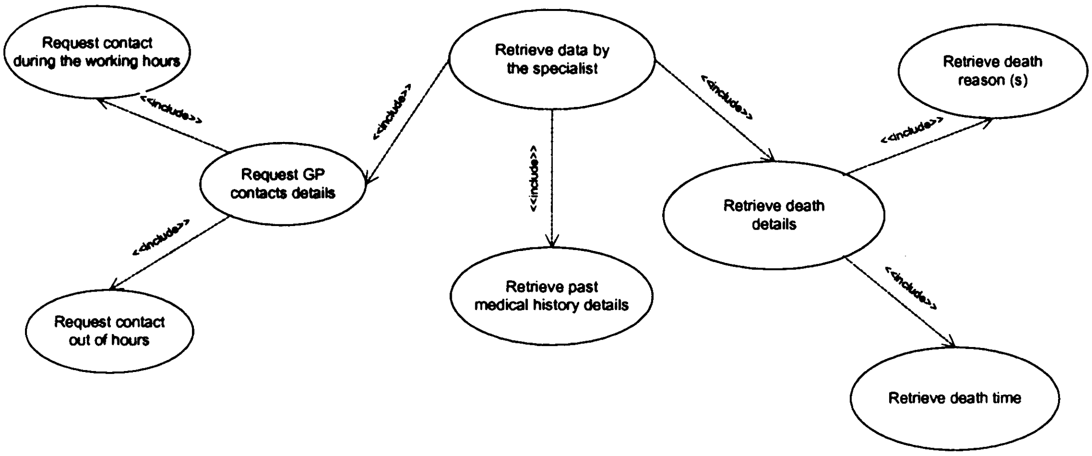


Figure B.12: Cancer specialist retrieve clinical data use cases as identified by the traditional approach

Appendix C

The Use of Soft Systems Methodology (SSM) in This Project

C.1 A Consensus Primary Task Model (CPTM) of the whole cancer treatment pathway

As discussed in section 4.4, a CPTM of the whole cancer care process was constructed and approved by all interviewees [Personal Communication 1 to 35]. This model included four types of activities namely: Transformation activities, Support activities, Linking activities and Planning, Monitoring and Control activities as detailed in section 4.4.

- The RD representing the Transformation activities (i.e. the core purpose of the entire cancer care process) is shown in Figure 4.5. The CM developed from this RD is shown in Figure 4.6.
- The two RDs representing the Support activities are shown in Figures 4.7a and 4.7b respectively. In this section we demonstrate the CMs developed from these RDs in Figures C1 and C2.
- The two RDs representing the Linking activities are shown in Figures 4.8a and 4.8b respectively. In this section we demonstrate the CMs developed from these RDs in Figures C3 and C4.
- The two RDs representing the Planning, Monitoring and Control activities are shown in Figures 4.9a and 4.9b respectively. In this section we demonstrate the CMs developed from these RDs in Figures C5 and C6.

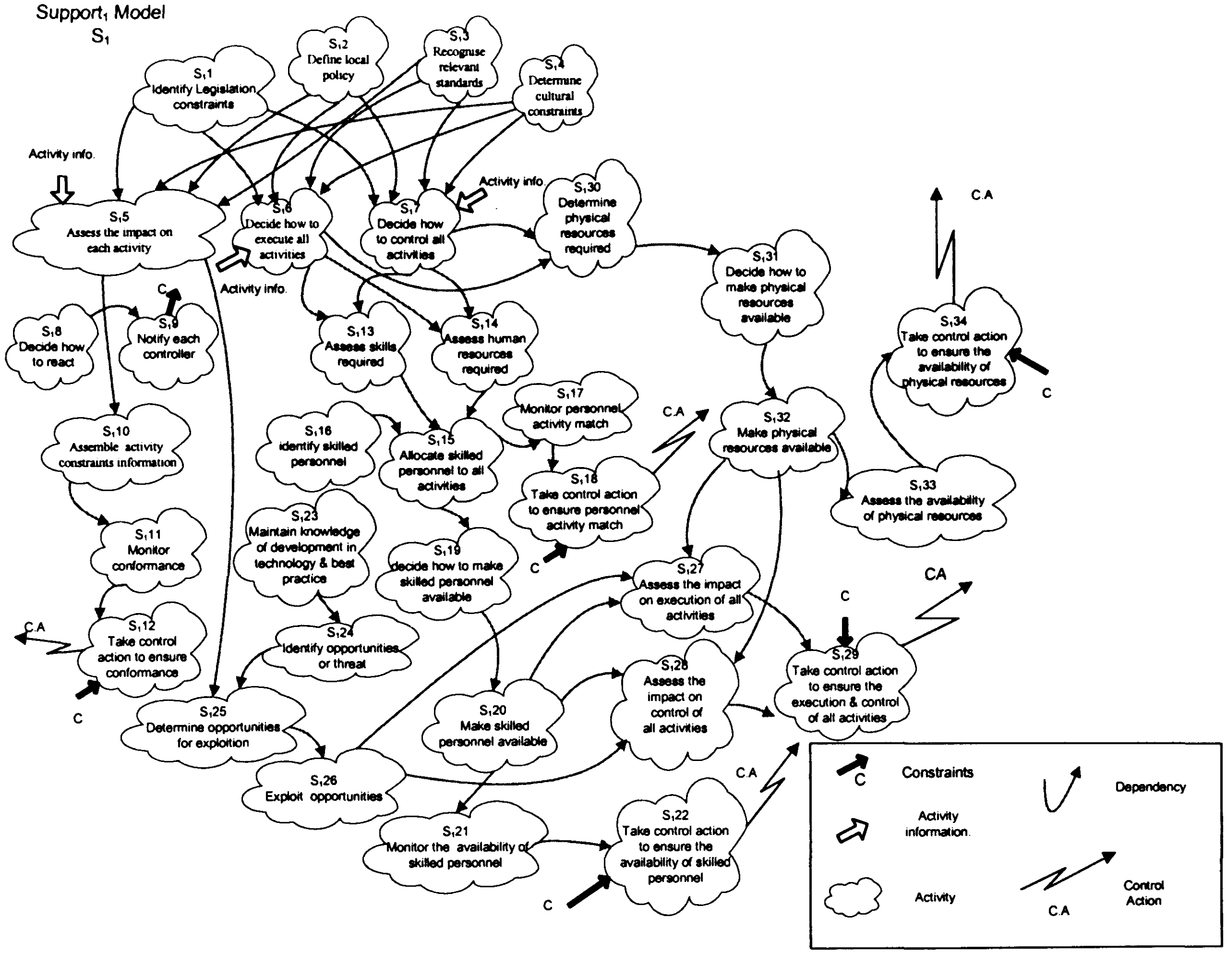
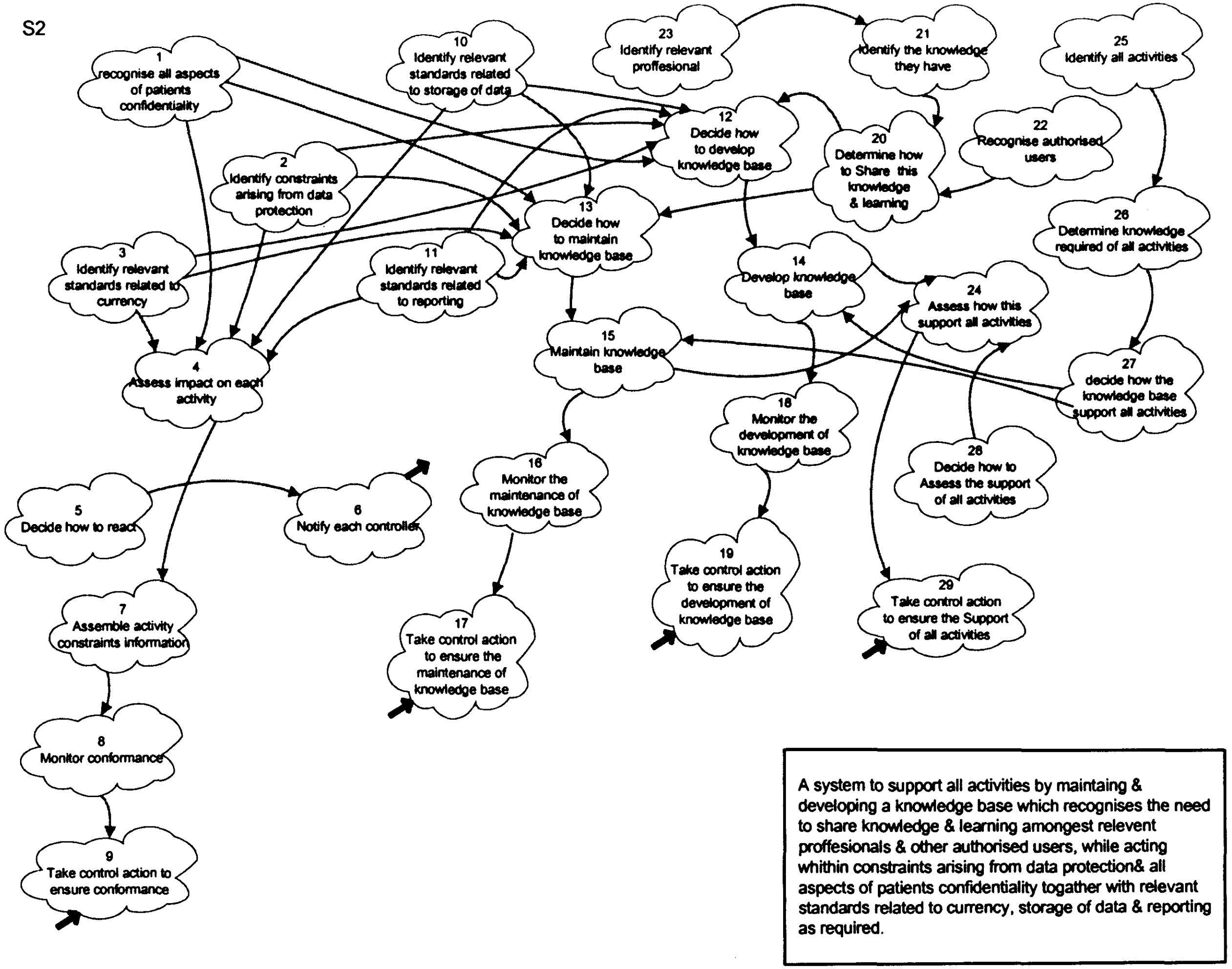
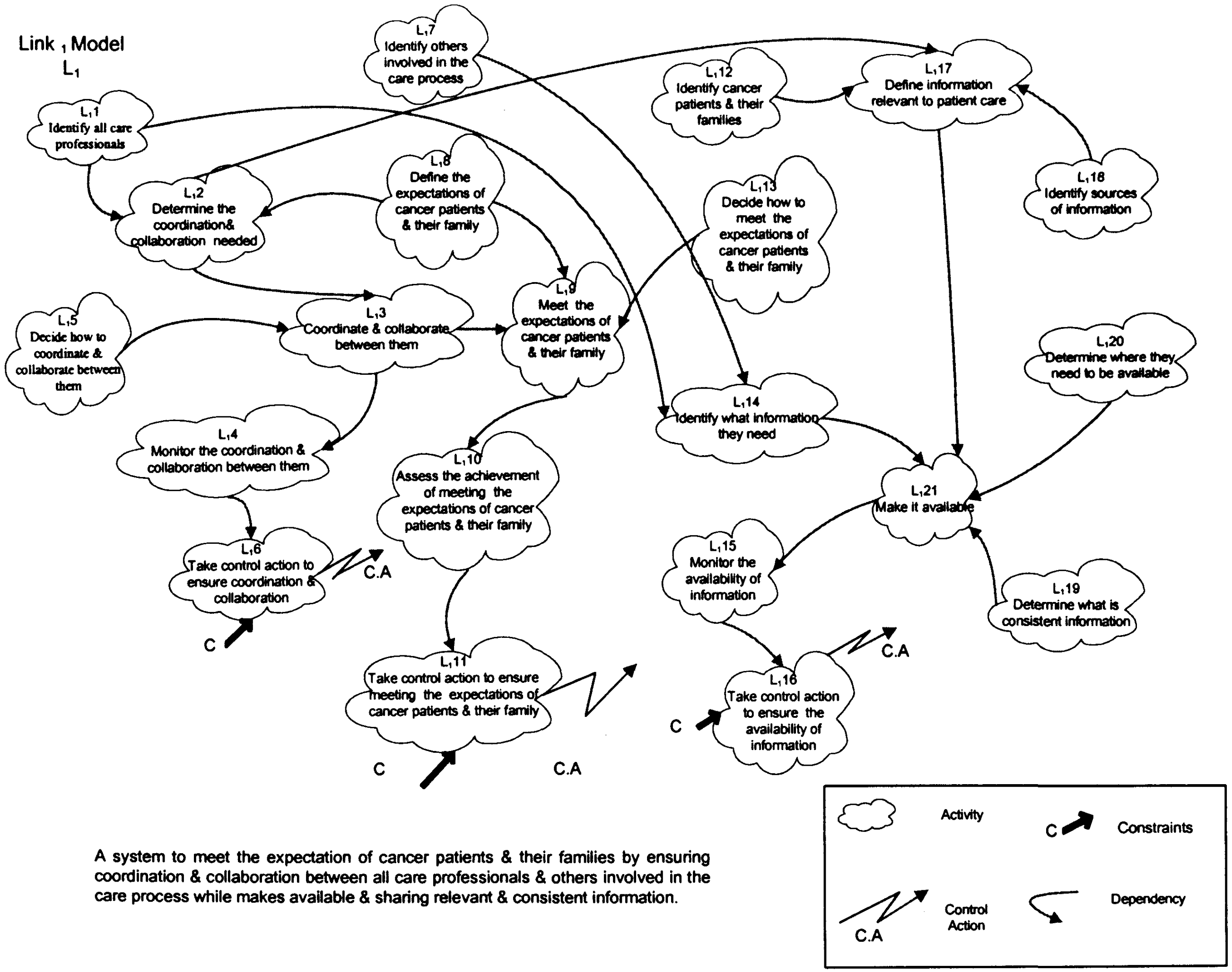


Figure C1: Support$_1$ model



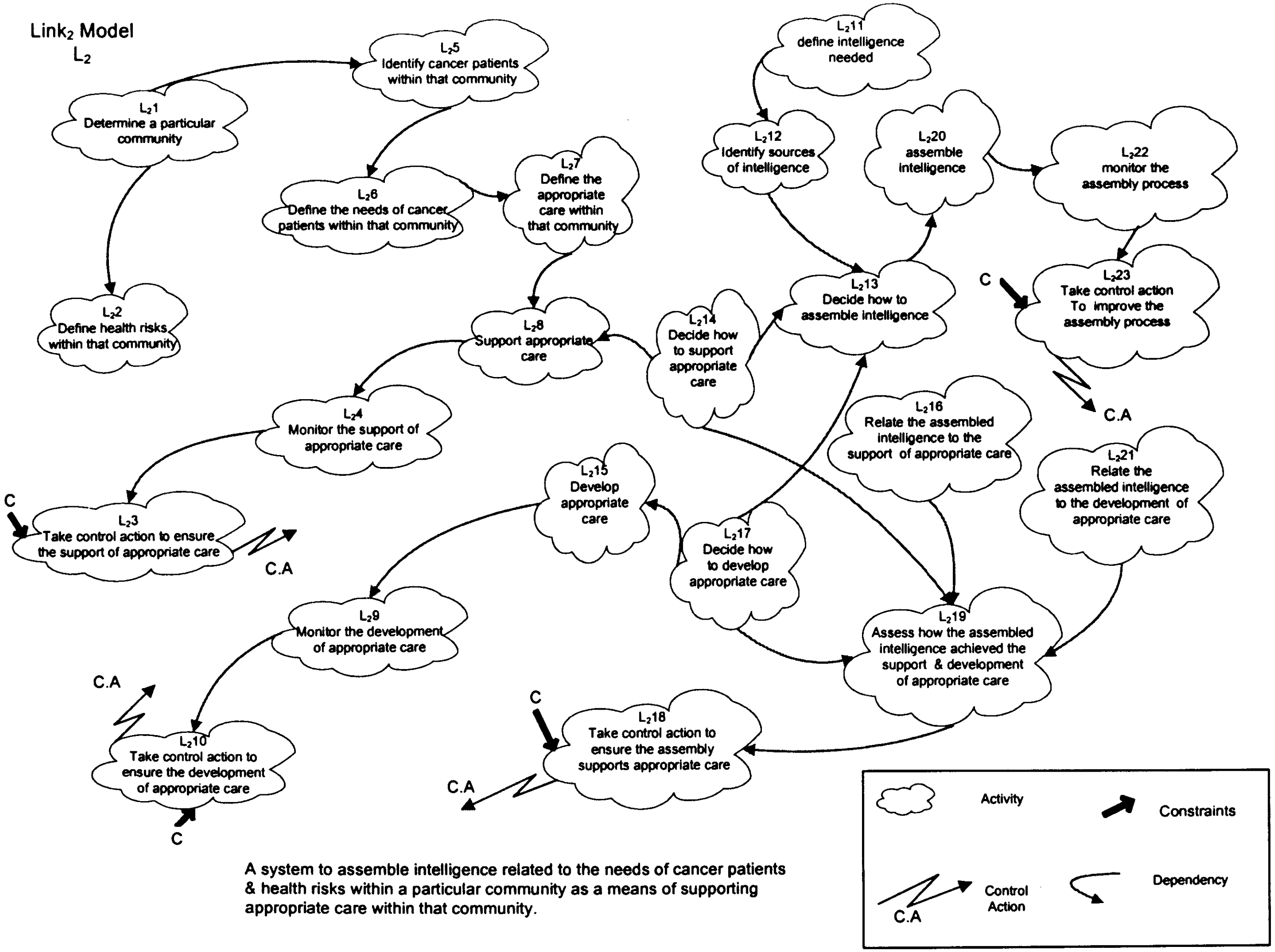
A system to support all activities by maintaing & developing a knowledge base which recognises the need to share knowledge & learning amongest relevent proffesionals & other authorised users, while acting whithin constraints arising from data protection& all aspects of patients confidentiality togather with relevant standards related to currency, storage of data & reporting as required.

Figure C2: Support$_2$ model



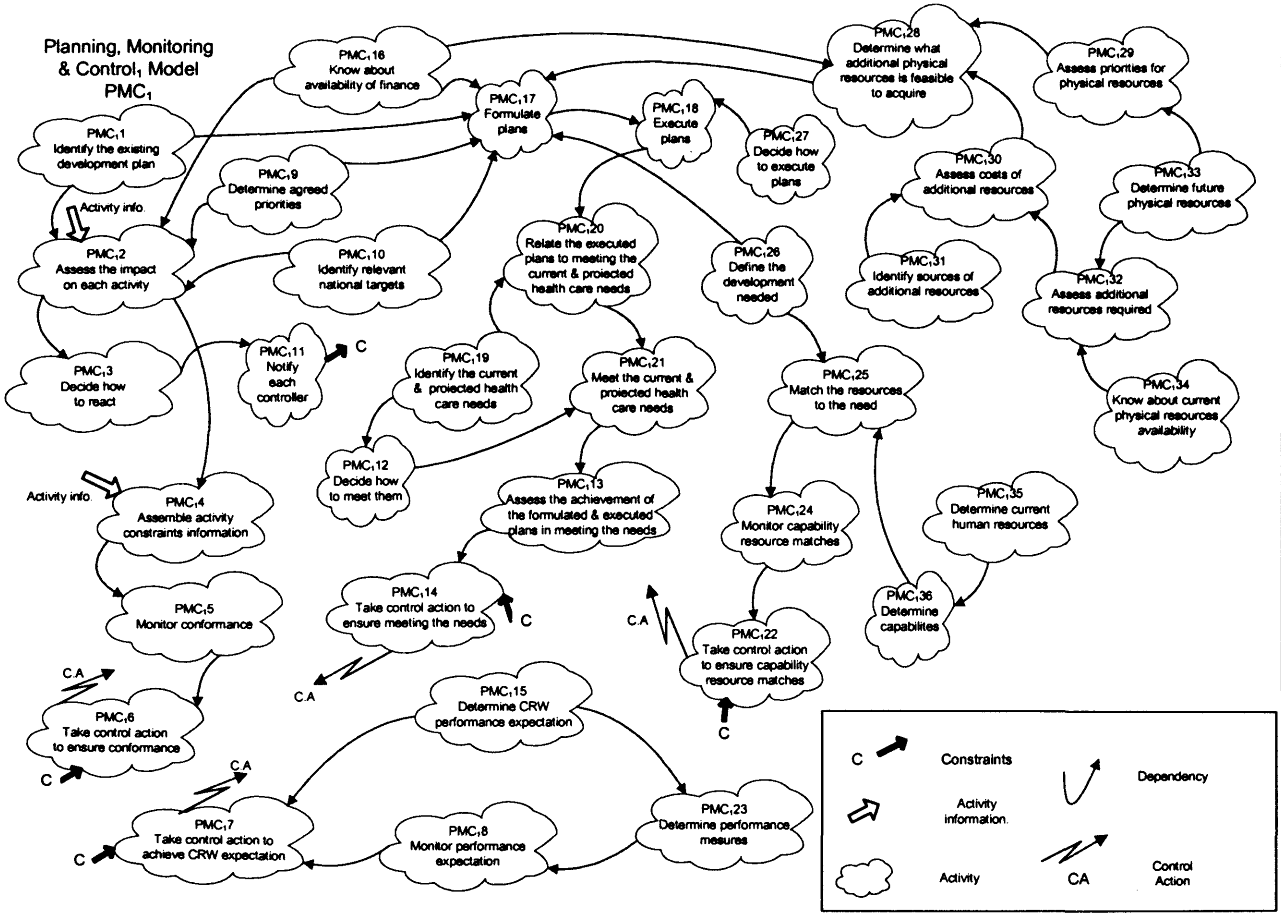
A system to meet the expectation of cancer patients & their families by ensuring coordination & collaboration between all care professionals & others involved in the care process while makes available & sharing relevant & consistent information.

Figure C3: Link $_1$ Model



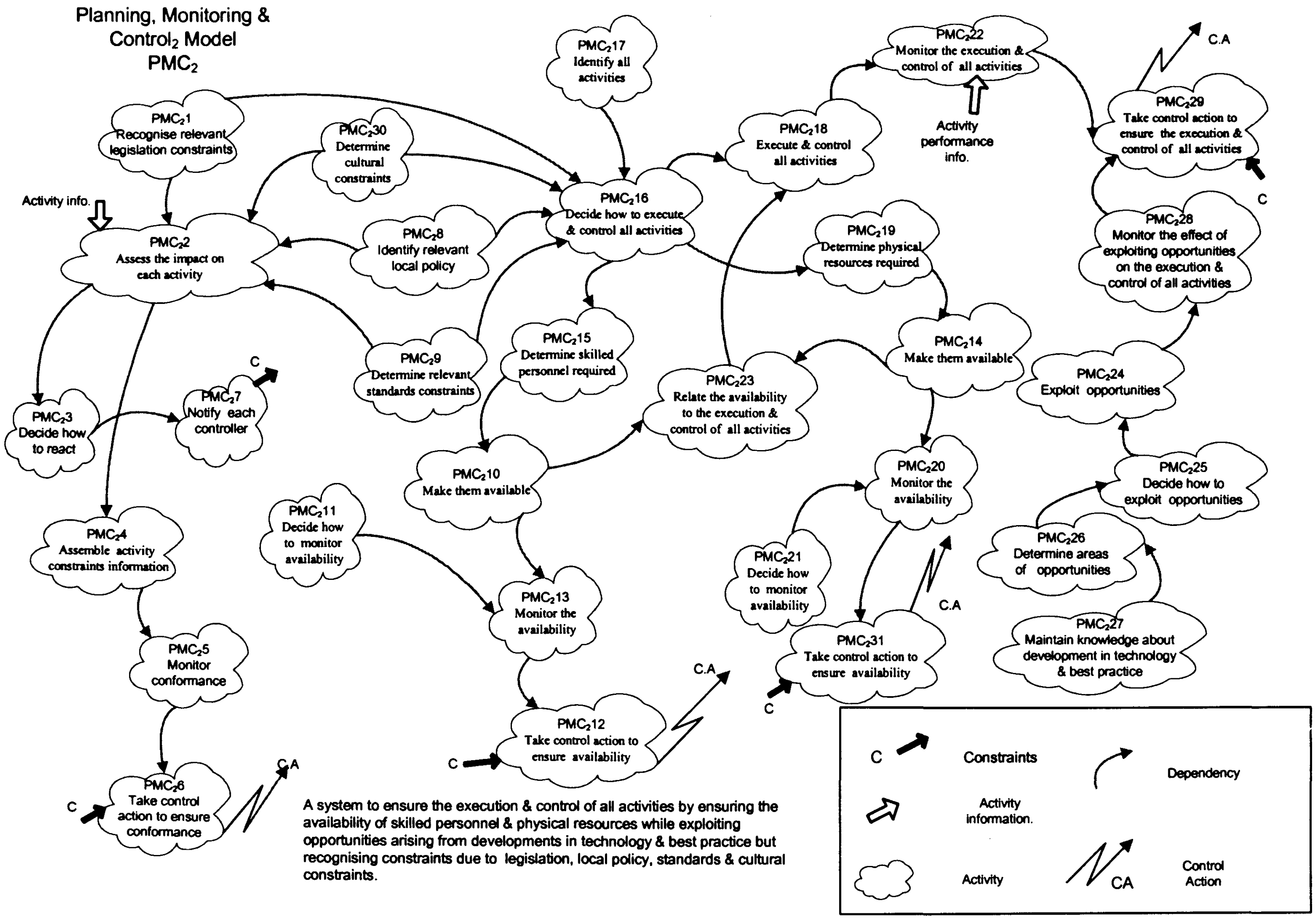
A system to assemble intelligence related to the needs of cancer patients & health risks within a particular community as a means of supporting appropriate care within that community.

Figure C4: Link $_2$ Model



A local area health board CRW owned system to formulate plans for the development of healthcare facilities in terms of both physical and human resources capabilities to meet the current and proiected healthcare needs of the defined community and to execute such plans in accordance with agreed priorities, finance availability, national targets and existing development plans

Figure C5: PMC$_1$ Model



A system to ensure the execution & control of all activities by ensuring the availability of skilled personnel & physical resources while exploiting opportunities arising from developments in technology & best practice but recognising constraints due to legislation, local policy, standards & cultural constraints.

Figure C6: PMC$_2$ Model

C.2 A consensus view of GPs activities

The key activities of GPs in the care process were derived from the CPTM as explained in section 4.5

Table C1 below provides a list of the 16 activity sets of the CPTM and their activities categorisation

Activity Number	**Activity Name**	**External**	**Border**	**Internal**
Screening subsystem				
T9	Identify suspected cancer patients			√
$L_1$12	Identify cancer patients and their families			√
$L_2$5	Identify cancer patients within that community			√
Diagnosing subsystem				
T10	Diagnose cancer			√
Medical assessment subsystem				
T8	Determine patient condition			√
Treatment subsystem				
T11	Determine individual care pathway			√
T18	Determine the cancer patients medical requirements			√
T12	Define what is appropriate treatment			√
T13	Decide how to make available treatment as appropriate		√	
T14	Provide care to cancer patients according to individual care pathway			√
T15	Make available treatment in terms of equipment, drugs application and surgery as appropriate			√
Information management subsystem				
$L_1$14	Identify what information they need			√
$L_1$15	Monitor the availability of information		√	
$L_1$16	Take control action to ensure the availability of information	√		

$L_1$17	Define information relevant to patient care			√
$L_1$18	Identify sources of information	√		
$L_1$19	Determine what is consistent information	√		
$L_1$20	Determine where they need to be available			√
$L_1$21	Make it available		√	
Knowledge base management subsystem				
$S_2$12	Decide how to develop knowledge base	√		
$S_2$13	Decide how to maintain knowledge base	√		
$S_2$14	Develop knowledge base	√		
$S_2$15	Maintain knowledge base	√		
$S_2$16	Monitor the maintenance of knowledge base	√		
$S_2$17	Take control action to ensure the maintenance of knowledge base	√		
$S_2$18	Monitor the development of knowledge base	√		
$S_2$19	Take control action to ensure the development of knowledge base	√		
$S_2$20	Determine how to Share this knowledge and learning			√
$S_2$21	Identify the knowledge they have	√		
$S_2$24	Assess how this support all activities		√	
$S_2$26	Determine knowledge required of all activities		√	
$S_2$27	decide how the knowledge base support all activities	√		
Patient expectation management subsystem				
$L_1$8	Define the expectations of cancer patients and their family		√	
$L_1$9	Meet the expectations of cancer patients and their family		√	
$L_1$10	Assess the achievement of meeting the expectations of cancer patients and their family	√		
$L_1$11	Take control action to ensure meeting the expectations of cancer patients and their family	√		
$L_1$13	Decide how to meet the expectations of cancer patients and their family	√		
$L_2$6	Define the needs of cancer patients within that community		√	

Care provision subsystem				
T16	Monitor the appropriate availability of treatment		√	
T17	Take control action to ensure appropriate availability of treatment	√		
T19	Decide how to assess the achievement of provision of care in meeting cancer patients requirements	√		
T20	Assess the achievement of provision of care		√	
T21	Take control action to ensure provision of care to the satisfaction of cancer patients	√		
$L_2$8	Support appropriate care		√	
$L_2$15	Develop appropriate care	√		
PMC$_1$26	Define the development needed	√		
Constraints management subsystem				
T2	Assess the impact on each activity		√	
T3	Decide how to react	√		
T4	notify each controller	√		
T5	Assemble activity constraints information		√	
T6	Monitor conformance	√		
T7	Take control action to ensure conformance	√		
$S_1$1	Identify Legislation constraints		√	
$S_1$2	Define local policy	√		
PMC$_2$8	Identify relevant local policy		√	
$S_1$3	Recognise relevant standards		√	
$S_1$4	Determine cultural constraints	√		
$S_1$5	Assess the impact on each activity		√	
$S_1$8	Decide how to react	√		
$S_1$9	Notify each controller	√		
$S_1$10	Assemble activity constraints information		√	

$S_1$11	Monitor conformance	√		
$S_1$12	Take control action to ensure conformance	√		
$S_2$1	recognise all aspects of patients confidentiality		√	
$S_2$2	Identify constraints arising from data protection	√		
$S_2$3	Identify relevant standards related to currency	√		
$S_2$4	Assess impact on each activity		√	
$S_2$5	Decide how to react	√		
$S_2$6	Notify each controller	√		
$S_2$7	Assemble activity constraints information		√	
$S_2$8	Monitor conformance	√		
$S_2$9	Take control action to ensure conformance	√		
$S_2$10	Identify relevant standards related to storage of data	√		
$S_2$11	Identify relevant standards related to reporting	√		
$PMC_1$2	Assess the impact on each activity		√	
$PMC_1$3	Decide how to react	√		
$PMC_1$4	Assemble activity constraints information		√	
$PMC_1$5	Monitor conformance	√		
$PMC_1$6	Take control action to ensure conformance	√		
$PMC_1$9	Determine agreed priorities	√		
$PMC_1$11	Notify each controller	√		
$PMC_1$16	Know about availability of finance		√	
$PMC_2$1	Recognise relevant legislation constraints		√	
$PMC_2$2	Assess the impact on each activity		√	
$PMC_2$3	Decide how to react	√		
$PMC_2$4	Assemble activity constraints information		√	
$PMC_2$5	Monitor conformance	√		
$PMC_2$6	Take control action to ensure conformance	√		

PMC$_2$7	Notify each controller	√		
PMC$_2$9	Determine relevant standards constraints		√	
PMC$_2$30	Determine cultural constraints		√	
Human resource management subsystem				
T1	Determine the available resources		√	
S$_1$13	Assess skills required	√		
S$_1$14	Assess human resources required	√		
S$_1$15	Allocate skilled personnel to all activities	√		
S$_1$16	identify skilled personnel	√		
S$_1$17	Monitor personnel activity match		√	
S$_1$18	Take control action to ensure personnel activity match	√		
S$_1$19	decide how to make skilled personnel available	√		
S$_1$20	Make skilled personnel available	√		
S$_1$21	Monitor the availability of skilled personnel		√	
S$_1$22	Take control action to ensure the availability of skilled personnel	√		
S$_2$22	Recognise authorised users	√		
S$_2$23	Identify relevant professional	√		
L$_1$1	Identify all care professionals		√	
L$_1$2	Determine the coordinationand collaboration needed	√		
L$_1$3	Coordinate and collaborate between them		√	
L$_1$4	Monitor the coordination and collaboration between them		√	
L$_1$5	Decide how to coordinate and collaborate between them	√		
L$_1$6	Take control action to ensure coordination and collaboration	√		
L$_1$7	Identify others involved in the care process	√		
PMC$_1$ 22	Take control action to ensure capability resource matches	√		
PMC$_1$ 24	Monitor capability resource matches	√		

$PMC_1$25	Match the resources to the need	√		
PMC_1 35	Determine current human resources	√		
PMC $_1$36	Determine capabilities	√		
PMC_2 10	Make them available	√		
PMC_2 11	Decide how to monitor availability	√		
PMC_2 12	Take control action to ensure availability	√		
PMC_2 13	Monitor the availability	√		
PMC_2 15	Determine skilled personnel required		√	
PMC_2 23	Relate the availability to the execution and control of all activities	√		
Physical resource management subsystem				
T1	Determine the available resources		√	
$S_1$30	Determine physical resources required		√	
$S_1$31	Decide how to make physical resources available	√		
$S_1$32	Make physical resources available	√		
$S_1$33	Assess the availability of physical resources		√	
$S_1$34	Take control action to ensure the availability of physical resources	√		
PMC_1 28	Determine what additional physical resources is feasible to acquire		√	
PMC_1 29	Assess priorities for physical resources	√		
PMC_1 30	Assess costs of additional resources	√		
PMC_1 31	Identify sources of additional resources	√		
PMC_1 32	Assess additional resources required	√		
PMC_1 33	Determine future physical resources	√		
PMC_1 34	Know about current physical resources availability		√	
PMC_2 14	Make them available	√		
PMC_2 19	Determine physical resources required		√	
PMC_2 20	Monitor the availability	√		

PMC_2 21	Decide how to monitor availability	√		
PMC_2 23	Relate the availability to the execution and control of all activities	√		
PMC_2 31	Take control action to ensure availability	√		
Technology management subsystem				
$S_1$23	Maintain knowledge of development in technology and best practice		√	
$S_1$24	Identify opportunities or threat		√	
$S_1$25	Determine opportunities for exploitation	√		
$S_1$26	Exploit opportunities	√		
PMC_2 24	Exploit opportunities	√		
PMC_2 25	Decide how to exploit opportunities	√		
PMC_2 26	Determine areas of opportunities	√		
PMC_2 27	Maintain knowledge about development in technology and best practice		√	
Planning management subsystem				
$PMC_1$1	Identify the existing development plan		√	
$PMC_1$17	Formulate plans	√		
PMC_1 18	Execute plans	√		
PMC_1 27	Decide how to execute plans	√		
Intelligence assembly subsystem				
$L_2$11	define intelligence needed	√		
$L_2$12	Identify sources of intelligence	√		
$L_2$13	Decide how to assemble intelligence	√		
$L_2$20	assemble intelligence	√		
$L_2$22	monitor the assembly process	√		
$L_2$23	Take control action To improve the assembly process	√		
National targets management subsystem				
$L_2$1	Determine a particular community	√		
$L_2$2	Define health risks within that community	√		

$L_2$7	Define the appropriate care within that community	√		
PMC_1 10	Identify relevant national targets		√	
PMC_1 12	Decide how to meet them	√		
PMC_1 19	Identify the current and projected health care needs	√		
Overall performance management				
$S_1$6	Decide how to execute all activities	√		
$S_1$7	Decide how to control all activities	√		
$S_1$27	Assess the impact on execution of all activities		√	
$S_1$28	Assess the impact on control of all activities	√		
$S_1$29	Take control action to ensure the execution and control of all activities	√		
$S_2$25	Identify all activities	√		
$S_2$28	Decide how to Assess the support of all activities	√		
$S_2$29	Take control action to ensure the Support of all activities	√		
$L_2$3	Take control action to ensure the support of appropriate care	√		
$L_2$4	Monitor the support of appropriate care	√		
$L_2$9	Monitor the development of appropriate care	√		
$L_2$10	Take control action to ensure the development of appropriate care	√		
$L_2$14	Decide how to support appropriate care	√		
$L_2$16	Relate the assembled intelligence to the support of appropriate care	√		
$L_2$17	Decide how to develop appropriate care	√		
$L_2$18	Take control action to ensure the assembly supports appropriate care	√		
$L_2$19	Assess how the assembled intelligence achieved the support and development of appropriate care	√		
$L_2$21	Relate the assembled intelligence to the development of appropriate care	√		
$PMC_1$7	Take control action to achieve CRW expectation	√		
$PMC_1$8	Monitor performance expectation	√		
$PMC_1$13	Assess the achievement of the formulated and executed plans in meeting the needs	√		
$PMC_1$14	Take control action to ensure meeting the needs	√		

PMC$_1$15	Determine CRW performance expectation	√		
PMC$_1$20	Relate the executed plans to meeting the current and projected health care needs	√		
PMC$_1$21	Meet the current and projected health care needs	√		
PMC$_1$23	Determine performance measures	√		
PMC$_2$16	Decide how to execute and control all activities	√		
PMC$_2$17	Identify all activities		√	
PMC$_2$18	Execute and control all activities	√		
PMC$_2$22	Monitor the execution and control of all activities	√		
PMC$_2$28	Monitor the effect of exploiting opportunities on the execution and control of all activities	√		
PMC$_2$29	Take control action to ensure the execution and control of all activities	√		

Table C1: CPTM activity sets and their activities categorisation

Appendix D

The use case diagrams

D.1 GPs use cases

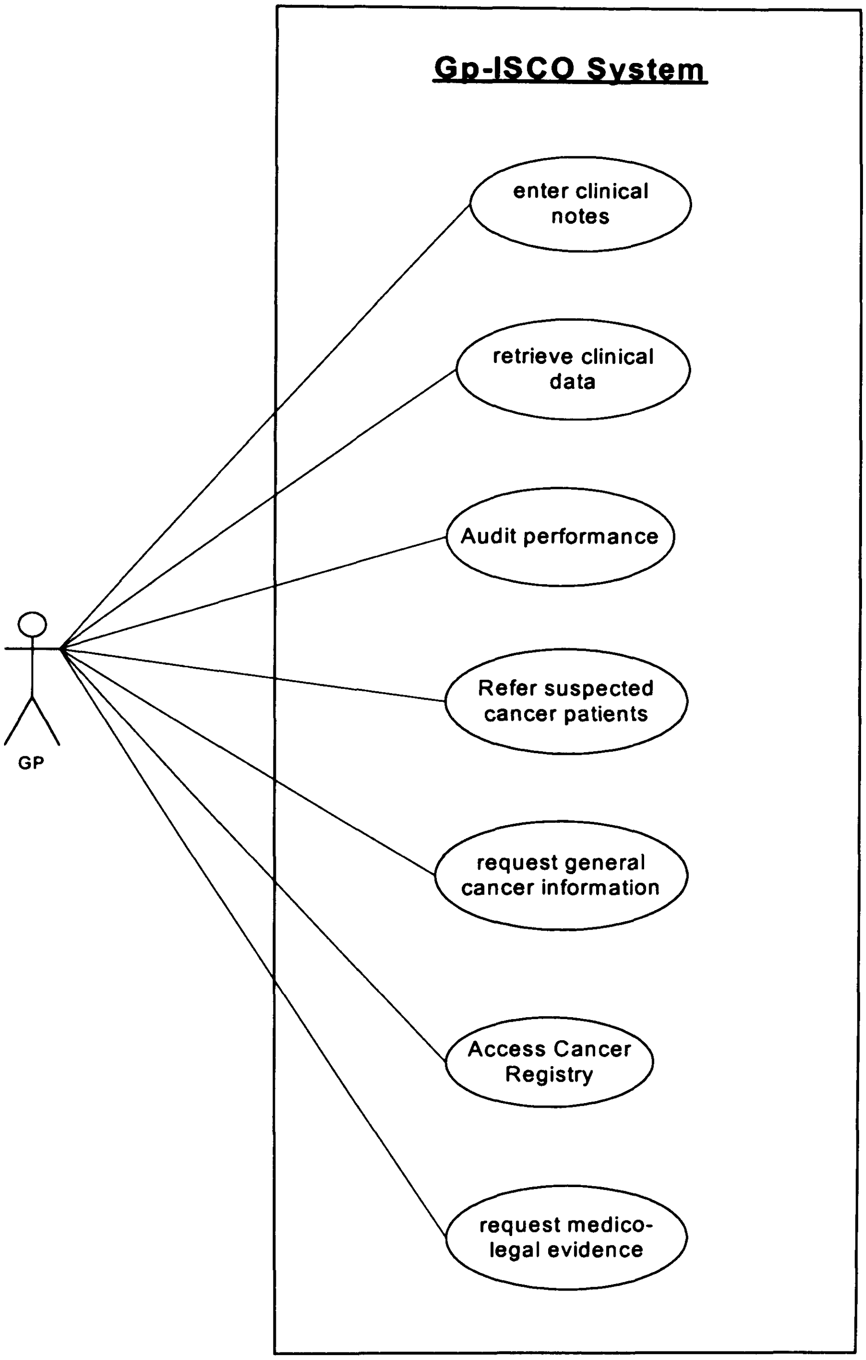


Figure D.1: GP top level use cases

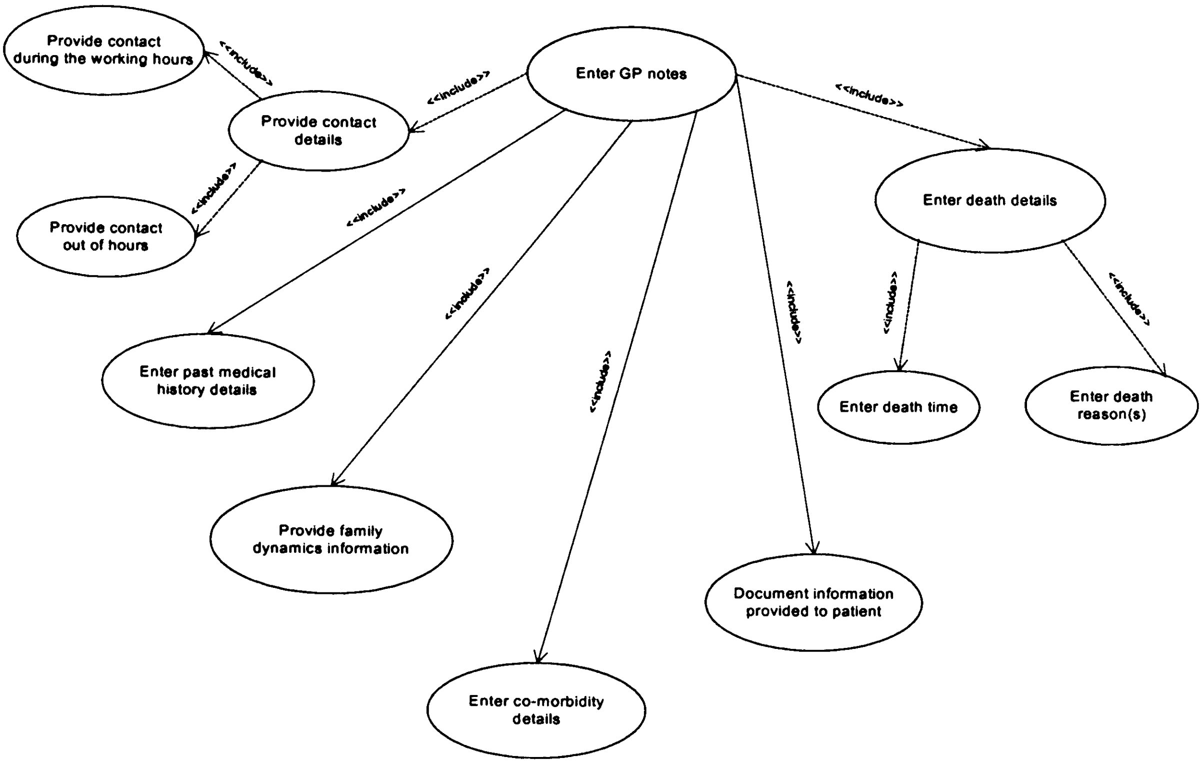


Figure D.1.1: Enter GP note use cases

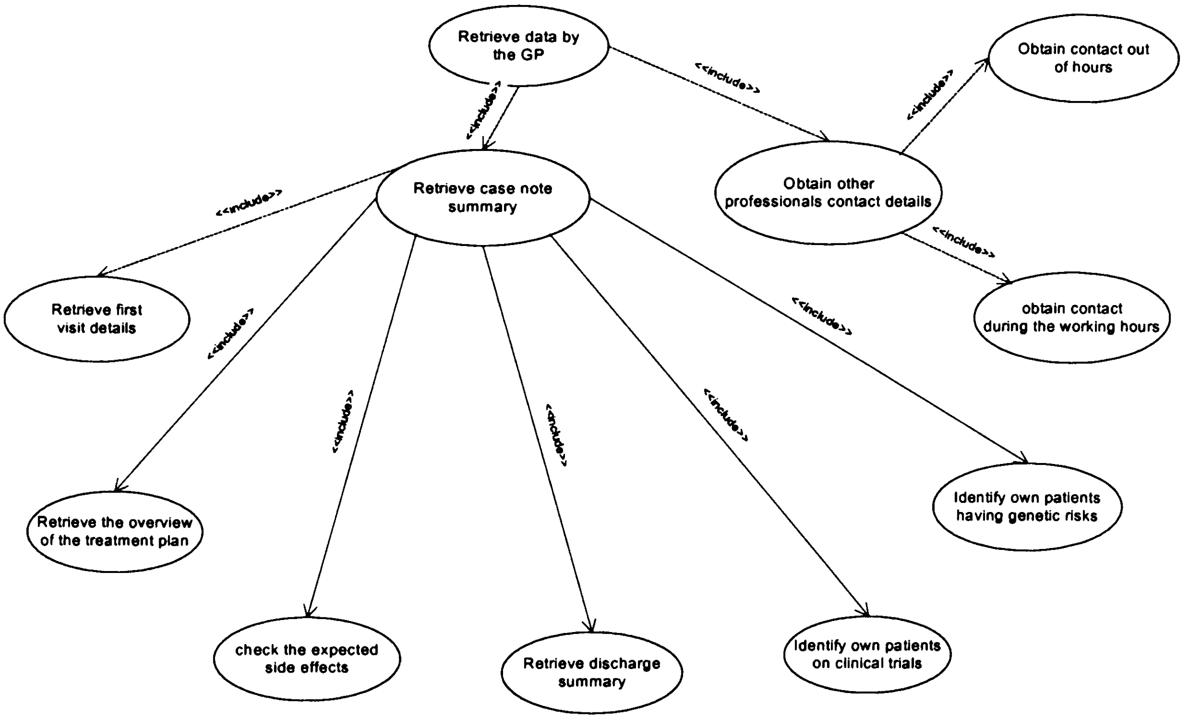


Figure D.1.2: Retrieve data by GP use cases

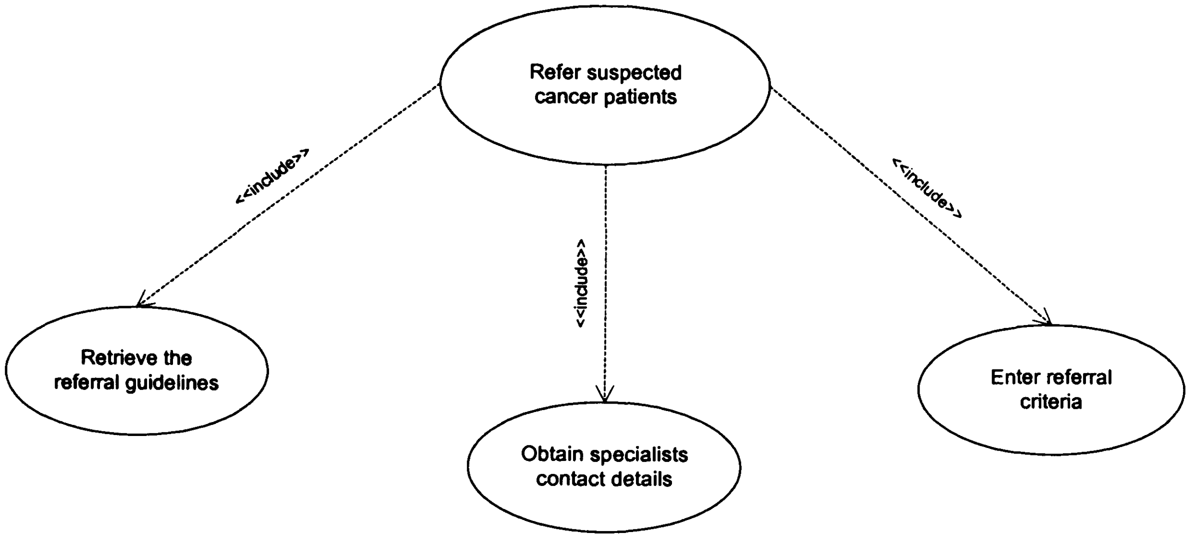


Figure D.1.3: Refer suspected cancer patient use cases

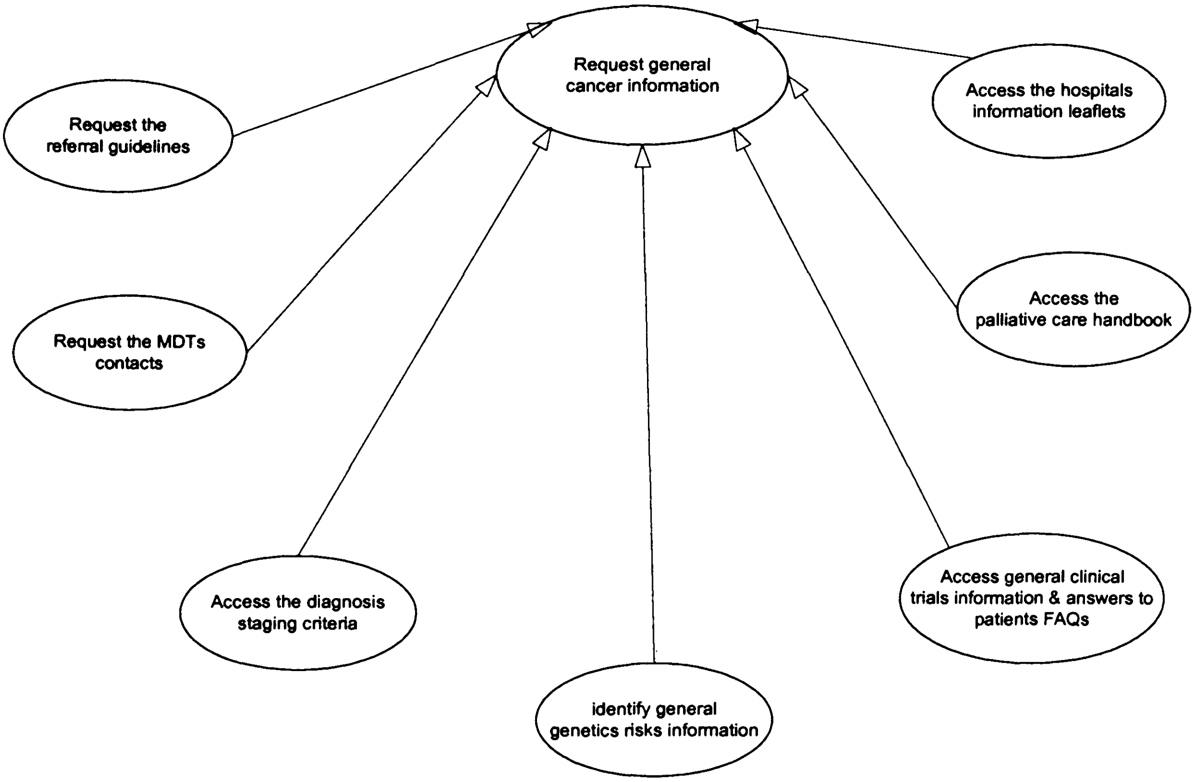


Figure D.1.4: Request general cancer information use cases

D.2 Cancer specialists use cases

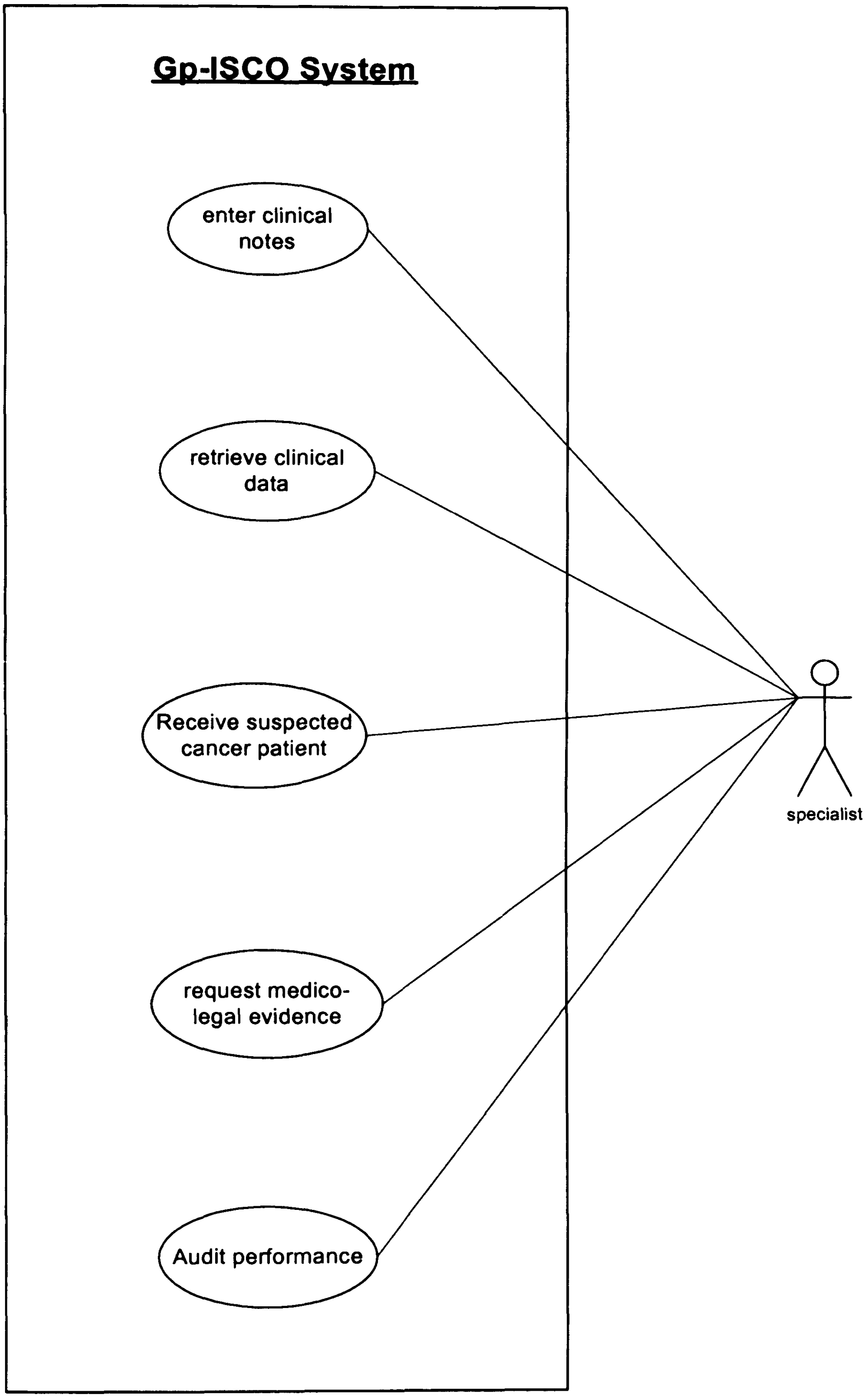


Figure D.2: Cancer specialist top level use cases

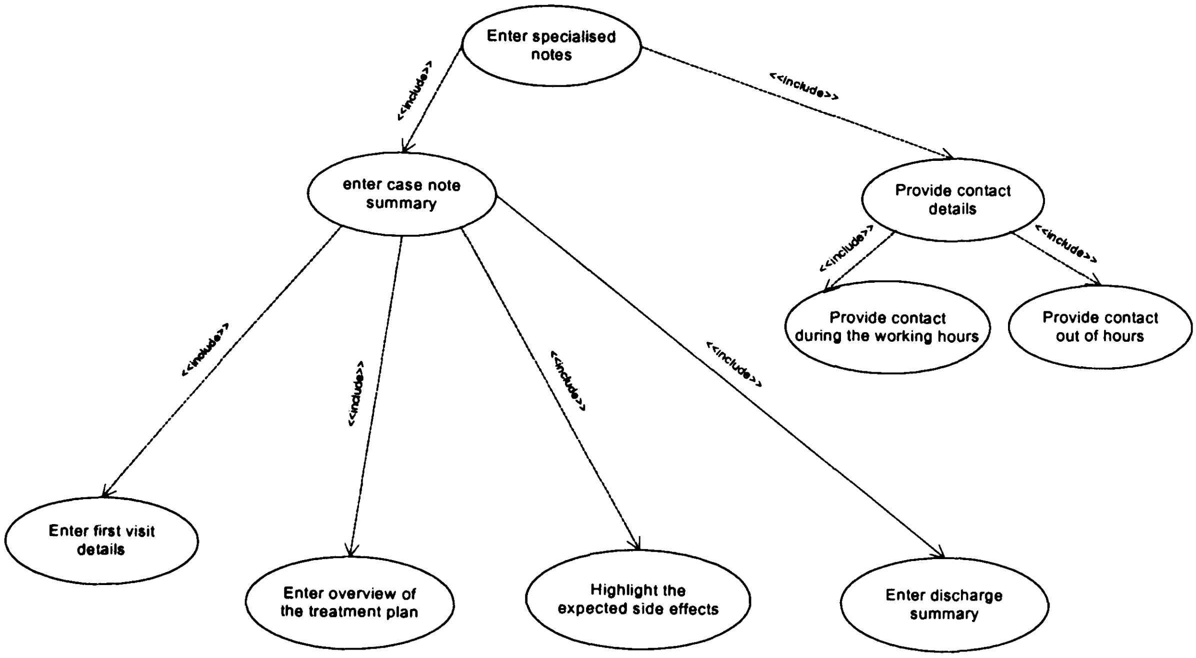


Figure:D.2.1: Enter specialist note use cases

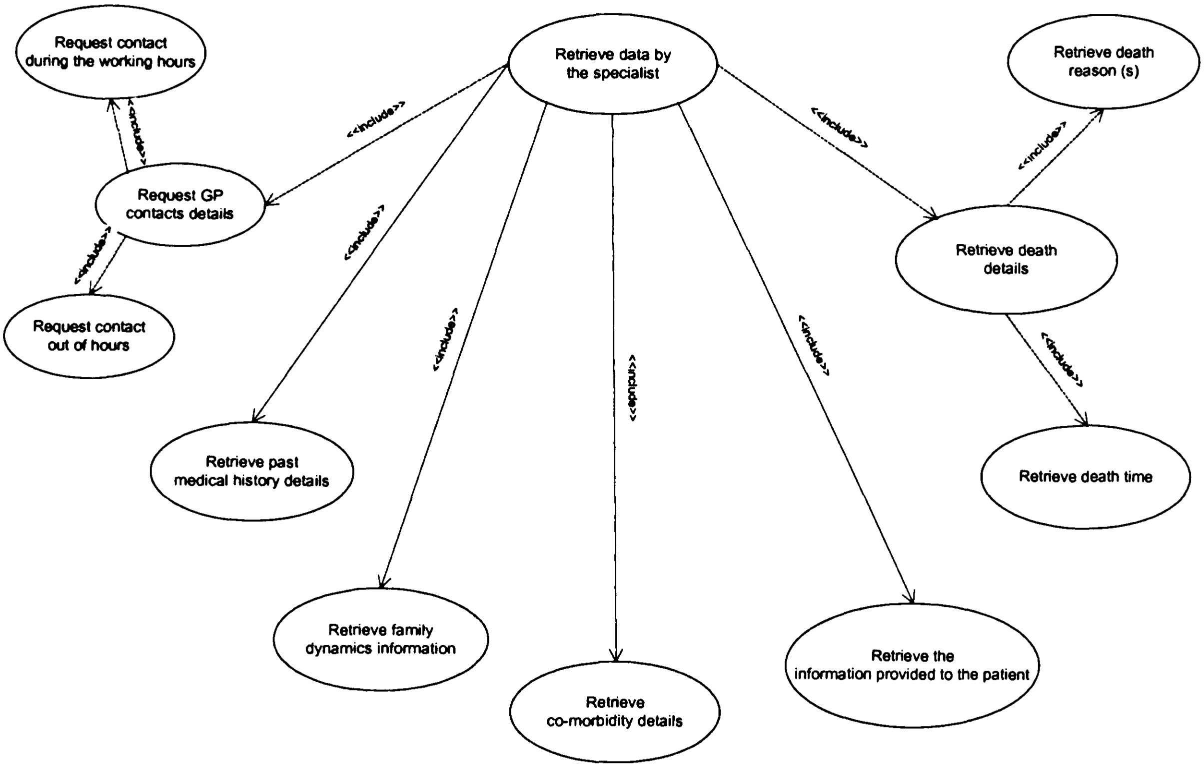


Figure D.2.2: Retrieve data by specialist use cases

D.3 Palliative care, cancer genetics and WCTN use cases

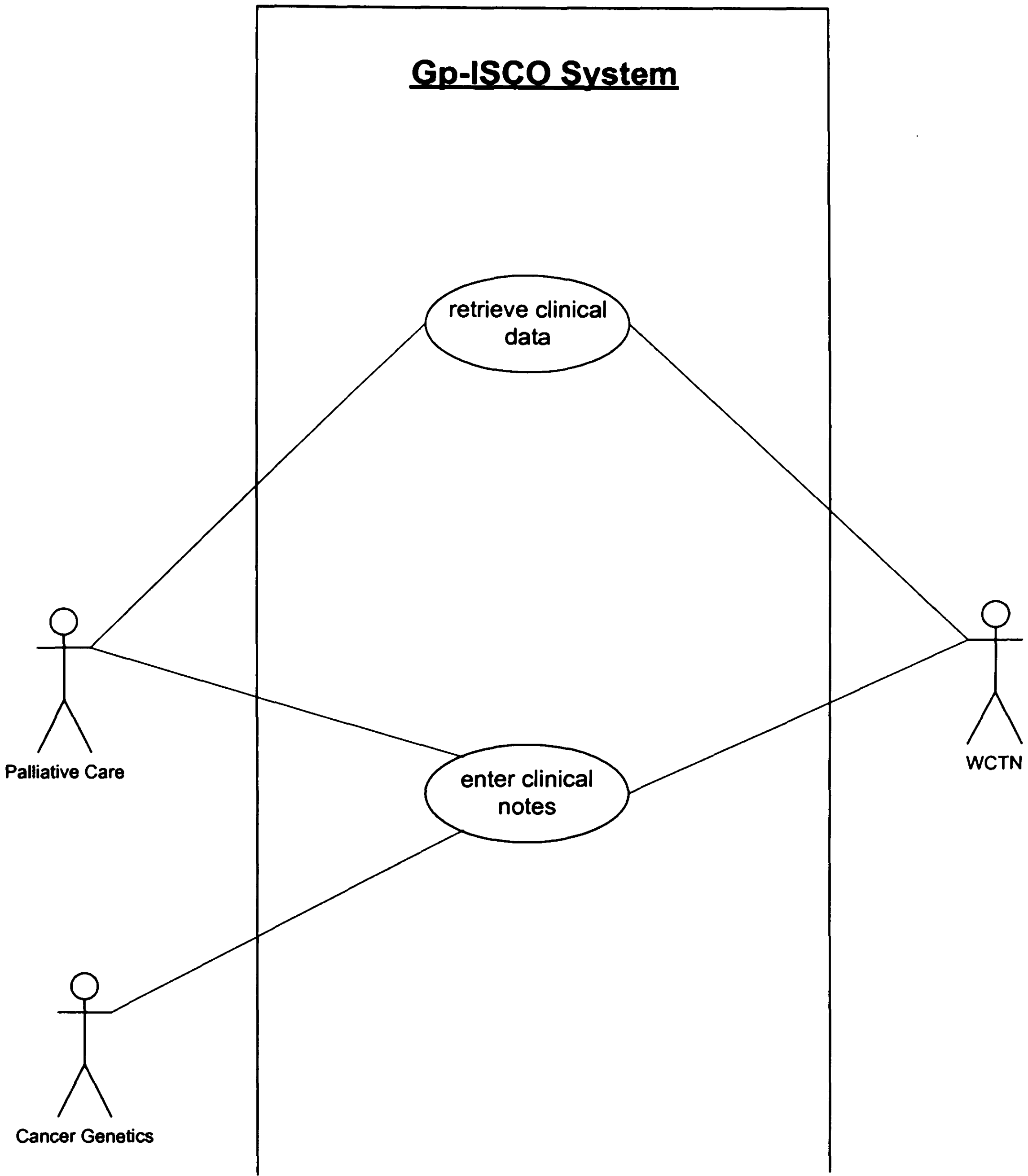


Figure D.3: Palliative care, cancer genetics and WCTN top level use cases

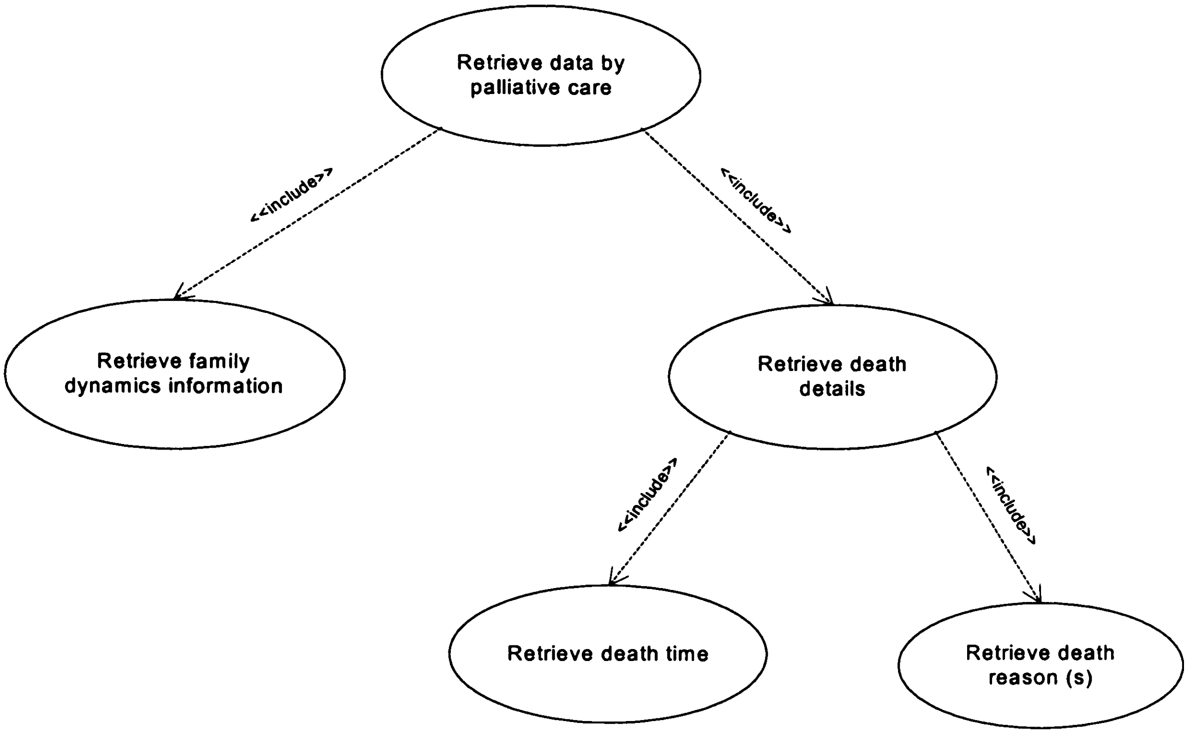


Figure D.3.1: Retrieve data by palliative care use cases

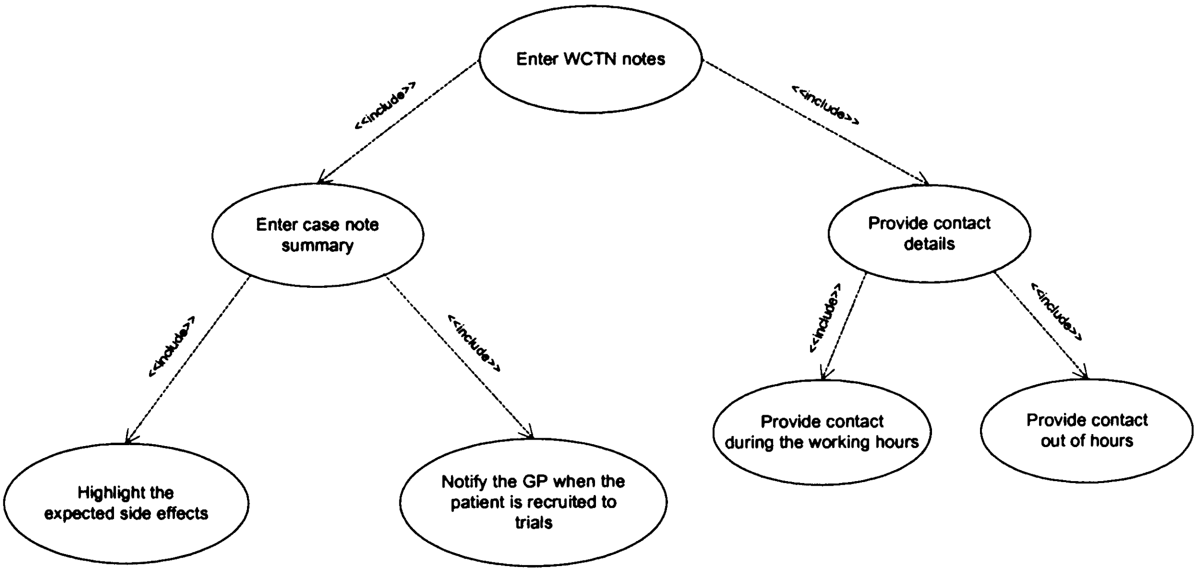


Figure D.3.2: Enter WCTN notes use cases

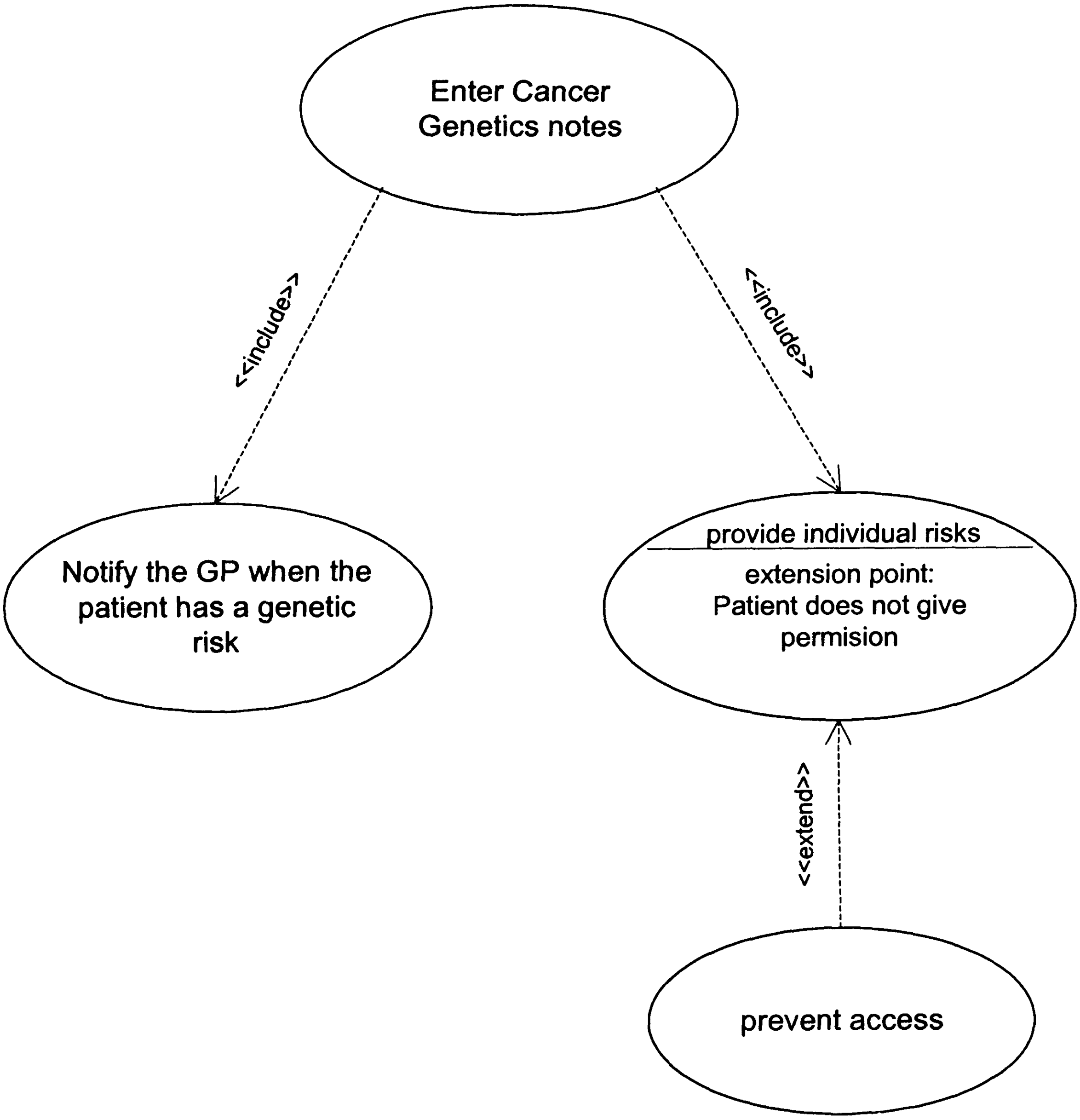


Figure D.3.3: Enter cancer genetics notes use cases

Personal Communications

All Wales Cancer Genetics Services:

[1] Dr Jonathan Gray	Director of Cancer Genetics
[2] Dr Mark Rogers	Cancer Genetics consultant

Cancer specialists

[3] Dr Alison Brewster	Consultant Oncologist
[4] Dr Peter Barrett-Lee	Consultant Oncologist
[5] Dr Tom Crosby	Consultant Oncologist

CSCG and NICE

[6] Dr Andrew Champion	Centre Manager, National Collaborating Centre for Cancer
[7] Dr Fergus Macbeth	Chair of CIF project, board member for CSCG, NICE representative
[8] Dr Jane Hanson	Director of the Cancer Service Coordinating Group

General Practitioners

[9 to 15] GPs at Ely Bridge Surgery in Cardiff

Dr Geoffrey Morgan	Special interests in medical education and assessment
Dr Peter Edwards	Special interests in asthma and psychiatry
Dr Huw Charles	Special interests in asthma and sports medicine
Dr Karen Santos	Special interests in maternity and gynaecological problems
Dr Trevor Thompson	Special interests in asthma/chest diseases and child health.
Dr Helen Lindsey	Special interests are child health, family planning and gynaecology
Dr Jane Evans	Special interests in the menopause and HRT, depression, child health and family planning
[16] Professor Glyn Elwyn	Director of Research, CAPRICORN Research Network
[17] Dr Richard Neal	Senior lecturer, College of Medicine
[18] Dr David Bailey	Ty Bryn Surgery, Trethomas

Informing Healthcare

[19] Mr David Davies	Informing Health Care project board

ISCO/CaNISC Team

[20] Dr Anthony Bater	ISCO Project Manager
[21] Dr David Morrey	Director of Information Management and Head of the Clinical Information Unit. Velindre NHS trust
[22] Mr David Howells	Senior ISCO software developer
[23] Mrs Hazel Bailey	Information Analysis
[24] Mrs Wendy Jones	Cancer Information Framework Project Manager

Nurses

[25] Ceri Hamlton	Clinical support manager
[26] Barbara Moore	Oncology research nurse

Palliative Care

[27] Dr Anthony Byrne	Palliative care Consultant Holme Towers
[28] Professor Ilora Finlay	Palliative care Professor

Practice Manager

[29] Mrs. Nicola Gardener	Practice Manager, Ely Bridge Surgery, Cardiff

South East Wales Cancer Network:

[30] Mrs. Ceri Jones	Cancer Services Coordinator, Royal Gwent Hospital.
[31] Mrs. Dawn Allen	Cancer Information Specialist
[32] Mr Hywel Morgan	South East Wales Cancer Network manager

Wales Cancer Trial Network (WCTN)

[33] Ms Lucy Branston	WCTN Manager
[34] Professor Tim Maughan	Consultant Oncologist and director of WCTN

WCISU

[35] Mrs Shelagh Reynolds	General Manager

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