Portal Technologies for Patient-centred Integrated Care

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Abstract: Integrated care pathways (ICP) are increasingly used in clinical settings to provide more effective care to patients. ICPs form part of local working agreements to assist co-ordination of multi-disciplinary teams to deliver evidence-based care plans to individual patients. They also document the expected progress of specific patient groups as part of clinical records. To anticipate increased use of ICPs, we have developed *Healthcare@Home*, a research-phase demonstrator for improving integration of information along the patient path. *Healthcare@Home* includes support for at-home, in-clinic and mobile wireless sensor devices feeding patient-proximal data hubs, timeline-based physiological trend analysis, data aggregation/dashboarding and individualised risk stratification. These and other decision support tools are embedded in portal designs supporting 'end-to-end' workflows as focused by the composite needs of a National Service Framework (NSF) for patients with diabetes. *Healthcare@Home* thus represents a scaleable, extensible personalised healthcare information system driven directly from national policy on disease early detection and prevention. Individual portlets have been mapped to stages in the ICP. The portal technologies employed, running on PCs, mobile phones or TVs are capable of highly cost-effective 'end-to-end, anywhere-to-anywhere' information integration.

Keywords: Health informatics, portals, integrated care pathway, graphical trend analysis, service oriented architecture, bio-medical sensor devices

1 Introduction

Emphasis on proactive patient-centred care has increased adoption of Integrated Care Pathways (ICPs) within a wide variety of disciplines. ICPs - also known as care profiles or protocols determine locally agreed (multidisciplinary) health practice, based on guidelines and evidence (where available) for a specific patient group. An ICP enables clinics to deliver healthcare to patients based on their particular needs. ICPs have potential benefits for patients and clinics adopting them [Ca98]. Definitions of ICPs have included -

"... being both a tool and a concept that embed guidelines, protocols and locally agreed, evidence-based, patient-centred, best practice, into everyday use for the individual patient." [WS04]

"... a multidisciplinary outline of anticipated care, placed in an appropriate timeframe, to help a patient with a specific condition or set of symptoms move progressively through a clinical experience to positive outcomes. Variations from the pathway may occur as clinical freedom is exercised to meet the needs of the individual patient." [RM00]

An ICP describes the essential steps in the care of patients with a specific condition and

the expected progress of the patient [Ca98]. An ICP is highly dependent on information that is timely, reliable, secure and specific for a given patient. Efficient and secure delivery of ICP-relevant data raises key design challenges for information systems, especially as part of decentralised care. It is widely anticipated that future health information systems (HIS) will need to move from "institution-based" models to those rely on near real time data integration close to the patient. These systems also need to support ethical data aggregation on outcomes of treatments and permit the stable development of 'rings of care' i.e. where professionals, family members, friends and volunteers can create a community or social support network *via* the Internet. These aspects require systems to be flexible yet robust enough to follow the 'patient path' - not only across different healthcare departmental facilities, but also into the home and out to mobile locations. In Wales, the process for evolving a patient-centred diabetes service has followed drafting of consensus integrated care pathways in order to achieve each of the 12 standards of the National Service Framework (NSF) for Diabetes [WS11]. The ICPs thus form the focus for data integration that is close to the patient.

Taking the above design criteria into account, the *Healthcare@Home* project has thus far focused on building an end-to-end framework to support development of outcomes-based decision support systems in diabetes. This includes research into generic information tools to stratify disease progression risk for better decision making. *Healthcare@Home* is also concerned with the mechanisms by which data may be ethically aggregated and searched to provide better insights into patterns of disease, its early detection and prevention. The wireless data recording methods embedded into the *Healthcare@Home* model helps avoid transcriptional errors and potential inconsistencies across different clinics that might operate the system. The portals also feature timeline-based recording that will be critical for visually integrating a large number of event and risk-related 'flags' in an accessible manner (e.g. signalling that a trend in data has occurred). Diabetes management systems that use continuous and discontinuous data feeds from physiological monitoring devices have the capacity to improve patient's quality of life [Vs05]. While *Healthcare@Home* represents an early-stage research model that does not yet use patient data, it has been designed to assist scale up of disease early detection and prevention services against the background of increased global incidence for diabetes in the adult population (c.135 million globally in 1995 to c.300 million in 2025 [KAH98]).

2 Related Work

There are many research-oriented informatics projects that overlap in purpose with requirements of integrated care. Most projects have some aspect of electronic health record (EHR) support which Iakovidis [Ia98] defines as "*digitally stored health care information about an individuals lifetime with the purpose of supporting continuity of care, education and research, and ensuring confidentiality at all times*". EHRs exist in many forms and through interoperability frameworks (e.g. XDS/CDA) can collate 'on the fly' or hold a wide range of medical information including results from laboratory tests, patient demographic information and treatments [Ei05]. European research programmes are wide ranging in scope and include *Health-e-child* [Fr06] focusing on developing an

integrated healthcare platform for paediatrics; *SmartHEALTH* [WS06], developing systems for improving quality-of-life for patients suffering from various types of cancer; and *SAPHIRE* [He06], concerned with developing a healthcare monitoring and decision support system targeting patients suffering from cardiovascular diseases, aided by wireless sensor devices in a home setting. The distinct concept of Personal Health Records (PHRs) [Ia98] is also relevant to the interaction of clinical and patient portals in *Healthcare@Home*. A PHR, exemplified by *iHealthRecord* [WS02], *myPHR*, *CapMed* [WS03] is a health record that is initiated and maintained by an individual to store self-managed health data. Some PHRs provide paths to personal health education and can host structured questionnaires. *MediCompass* [WS01] permits a user to access their PHR using a web browser. *DiabetEASE* [WS13] is a web-based monitoring system for people with diabetes that uses a graphical timeline model for disease management functions. A major development directly related to portal development for use in the UK NHS has been the Common User Interface (CUI) [WS05] for clinical applications, designed to help ensure that critical patient data such as drug information is displayed in a standard way; the CUI (built on .NET with AJAX extensions) gives a standard patient overview, together with prescribing screens that enable clinicians to easily identify the right patient and ensure they receive the correct medications. Tools for meta-tagging clinical notes (e.g. automatic prompting for SNOMED CT coding) are a move towards developing an integrated EHR. Other key aspects of this project include standardised date/time formats, consistent UI, availability of a design guide, resource integration (e.g. British National Formulary) and a toolset for independent software vendors to incorporate the CUI into their own application front ends. *Healthcare@Home* will utilize the outputs of the CUI project in due course.

In *Healthcare@Home*, the clinical and patient portals are inter-dependent, but only to the extent defined by the diabetes clinical guidelines. There are features in the *Healthcare@Home* patient portal that permit volunteering of additional information to supplement existing data stored in the EHR. High quality timeline-based information on aspects such as food, medication, alcohol consumption, physical activities etc can be helpful in creating care plans that are specific to the needs and preferences of the patient. *Healthcare@Home* has additional web-based toolsets that will be developed to follow the success of individual interventions, permit the monitoring of disease progression, enable specialist professional statistical functions for clinical and ethical population-based research, integrate wireless-enabled biomedical sensor devices in home/clinical settings and a generic risk stratification system (QUIRA) to inform clinical decision making.

3 Clinical portal content defined by policy and dataset standards

The project as a whole sat within the extended context of the Diabetes ICP relating to parts of the prevention-driven ICP framework published by Diabetes UK (Figure 1). The scope of the *Healthcare@Home* research model covers several aspects described in figure 1 but does not yet fully support an end-to-end system. We also used available domain dataset standards, in particular the Diabetes Continuing Care Reference (DCCR) Dataset [DH05] to harmonise the multiple types of stored data. The adoption of DCCR definitions at each participating site (giving a semantic equivalence and therefore interoperability for

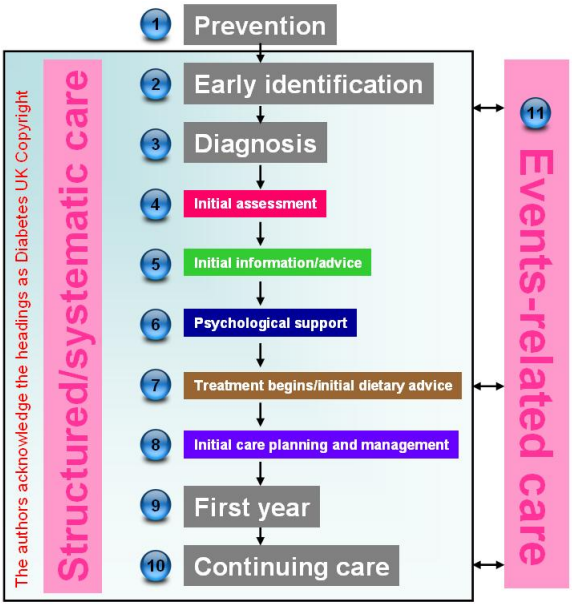

Figure 1: ICP stages (Figure portions copyright Diabetes UK)

data being collected) was considered essential for the success of any subsequent multi-site integration steps, e.g. in forming an interoperable information service family dependent on local and national healthcare messaging fabrics. In order to best articulate needs for the clinical portal, recommended clinical service practice encompassed by selected parts of the draft consensus documents for the Wales National Service Framework for Diabetes were analysed for specific workflows such as registration procedure, initial assessment, consultation / discussion of results leading to individualised target setting plus various types of selectable 'at-home' monitoring services. This process identified the data elements in each part of the consensus pathway defined as within scope.

The clinical portal was built in a tabbed browser interface, mirroring a set of scenario descriptions that occur along the patient path. Data collection practices were explicitly defined by the Wales NSF for Diabetes [WS11]. The initial specification also included detailed considerations of the obstacles to effective self-management; and this was used to identify core information significant for determining individualised risk in 'near real time'. The NSF also set standards specifying the type and extent of monitoring expected - e.g. for HBA1c tests, blood pressure monitoring and blood lipids determination (e.g. cholesterol, see Figure 2). Subsequently, the consensus guidelines were translated into a set of detailed modular workflows. These processes were drafted in BPEL (Business Process Execution Language) to define the requirements of the clinical portal. As illustrated in Figure 2, the Initial Assessment workflows provide quality-controlled data as a baseline for data that can later be acquired from home or mobile locations.

The initial assessment workflow also captures patient history and medical examination

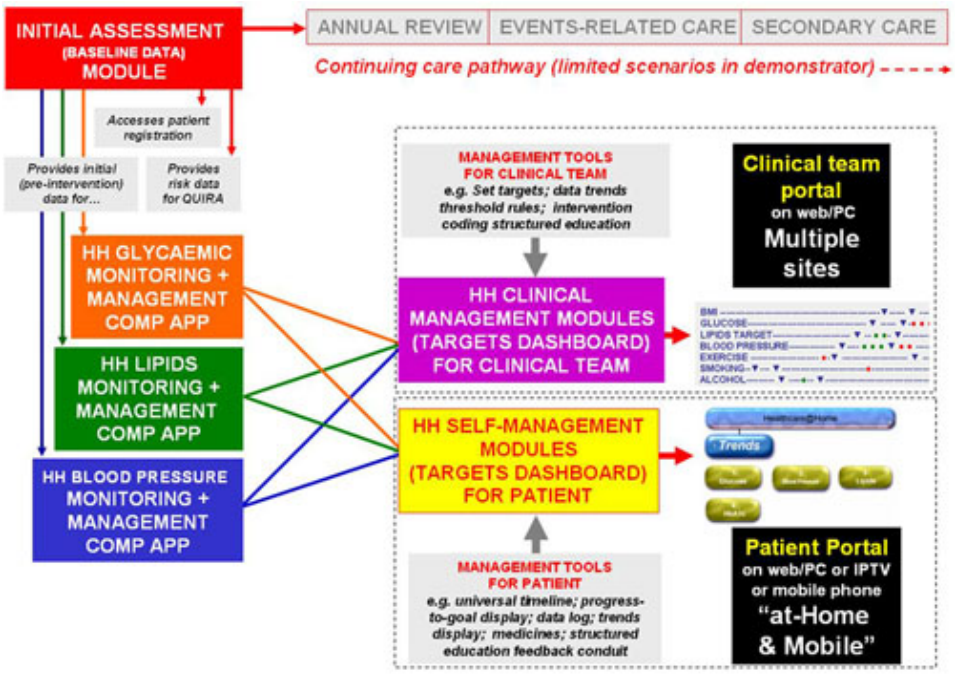

Figure 2: Patient-proximal monitoring services merged by portal supporting information flow in ICP

data for signalling 'immediate risk' triggers e.g. for additional diagnostic tests or screening for complications of diabetes (i.e. conditions that may require urgent referral). The ICP is designed so that a negotiation of 'self-management goals' with the patient is given priority.

3.1 Portals that support continuous care from clinic to home

The workflows suggested by the Wales Diabetes ICPs emphasise continuous care. Treatment decisions are made according to consensus documents on the basis of frequent review of outcomes in episodes of care. The portal-based information support system (Figure 3) summarises the steps involved and how the portals are critical to management of the continuous care process. Essentially through monitoring of patient-specific data, the portals permit analysis of the success or otherwise of a particular intervention, ranging from dietary and lifestyle changes to staged therapeutic regimen. The portals permit the continuous management of conditions within the control of the patient, who has full access to their physiological trend data on a timeline.

The flow of information assisted by the portal technologies can be summarised in steps. As illustrated in Figure 3, the initial assessment clinic uses a portal to capture a range (approx. 57) of data items from taking of history and physiological measurements using

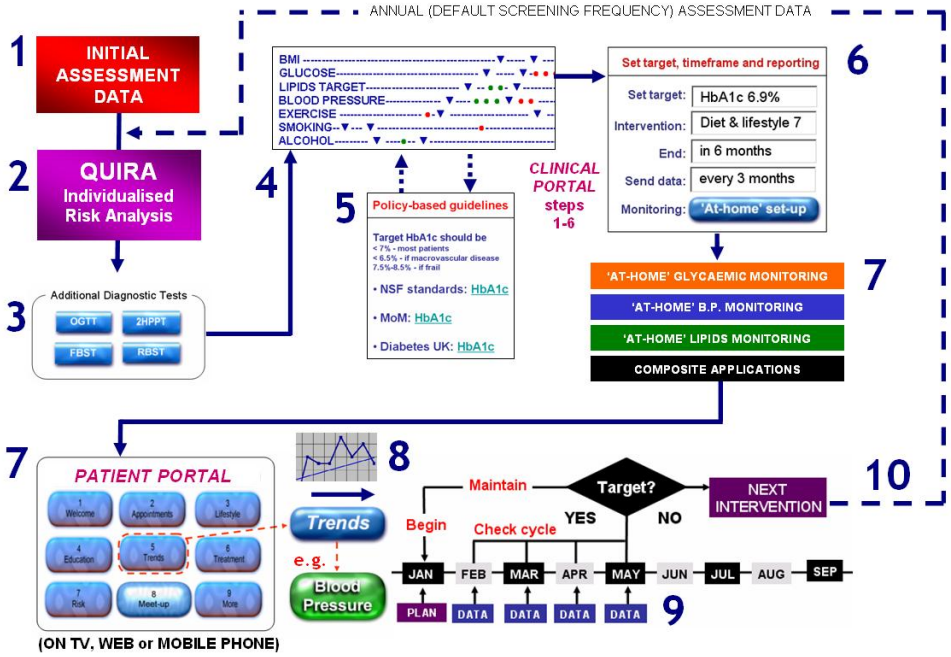

Figure 3: Portal technologies assisting information flow in patient-centred ICPs

a set of wireless instruments. In step 1, the results from a list of tests selected for the patient are sent directly from instruments to the portal via a clinical data integration hub (not shown). In step 2, data is assessed for 'individualised risk' to prioritise patients in need of urgent referral and to compare their status with a 'risk signature' that might indicate an immediate preventative or screening action to be taken. In step 3, a number of optional specialised diagnostic tests may be triggered. Step 4 includes the collated data populating an individualised patient 'dashboard' to help the clinician judge the status of the condition against observed ranges - and help determine the best stepwise options for the individual's care and treatment. More detailed policy-based guidelines relevant to the options at the 'decision point' are presented at step 5. Following discussion of options with the patient, a specific intervention is selected and an appropriate personal outcome 'target' is set with active engagement of the patient. In step 6, the agreement on the target sets up composite applications that communicate with the patient's portal (step 7) for comprehensive 'at-home' monitoring to manage the entire intervention 'episode'. These (prescriptive) actions write 'procedural' content into the detailed individualised care plan, together with a schedule of appointments. At this point, different members of the care team (through their view of the clinical portal) are alerted with additional professional support of pertinence to the type of care/treatment intervention. An 'end-to-end' intervention analysis application (step 8) systematically monitors progress against a single timeline to track multiple (physiological) trends via the prescribed measurement modalities for evaluation of interim outcomes (capturing any deviations from the plan) towards the agreed personal

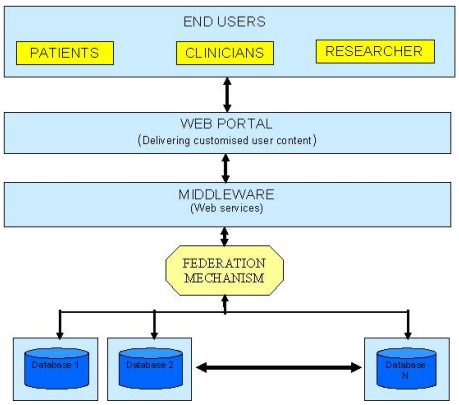

Figure 4: Logical Architecture

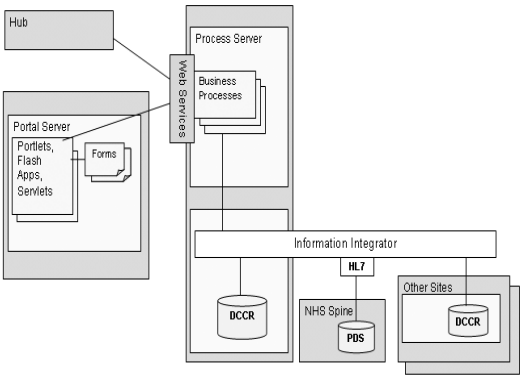

Figure 5: Physical Architecture

target (step 9). Automating the recording of steps in the ICP in this way can capture new evidence-based criteria i.e. whether patients revisit the clinic or 'progress' to the next part of the care pathway according to the outcomes (i.e. the dotted line back to 'QUIRA'). This end-to-end continuous care system has an advantage that patient status can be checked in near-real time and should be flexible enough to overcome barriers to self management. The improved data quality inherent in the device integration methodology provides a more robust basis for clinical judgement.

4 System Architecture

The logical architecture (figure 4) provides role-based access to data maintained within multiple databases. Roles within the system include: (1) patient: an individual registered with the system - in the context of the Diabetes NSF, a patient enrolled on a register; (2) clinical team members: clinician, e.g. a doctor, a member of administrative staff, or a nurse (each of these roles are treated differently for data access rights); (3) researcher: a user with express ethical permission and authority to access anonymised patient data to study trends, generate statistics etc. Researchers are not given access to data from any individual patientand can only permitted to analyze generalised trends from anonymised data. Access control mechanisms are associated with each of these roles and are in keeping with ethical guidelines.

4.1 Physical Architecture

The System architecture described in Section 4 has been realised as illustrated in figure 5. A portal server provides a secure and customisable interface between the end-user (clinicians, patients and researchers) and the middleware. A suite of portlets have been created where each portlet maps to a stage in the ICP. A process server allows data management processes to be deployed and invoked on the server, allowing new processes to be added

for additional capability. The process server operates primarily as a workflow enactment engine. The initial request to the process server is generated through Web Service. A database is used for storing patient information in a particular geographic location and a mediator architecture is then used for federating geographically-distributed databases.

4.1.1 Implementation of the Clinician Portal

A portal intended to be used by clinicians built for supporting phases of the Wales Diabetes NSF (as described earlier) has been implemented. The portal is divided into six portal pages, four of which reflect a phase in the overall clinical workflow. These pages are: "Registration", "History", "Measurement", and "Management". Following registration, the history page (stage 4 in Figure 1) permits recording of lifestyle information such as smoking habits and alcohol intake. The measurement page (stage 4 in Figure 1) allows a range of device data recorded in an assessment clinic to be entered into a database organised by the dataset conventions of the DCCR. Later stages (stage 7, 8 and 9 in Figure 1) permit a clinician to set timeline-based targets on blood pressure, glucose and lipid concentration, and subsequent comparison of these targets with measured values (refer to Figure 6). An evaluation at the end of each stage for each metric (e.g. blood pressure, glucose/HBA1c and lipid concentration) determines the subsequent path and further interventions to manage the condition.

Figure 6: Snapshot of glucose management stage 2 (Maps to stages 7, 8 and 9 in Figure 1)

The remaining two portal pages -"Dashboard" and "Risk" - are intended to provide further decision support features. The dashboard page enables clinicians to visualise patient data over time. Apart from sensor-based data trend, the graph can incorporate metadata-tagged notes that clinicians may have made regarding targets and interventions. The 'Risk'

functions have the capability of evaluating scores pertaining to individualised risk of specific outcomes; within an ethical decision-making framework, risk engines like this can be enormously valuable in identifying patients with high risk of adverse outcomes. Each portlet can be considered as a separate (composite) application, and the design is such that it permits portlets to exchange data with each other. In addition, composite applications may exchange data using a standardised messaging fabric, giving access to (wider) common clinical service data. The modular design of the information services also permits easier integration of cross-enterprise document sharing (XDS) models and the production of clinical statements. Within *Healthcare@Home*, data exchange is achieved by initialising a portal session for each user, and subsequently sharing session parameters between all the portlets. The session stores the parameters that need to be passed between the portlets. In this way, the portal provides a single sign-on capability, via a username/password pair (or extensibly through physical access devices such as smartcards). In the clinical role, only the patient selection portlet is enabled. Once a patient has been selected, the patient identity is stored in the portal session, and other portlets are enabled. Adobe Flash forms technology has also been used to create a dynamic user entry form, and for data binding between the form and the Web Services. The portlet passes the patient ID to the form, resulting in a SOAP call to the relevant Web Service to retrieve relevant patient data. The returned data (in XML format) is displayed in the Flash form.

4.1.2 Research portal

A research portal in *Healthcare@Home* designed to supply anonymised data to authorised statisticians, researchers and policymakers for service-based trends analysis subject to ethical permissions. There is much value in the automated aggregation of service or clinical facility data (through federated interoperable mechanisms) especially for evaluating the impact of research or health policy interventions across the population.

4.1.3 Patient portal

The patient portal (only discussed briefly here) was designed and implemented to address the following requirements: (1) to present information in a straightforward manner (2) to enable the patients to follow prescribed treatment and guide them when necessary (3) to enable patients to provide additional information on their daily activities that may have a bearing on their condition (4) to make the portal accessible from a variety of devices including mobile phones, PCs and the most common display device in the home - the TV. Data can be visualised as graphs, a log of daily activities, and document pointers (or references) to materials recommended for reading by the clinical team (e.g. doctors, nurses, dietitians). Patient portals can also host structured questionnaires that can be used with ethical guidance to input risk data. The interface has a simple design so it can be accessed from various devices including: mobile phones, internet browsers and IPTV clients. The patient portal overlaps with classical PHR functions which can be used in conjunction with EHR information (see earlier). The overall objective is that patients gain better insight into their conditions. The patient portal shall be discussed in detail elsewhere; Figure 7 shows a typical longitudinal plot of device data that would be visible within the web-based client. The design has been influenced by the requirements to use this technology with the healthy population as part of lifestyle management. The patient portal has an open design to per-

mit visualisation of multiple trends and events in a menu-driven uncluttered manner. We have also considered how this portal technology needs to be integrated with telehealth/care call centre-type monitoring to provide sustainable and flexible monitoring services (to be described elsewhere).

Figure 7: Visualisation of sensor data annotated with patient log activities

5 Evaluation

When our system is fully developed, we would like to test the performance and usability of the *Healthcare@Home* portals by formal and systematic evaluation. This will include HCI issues aided by the impact of the NHS Common User Interface (CUI) guidelines (see Section 2) as well as steps suggested by Ian [So95] for interface evaluation. Furthermore, tools such as JMX can be used to measure the performance of web applications. Relative performance of the portal framework against other interfaces such as applets, JSP and HTML providing browser based access needs to be evaluated. There are opportunities to test the portal framework in the implementation of ICPs themselves; we need to evaluate and solve in an integrated creative way those user problems that arise when moving from paper-based to electronic systems. There are interesting challenges in using *Healthcare@Home* to analyse reasons underlying exceptional variation and deviation from care plans to permit service improvement. Other key areas to evaluate are portlet interoperability - i.e. how portable JSR168 portlets are when deployed in other portal containers. Currently, the demonstrator is built on an IBM Websphere portal environment. There are security-related issues - i.e. evaluating physical data security and effectiveness of access rights for various users. There are also requirements to evaluate methods for efficient integration of data between different clinical sites and between health and social care services for critical risk management purposes (e.g. via XDS). Other issues relate

to auditing of transactions taking place and enforcing accountability. In keeping with the purpose of designing portals to translate detailed aspects of the ICPs, we will evaluate the portal functionality in partnership with multidisciplinary clinical teams.

6 Conclusion

Developing an end-to-end workflow supported by integrated clinical and patient portals has significant advantages for individualised patient care. Portal-based data gathering is key for enabling coherent 'evidence-based' practice. Since ICPs focus on outcomes following interventions, portal techniques can be used to track variations in care/treatment (i.e. inputs to systems which are then correlated with exceptions in outcomes). Analysis of inputs and outcomes can help pinpoint how care/treatment (or the ICP itself) can be improved. Naturally, in many areas of current practice, outcomes may not be recorded. Effective management of complex conditions like diabetes require a more fastidious, continuous, personalised approach. Decisions must be based on high quality, time-critical data in multi-step pathways so that the best options in care/treatment can be reviewed in the light of clear evidence for 'impact'. Progression in the pathway will accord to a patient's individual needs, with their full understanding and active participation. Portal technology can assist this engagement process, helping patients gain insight for management of their own conditions. The challenge is to make this type of management routine and design the 'right' tools to support it in real-world situations. Additional visualisation and intervention analysis tools to help joint/participatory decision making based on high quality "near real time" information are also needed. In this regard, clinicians have commented that adherence to defined workflows supported by portals (to take "the service" to the patient in home and mobile settings) are instrumental if obstacles to self-management are to be finally overcome. Other support points that are critical to self-management (but not discussed further here) include provision of targeted educational materials, recognising a wide diversity of patient types and motivational systems to 'move the patient along the pathway' An optimised ICP support system would be able to discover the "right" range/depth/timeline coverage of data pertinent to an individual patient's needs to permit good clinical judgement on individualised risk stratification and options for intervention. End-to-end integration of portal-based functions adds value in aspects like systematic intervention analysis for quality improvement.

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