Supporting Integrated Care Pathways with Workflow Technology

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2012

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A thesis submitted in partial fulfilment of the

requirement for the degree of Doctor of Philosophy

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This thesis is dedicated to my mother Laila Khadr who made every effort to keep me going. It is also dedicated to my father Abdullah Alsalamah who always believed in me.

Summary

This research investigates the use of Workflow Technology to support the implementation of the Integrated Care Pathway for a patient. This is to support team communication and care coordination along the treatment process, by identifying the information requirements at the different treatment stages and ensuring that these are met at the point of care. The proposed approach maps the national clinical guidelines into a Workflow Management System. This constructs an independent layer which interact with the discrete hospital information systems. Moreover, it evolves the functionalities of legacy systems by integrating its interface with legacy system interfaces. It constructs a Virtual Organisation around the unique needs of each patient by virtually integrating the data in these distributed legacy systems. A proof-of-concept prototype showed that this approach can, formalise the treatment process, ensure care continuity, filter and gather medical information, and pro-act to changes. This is an innovative, useful and applicable approach. It changes the use of data from passive to active. More importantly, it supports patient-centred care.

Abstract

Modern healthcare has moved to a focus on providing patient centric care rather than disease centred care. This new approach is provided by a unique care team which is formed to treat a patient. At the start of the treatment, the care team decide on the treatment pathway for the patient. This is a series of treatment stages where at the end of each stage, the care team use the patient's current condition to decide whether the treatment moves to the next stage, continues in the treatment stage, or moves to an unanticipated stage. The initial treatment pathway for each patient is based on the clinical guidelines in an Integrated Care Pathway (ICP) [1] modified to suit the patient state.

This research mapped a patient ICP decided by the healthcare providers into a Workflow Management System (WFMS) [2]. The clinical guidelines reflect the patient-centric flow to create an IT system supporting the care team. In the initial stage of the research the IT development team at Velindre Hospital identified that team communication and care coordination were obstacles hindering the implementation of a patient-centric delivery model. This was investigated to determine the causes, which were identified as difficulty in accessing the medical information held in dispersed legacy systems. Moreover, a major constraint in the domain is the need to keep legacy systems in operation and so there is a need to investigate approaches to enhance their functionalities. These information systems cannot be changed across all healthcare organisations and their complete autonomy needs to be retained as they are in constant use at the sites.

Using workflow technology, an independent application representing an ICP was implemented. This was used to construct an independent layer in the software architecture to interact with legacy Clinical Information Systems (CISs) and so evolve their offered functionalities to support the teams. This was used to build a Virtual Organisation (VO) [3, 4] around a patient which facilitates patient-centric care. Moreover, the VO virtually integrates the data from legacy systems and ensures its availability (as needed) at the different treatment stages along the care pathway.

Implications of the proposal include: formalising the treatment process, filtering and gathering the patient's information, ensuring care continuity, and pro-acting to change. Evaluation of the proposal involved three stages; First, usefulness evaluation by the healthcare providers representing the users; Second, setup evaluation by developers of CISs; and Finally, technical evaluation by the community of the technology. The evaluation proved; the healthcare providers' need for an adaptive and a proactive system, the possibility of adopting the proposed system, and the novelty and innovation of the proposed approach.

The research proposes a patient-centric system achieved by creating a version of an ICP in the system for each patient. It also provides focussed support for team communication and care

coordination, by identifying the treatment stages and providing the care team requirements at each stage. It utilises the data within the legacy system to be proactive. Moreover, it makes these required data for the actions available from the running legacy system which is required for patient-centred care. In the future the worth could be extended by mapping other ICPs into the system.

This work has been published in four full papers. It found acceptance in the health informatics community [5, 6, 7] as well as the BPM community [8, 9]. It is also the winner of the 2011 "Global Award of Excellence in Adaptive Case Management (ACM)" in "Medical and Healthcare" [10] of the Workflow Management Coalition (WFMC) [11].

Acknowledgements

This thesis would not have been possible without the help and support of the kind people around me. I would like to extend my thanks to all individuals who stood by me throughout the years of my study, but I wish to particularly mention a number of people who have had a profound impact on my work.

Above all, I am heartily thankful to my supervisor, Prof. Alex Gray, whose encouragement, guidance and support from start to end enabled me to develop my research skills and understanding of the subject. His wealth of knowledge, and sincere advice made this research fruitful as well as enjoyable. I must also thank Dr. Omnia Allam, my second supervisor, for her continuous encouragement and support.

It is an honour for me to extend my thanks to my employer King Saud University (KSU), Riyadh, Saudi Arabia, for offering my postgraduate scholarship, and providing all financial support needed to complete my degree. I am also thankful to the members of the IT Department of the College of Computers and Information Sciences at KSU, for their support and encouragement during the years of my PhD program.

I am also grateful to Velindre Clinical Information Unit for their help throughout this project. Special thanks go to Dr. David Morrey and Mrs Hazel Bailey who provided me with insight knowledge of the NHS, Canisc, and working practices at Velindre NHS Trust, and being very supportive. I am also very thankful to other members of the Velindre staff who so kindly gave their time to evaluate this research.

I also acknowledge the support of Ralph Snook and Alan Jones at Alia Systems.

I would like to acknowledge the academic and technical support of the Staff member at the School of Computer Science & Informatics at Cardiff University, UK, specially Dr. Wendy Ivins, who always found the time to discuss research with me. I am also grateful for the kindness, help and support of all my colleagues at Cardiff University specially Dr. Manar Hosny, Dr. Alysia Skilton, Haya AlMagwashi, and Mona Ali.

I owe my deepest gratitude to my beloved husband Abdullah Alfassam who always supported

and encouraged my career, and my children Fahad and Sarah who had no choice in all of this for their love, patience and support.

Last but by no means least, this project could not have been accomplished without the constant support of my bigger family, my mother who gladly watched my children while I am away, my father who always valued every little thing I do, my brother Abdulrahman who started this journey with me, my brother Ibrahim who made himself always available when needed, my brother Mohammad who kept me up to date with the latest technology, my sisters Noura and Sara who added more pressure on me to be a good role model as I added more pressure on them to keep going, and my sister Shada who stood by me throughout the hardest bits of this research as a colleague, and a sister for their unconditional support and patience from the beginning to the end of my study.

Thank you all. I could not have done this without you.

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List of Acronyms

ACM Adaptive Care Management. *ch.12, p.155*

AHRQ Agency for Healthcare Research and Quality. *ch.5, p.42*

API Application Programming Interface. *ch.9, p.95*

B2B Business-to-Business. *ch.7, p.60*

BAM Business Activity Monitoring. *ch.7, p.61*

BPM Business Process Management. *ch.1, p.5. ch.8, p.79*

Canisc Cancer Network Information System Cymru. *ch.1, p.6. ch.2, p.13*

CBD Component Based Development. *ch7, p.61*

CfH Connecting for Health. *ch.1, p.3*

CIS Clinical Information System *ch.1, p.3. ch.6, p.50*

CIU Clinical Information Unit. *ch.1, p.6. ch.2, p.12*

CORBA Common Object Request Broker Architecture. *ch.7, p.60*

DCOM Distributed Component Object Model. *ch.7, p.60*

DERI Digital Enterprise Research Institute. *ch.8, p.82*

DoH Department of Health. *ch.6, p.51*

e-IRMER electronic Ionising Radiation Medical Exposure Regulations. *ch.12, p. 160*

EAI Enterprise Application Integration. *ch.7, p.60*

EMR Electronic Medical Record. *ch.5, p.45*

EPR Electronic Patient Record. *ch2, p.15*

ERP Enterprise Resource Planning. *ch.7, p.61*

GP General Practitioner. *ch.2, p.16*

GLIF Guideline Interchange Format. *ch.7, p.67*

GPAC Guidelines and Protocols Advisory Committee. *ch.5, p.42*

HCI Human Computer interaction. *ch.13, p.168*

HIN Hospital Information Network. *ch.5, p.45*

HL7 Health Level Seven. *ch.12, p.161*

ICP Integrated Care Pathway. *ch.1, p.2. ch.5, p.41*

ICT Information Communication Technologies. *ch.1, p.3*

IHC Informing Healthcare. *ch.1, p.3*

IHR Individual Healthcare Record. *ch.6, p.53*

IOCN Inter-Organisational Communication Network. *ch.7, p.61*

ISCO Information System for Clinical Organisations. *ch.2, p.13*

IT Information Technology. *ch.1, p.3*

LIMS Laboratory Information Management System. *ch.2, p.13*

LSDIS Large Scale Distributed Information Systems. *ch.7, p.66*

MDT Multi-Disciplinary Team. *ch.1, p.8. ch5, p.40*

MoM Map of Medicine. *ch.1, p.3*

NHIN National Health Information Networks. *ch.5, p.45*

NHIS National Healthcare Information System. *ch.6, p.61*

NHS National Health Service. *ch.1, p.3. ch.5, p.38*

NICE National Institute for Clinical Excellence. *ch.1, p.3*

NSF National Service Framework. *ch.5, p.41*

NWIS National Welsh Informatics Service. *ch.1, p.6*

OO Object Oriented. *ch.7, p.61*

PICS Prescribing Information and Communications System. *ch.7, p.66*

SCR Summary Care Record. *ch.1, p.3*

SOA Service Oriented Architecture. *ch.7, p.61*

UDP User Data Properties. *ch.9, p.94*

VCC Velindre Cancer Centre. *ch.2, p.12*

VO Virtual Organisation. *ch.1, p.8, ch.7, p.59*

VOICE Virtual Organisation access to Information sources and services in a Collaborative Environment. *ch.2, p.15*

WCP Welsh Clinical Portal. *ch.1, p.3, ch.2, p.13*

WffICP Workflow for Integrated Care Pathway. *ch.1, p.5. ch.10, p.99*

WfM Workflow Management. *ch.7, p.61*

WfMC Workflow Management Coalition. *ch.1, p.6*

WfMS Workflow Management System. *ch.1, p.5. ch.8, p.72*

WPoCS Wireless Point of Care System. *ch.2, p.16*

XMI XML Metadata Interchange. *ch.7, p.68*

Chapter 1

Introduction

Overview

This chapter introduces the research and outlines the thesis structure.

1.1 Introduction

The delivery of healthcare has been traditionally "disease-centred". In a disease centred delivery, specialists treat their patients in isolation according to their speciality, regardless of other illnesses and medications taken by these patients. Lately, there has been strong support worldwide to changing the healthcare delivery model from a disease-centred to a "patient-centred" approach, where care provision focuses on treating the whole patient rather than managing separate diseases. In order to implement the patient-centric approach healthcare professionals need to collaborate and centralise the treatment process around patients. This is aimed at improving the quality of care by avoiding conflicts that might affect a patient's care and satisfaction with the treatment as well as ensuring the best use of the resources.

Healthcare delivery within a modern patient-centric model follows an Integrated Care Pathway (ICP) [1, 18, 19, 20]. ICPs are national clinical guidelines which standardise the quality of the healthcare service provided by the healthcare providers by defining the treatment process to be followed. Usually an ICP involves multi-professionals located at distributed healthcare organisations working as a team. Communications among these multi-professionals use different routes and techniques and take multiple paths. The treatment process is usually dynamic, long, and unpredictable. Moreover, it is common to have patients with multiple conditions following more than one ICP for these different conditions. Therefore, the treatment journey for each patient is often unique and can be extremely complex.

The challenge that evolved with the move to a patient centric healthcare delivery model is that: multiple healthcare professionals of different specialities located at different locations using heterogeneous information systems, need to communicate to share and access their patients care information particularly the most recent information. They need to exchange patient data and information and ensure that it is available and easily accessible as appropriate when needed. This information not only needs to be exchanged among the different departments and healthcare professionals in a single organisation but also across the multiple organisations involved in the treatment process. Moreover, treatment of patients for a single disease can involve multiple organisations and it is often the case that a patient has multiple diseases. This requires care coordination across the different locations according to the clinical guidelines for the diseases. Data and information are extremely sensitive and mistakes can affect lives. This massive cumulation of sensitive data emphasises the importance of its management and maintenance.

Thus there is a need for an information system that can support the healthcare *team communication* and *care coordination*. The biggest challenge is that, information systems used in the distributed healthcare organisations were originally designed to be organisational-centred. This means, medical data collected by each medical division are stored within their information

systems. Information within these systems are passive and retrieved only upon request. Also, information systems within the different healthcare departments are inherently heterogeneous.

Currently healthcare professionals work as a team in a patient-centric healthcare delivery model. They manually follow the national guidelines when planning a patient's treatment journey. These professionals use multiple approaches to overcome the limitations in the support for team communication and care coordination due to the existing legacy Clinical Information Systems (CISs). They still rely on traditional synchronous communication tools, including: face-to-face meetings, telephone calls and video calls as well as asynchronous communication tools, such as: e-mails, faxes, and postal mails. Each of these approaches has its advantages and disadvantages yet none is reliable enough to deal with such a sensitive domain. Reliability in this context includes: availability, accessibility and accuracy of the latest medical information as well as the medical history of patients. Nevertheless, reliability is also affected by factors such as: presentation of information and timely processing of requests. The sensitivity of the domain involves: security, confidentiality as well as the serious effect any mistake can cause.

Different national programs are under development in the UK, Saudi Arabia and worldwide to improve and modernise the Information Technology (IT) infrastructure of healthcare organisations. Thus, huge budgets are being assigned for these projects. Each of these programmes has its own agenda and framework but they all have a shared ultimate goal to provide the best possible healthcare service to their patients. They also agree on the keys to achieve their ultimate goal which is through implementing standards, providing access to knowledge resources and improving access to patient data.

We studied the English and the Welsh national IT programmes during this research. The National Health Service (NHS) Connecting for Health (CfH)[21], is the agency responsible for maintaining and developing the English national IT infrastructure. CfH projects include: Summary Care Record (SCR), choose and book and electronic repeat prescription issuing. Informing Healthcare (IHC)[22], is the Welsh national program to modernise their IT infrastructure. IHC projects include: Welsh Clinical Portal (WCP), and Individual Healthcare Record. Moreover, to secure consistent, high quality, evidence based care for patients, guidelines are made available for clinicians and healthcare providers through ICPs on Map of Medicine (MoM) and the National Institute for Health and Clinical Excellence (NICE). Recently, these guidelines have been adopted by the NHS in Wales and England. The guidelines are also available and can be used by patients to educate themselves [23, 1].

These different Information Communication Technologies (ICT) initiatives are extremely beneficial and will improve and support the treatment process of patients when they are operational. These projects promote information access, resource access, and automation as well as empowering patients. These projects form a good understanding basis for the ICTs in CISs.

However, these projects lack support for a customised access to clinical information required by the healthcare providers as they follow their patient's treatment progress. Team communication is essential for the healthcare professionals to successfully implement the ICP. However, this is only the basis for information exchange and we believe that care coordination is the key to successfully implement the ICP. In conclusion, the current ICTs in use or underdevelopment for healthcare lack support for teamwork along the multi-disciplinary care pathway and this is important if care teams are to work effectively.

As mentioned previously, each patient is different. For each patient, a combination of medical problems, medications, treatments and personal choices creates a unique treatment journey. Along the dynamic treatment journey different decisions will be made and different elements will interact which means it requires an "adaptive" and "pro-active" communication and coordination approach to utilising its management tools.

Adaptive to the case and the treatment stages. In that it considers the treatment history, anticipated pathway, current stage, care team involved, healthcare issues and any changes that might occur along the treatment pathway.

Pro-active in that it automatically detects changes, identifies the care team members involved in the treatment and the members affected by a change and takes appropriate actions. Actions include: routing, notifying, alerting, updating, referring, controlling timelines and/or scheduling.

This research proposes an independent solution. It does not depend on existing legacy system, however it evolves these systems. Moreover, it does not assume current planned projects, to modernise the NHS, take place to be used as a basis for this research. Yet it can take advantage of these projects once implemented. These programs and projects within the UK NHS, promise to support access to clinical guidelines, and clinical information through shared portals. These projects are a good foundation that support team communication. However, this project can extend these projects or current legacy systems to include advanced team communication support and care coordination. Therefore, the assumption is that these projects may or may not occur, and this research proposes an evolutionary approach which builds on any running system.

This research aims to improve team communication and care coordination by virtually integrating patients medical data from the distributed CISs. It aims to select the required information and make it available to the healthcare providers at the point of care. By having this achieved, better informed medical decisions will be made by being adaptive to the current state of each case. Moreover, it facilitates a better use of the passive medical data in the silo databases connected to the distributed CISs, by being proactive.

This research investigates an approach to support teamwork along the multi-disciplinary care pathway. This is achieved by mapping the ICP representing the national clinical guidelines into

system based on a Workflow Management System (WfMS) or a Business Process Management (BPM) system. This approach was selected because the treatment ICP actually represents a workflow which these system aim to support. A workflow consists of processes, paths, routing decisions and different roles acting in a system which can be mapped to the components of the ICP as follows: processes represent diagnoses and treatments, paths represent flow of treatments, routing decisions, which are associated with clinical decisions on treatment and diagnosis and finally the different roles of people acting in the system are representing the multi-disciplinary care team member's actions [5].

Workflow for Integrated Care Pathway (WffICP) is the research prototype system developed in the project. A constructive study was conducted to implement WffICP; which followed a hybrid software development methodology. This involved designing and building a WFMS as a prototype to present the proposed concept for the new approach. Continuous revision was conducted through iterative and incremental cycles as we progressed the research.

WffICP is an independent information system which consists of an ICP mapped into a WfMS. It supports seamless interaction between the different CISs involved in the ICP. This is achieved by incorporating the WfMS's interface into an evolutionary development approach for existing CISs and therefore augmenting the functionalities of these systems. The aim of this is to support team communication and care coordination among the multi-professional care team members along their shared patient treatment journey(s) according to the clinical guidelines.

WffICP is implemented as a proof of concept prototype, to show the concepts and investigate the potential implications of the technology on the implementation of the ICP followed by patients, and also its effect on healthcare delivery. We mapped the ICP for breast cancer diagnostic and treatment options from MoM [23], representing a possible treatment pathway, into the Stateframe BPM system [24]. We identified the critical and clinical decision stages within the care pathway and programmed the system's logic to support the needs of each step [8]. We showed that the proposed approach supports the following functionalities:

- *Formalising the treatment process* through automatic routing of treatment processes. This is completely driven by the healthcare provider as the user of the system who accepts, rejects, or suggests a new route.
- *Ensuring care continuity* of patients especially when their treatment is undertaken by multiple departments/ organisations in distributed sites where the team members work.
- *Filtering and gathering the information* presented to the multi-professional care team members according to their need at the current point of care in the treatment pathway.

- *Pro-acting to changes* by automatically detecting change triggers, identifying involved care team members in the current multiple pathways followed by a patient, and managing the change by activating appropriate actions. Examples of these actions include: referral, notification, alert, schedule, and setting timers.

This proposal has been evaluated at different development stages for its usefulness, technicality and setup possibility. The *usefulness evaluation* involved a number of healthcare providers who represented the actual users of the information system and the direct providers of care. The majority of the healthcare providers interviewed confirmed that they have problems with existing systems and they all found that the potential benefits from this approach will support the treatment process in a beneficial way. The *technical evaluation* involved leading members/judges of the Workflow Management Coalition (WfMC). These are experts in the implementation and application of the technology and its research and therefore are best able to advise on the technicality and novelty of the proposed approach. This was also supported by the feedback of the reviewers on the peer-reviewed international conferences in BPM where ideas of this research were submitted [7, 5, 6, 8]. The reviewers thought that this proposal was very promising, they thought that it realised the key benefits of using such a tool in automation while preserving user control, flexibility, and adaptability. The *setup evaluation* involved a group of the developers at the Clinical Information Unit (CIU) at Velindre NHS trust, who are involved in implementation and support of the all Wales cancer information system; Cancer network information system cymru (Canisc) [25]. This was a very important part of the evaluation as it validated the technical possibility of incorporating the interface of the proposal with the currently used legacy systems. The developers also discussed the challenges and the adaptability issues of the technology. The setup possibility was also evaluated by the developers of the Stateframe BPM who were able to advice on the technical possibility for integration with different systems. The team at the CIU identified that the potential benefits of the proposed system are functionalities that are needed and are in their future development plans to improve the existing system. They found that some of the workflow elements that they already implemented in Canisc could be done better using the proposed approach. They also suggested a possible position for the proposal within the current scene in the NHS Welsh Information Services (NWIS).

This proposal's ultimate goal is to ensure a better healthcare service is provided to patients by empowering healthcare providers to make better informed medical decisions. This is achieved in the prototype by supporting team communication and care coordination among the health care providers operating as a team. This support has been achieved by providing relevant, timely, and up-to-date medical information at the point of care. This improves the patient's care and satisfaction in addition to optimising the use of resources.

WfMS and BPM has proved to be a successful approach in linear process automation and sub-

mission [26, 27]. It has been widely used in scientific [28, 29] and business [30, 31] domains. It has also been used in the healthcare domain to automate laboratory tasks and departments' predefined logic defining a clinical process [32, 33, 34, 35, 36] (see section 7.5). The use of this technology and its capability to incorporate human and machine interaction has also been demonstrated [37, 38, 39]. A full literature review conducted for this research investigation, showed that WfMS and BPM has not been proposed to support team communication and care coordination in the patient-centric delivery model and that it has not been used to operate as an independent tool to support the linkage between the heterogeneous distributed CISs used in a patient's treatment. There has been no research on how to provide this seamless virtual logical linkage according to national clinical guidelines to support its implementation [7, 5, 6, 8]. Throughout this thesis WFMSs refers to a *business WFMS* unless stated otherwise.

This research aims to present the concept of the application of workflow technology in healthcare and how it can be used to support the decision making process in a patient centre care process. We focus on clinical information management rather than management information which deals with administration and finance data. This exclusion of the administration information will not have a direct affect on the results. We are also looking at the concept of the proposal regardless of technical issues, such as: training, human computer interaction, access, etc. The exclusion of these technical issues has no effect on the concept being studied. Moreover, we focused on the breast cancer scenario as it represents a good and typical example of an ICP which allows us to evaluate our approach at Velindre NHS cancer centre. Finally, we looked at the approach at a high level as this will allow generalising the findings and approach for other care treatments.

The research is part of a long-term cooperation between Cardiff School of Computer Science & Informatics and Velindre NHS Trust. The problem was initially brought to our attention by the CIU team at Velindre NHS. Throughout this research, the team at the CIU at Velindre NHS Trust supported the validation and the evaluation of some of the research stages.

This research shows that using Workflow technology in the healthcare domain supports the implementation of the ICP in a patient centric model. It supports teamwork practice along the shared patient's treatment pathway according to the treatment stage. This actually adds support to "treatment-centred" as well as patient-centred care.

This is an empirical scientific research based on observation. Observation of the user needs, current system behaviour and usage. This is followed by a focused attention to the user's perspective on the proposed approach by this research. The *user* throughout this thesis refers to a healthcare provider who uses the CIS to access medical information about a patient.

1.2 Thesis Structure

The thesis is structured as follows:
Chapter one introduces the research.

Chapter two explains the context of this research and how it was suggested. It introduces the Velindre NHS Trust and introduces the CIS in use at the trust. This is followed by an overview of the cooperation between Cardiff School of Computer Science & Informatics and Velindre NHS Trust cancer centre. Finally, the different health informatics projects at Cardiff School of Computer Science & Informatics resulting from this cooperation recently are introduced. These will be discussed to show how each relates to this projects.

Chapter three outlines and states the following: research background, research hypothesis, research driver, research aim, research achievements, and research scope.

Chapter four introduces the scientific research methodology. It explains the stages involved within the empirical research method followed to develop this research. Within the empirical study, the proof of concept prototype was developed through a constructive study which is also explained.

Chapter five explains the healthcare system and its structure. It also describes the recent modernisation plans and clarifies related concepts introduced by these emerging new plans such as: patient-centric, ICPs, and Multi-Disciplinary Teams (MDTs). This chapter describes the communication and coordination difficulties raised by these modernisation plans, current approaches to tackle these difficulties, and finally the suggested approach in this thesis to address them.

Chapter six explains the informatics side of the healthcare system. The CIS in use and the IT national and international projects to modernise and improve these systems. This will be followed by a gap analysis of these projects.

Chapter seven overviews the different technologies and techniques to virtually integrate the medical information attached to the independent legacy systems. Moreover, a justification of the choices made in the development of this research will be discussed. This includes choosing the development methodology to be evolutionary, the approach to be achieved through a Virtual Organisation (VO), and the main tool to be a workflow technology. Finally, the chapter analyses the different usages of workflow technology in the healthcare domain and explains the novelty of the research proposal.

Chapter eight is the workflow technology chapter. It explains the terminology, workflow types, type of flows, and WFMSs types. This will be followed by an introduction to different WFMSs

and a comparison between them. Finally, it concludes with a list of the characteristics of a WFMS's engine that best suit the problem domain. According to the specified characteristics, a system is then selected to be used in implementing the prototype.

Chapter nine explains the architecture of the proposed system, WffICP. This will position the WffICP with current CISs and show how the functionalities of these systems can be evolved. This is followed by an explanation of the architecture of WffICP and the particular WFMS used in the project. Finally, an explanation of how the proposed prototype will work is given.

Chapter ten explains the implementation and design of WffICP. This chapter introduces the selected breast cancer scenario and the mapping process of the scenario into the WFMSs. This includes mapping the processes and activities as well as defining process objects and cases. This also includes the coding that was involved and how the system is programmed to meet the requirements of the healthcare providers along the ICP.

Chapter eleven lists the implications of WffICP. The functionalities are then discussed to show how they support the care pathway. The operation of the implications will also be explained. This will be supported by some examples and screenshots.

Chapter twelve discusses the evaluation of the proposal. This includes: a usefulness evaluation by healthcare providers, a technical evaluation by the workflow technology community and a setup evaluation by CIS developers at the Velindre NHS Trust. This chapter concludes with an analysis of the results of these evaluations.

Chapter thirteen suggests future work which could be carried out based on this research and areas identified by this research which will be worth further investigation.

Chapter fourteen highlights the key aspects of the work, assesses the achievements against the aims and concludes with an appraisal of the overall research experience and outcomes.

Chapter 2

Research Background

Overview

This chapter provides an overview of the context of the research. It aims to present how this project started and developed. Moreover, it positions this research among other projects, and clarifies how its outcome can be taken forward.

This chapter begins with a brief introduction to the Velindre NHS Trust and the CISs used at Velindre Hospital. This is followed by a focus on the partnership between the Velindre NHS Trust and Cardiff School of Computer Science & Informatics which led to this project. Finally, an overview of other recent health informatics projects at Cardiff School of Computer Science & Informatics will be presented showing how some of these projects overlap and/or complement this research.

2.1 Introduction

Velindre NHS Trust and in particular the CIU at Velindre Cancer Centre (VCC), has a leading role in the development of the cancer information system Canisc used across cancer centres in Wales. There is a long-term cooperation between Cardiff School of Computer Science & Informatics and the CIU at the Velindre NHS Trust. This research is part of this cooperation. On one side, Velindre NHS Trust test bed the school's research in this area where they believe it will improve the system. While on the other side, the school researches areas where the hospital believes improvements are needed [40]. Different parties are involved in this cooperation and the resulting projects will be introduced to give a wider view of the context in which this research started and developed.

2.2 Velindre NHS Trust

Velindre NHS Trust, was established in 1994 [41]. The Trust has grown to manage a budget of 154 million pounds in 2010/2011 which makes it one of the largest tertiary specialist cancer centres in the United Kingdom [41]. Velindre NHS Trust consists of two divisions: VCC and the Welsh blood service. Velindre NHS Trust services are provided at local, regional and all Wales levels.

2.2.1 VCC and CIU

VCC [42] is a division of Velindre NHS Trust, which provides specialist cancer care services to over 1.5 million people in South East Wales and beyond [41]. Around 50,000 new outpatient appointments and over 5,000 new referrals are seen at VCC every year [41]. The CIU at the VCC is responsible for its clinical and business information management to support clinical care, audit and research.

2.3 CISs used at Velindre NHS Trust

At VCC and across the Welsh cancer centres, Canisc [25] and the WCP [43] are used. The following sections will introduce these systems.

2.3.1 Information System for Clinical Organisations (ISCO)

ISCO [44] was developed by the CIU at Velindre Hospital in 1991[42]. At first, ISCO was used for collecting clinical information. This system has now evolved to include administrative and clinical changes in patient management [42]. Currently ISCO is used across Wales as the national cancer system. In this role it is known as Canisc [25].

2.3.2 Canisc

Canisc was launched as a national service in April 2009 [25]. Canisc is used at cancer units and centres, holding important information entered by healthcare professionals during clinic visits. Entry can be online during clinical interactions, electronic by integration with other IT systems, or following data collection using specific forms. Canisc aims to ensure information is available to health professionals at all times and in all places, to support the provision of the best possible care to patients. It covers emergency and elective care information entered by cancer units and centres. The National Assembly of Wales has now agreed to back Canisc as the national system as it has evolved to meet the majority of cancer information needs and become the single system for Wales [42, 25]. Currently Canisc is maintained by the NWIS [25].

2.3.3 WCP

The WCP is a "...secure health space uniting key patient information from the many computer systems and databases used in NHS Wales, such as those found in pathology, radiology, cancer and primary care settings" [43]. The WCP provides information about medications, discharge and allows requests for tests to be undertaken and requests for the results. It also provides personalised pages for professionals with their patients' list.

The development of the WCP follows incremental phases, currently in most hospitals the following projects are operating: "pathology test ordering and result reporting", "graphing and tabulation for pathology test results", "sensitive data and break-glass ", and "direct results viewer " [45] . Future increments under development for the WCP are mainly for: "secure use enhancements", "alerts and notifications", "Laboratory Information Management System (LIMS) Ready", "medical transcribing and e-discharge", "prioritisation of referrals", and "viewing of clinical documents" [46].

The WCP is currently accessed at Velindre NHS cancer centre, to complement Canisc. It is used by the healthcare providers to access patient's medical information when this information is not available or updated in Canisc. The WCP is available as an independent system to Canisc, which

requires a separate login process. This process doubles the effort of fetching an information which can be time consuming and inconvenient in a clinical setting.

2.4 Velindre NHS Trust and Cardiff School of Computer Science & Informatics

Cardiff School of Computer Science & Informatics at Cardiff University formally started working in partnership with Velindre Hospital in 1991 [40]. This was before the Velindre Hospital was incorporated into the Velindre NHS Trust, when it was formed in 1994 [41]. However, the initial cooperation between the school and Velindre was actually in 1986 when David Morrey, the current head of the CIU at Velindre NHS Trust, did his PhD research [47].

The CIU at Velindre is responsible for Canisc. It continues to use iterative prototyping to identify improvements for Canisc. This requires health informatics research to investigate areas of concern and identify how to address them. The association between the school and the CIU has been involved in this development.

The team at the CIU usually brings to the school's attention limitations encountered with existing CISs. Researchers within the school research these issues, investigate how aspects of the latest technology can be used to address these limitations and recommend solutions. The school outcomes are usually evaluated by the developers and healthcare providers at the cancer centre. If the CIU team are convinced by the school's ideas, they adopt them for implementation in a future evolution of Canisc. This project concentrates on one of these concerns as the initial problem was brought to our attention by the CIU team.

During a research project, the researchers meet with the team at the CIU for initial validation of the ideas and the approach. The CIU also supports the researchers as they learn about the current approach and the CISs used. If required/requested, the proposed system gets evaluated by the CIU team to examine the technical feasibility while the healthcare providers and the system's users evaluate the usefulness of the proposal. The evaluation results are then used by both the school and the CIU. For the school, the research adds to the university's research studies while for the CIU, the research identifies improvements to currently used information systems.

2.5 Cardiff School of Computer Science & Informatics Health Informatics Projects

This section provides an overview of some of the health informatics PhD research projects at Cardiff School of Computer Science & Informatics with VCC. Within the school most of the different health informatics projects complement each other and can be integrated to create a more comprehensive system. Some of the projects in this overview have been completed while others are ongoing and current projects. In this section some of the School's health informatics projects will be introduced. The linkage and interaction between this research and these projects will be explained.

2.5.1 Virtual Organisation access to Information sources and services in a Collaborative Environment (VOICE)

This project was undertaken by Alysia Skilton [48]. She proposed a conceptual model which uses care team meta-data to track and manage team members and professional roles as a means to meet the broader range of requirements of the patient-centric approach beyond the Electronic Patient Record (EPR) held in Canisc. The proposal will help provide tailored information access, targeted notifications and alerts, and patient and team management functionality [48, 49, 50].

Integration of this project with Skilton's project is part of the planned future work (section 13.2.1). There is some overlap between Skilton's project and this project as both projects look at tracking team members. However, Skilton's project looks at tracking team members and their different roles, while this research looks at tracking the treatment progress and the care team members involved in each patient's treatment stage. The integration of both approaches will extend the benefits that each of our projects provide to Canisc [7]. The integration of the database Skilton proposes with the WFMS would extend this research to a higher level which considers not only the health care providers but also their roles and the roles of related information access and policy.

2.5.2 Healthcare Teams Information Security Needs for Cross-Organisational Information Exchange

This project is undertaken by Shada Alsalamah [51]. She is looking at the security requirements of the patient-centric approach. It focuses on providing different security levels while the

information is shared across healthcare organisations [51].

Shada's project is a logical extension to this research and has been discussed for inclusion in future work (see section 13.2.2). First, both projects look at the collaborative environment and information sharing across the multiple healthcare organisations while implementing the patient-centric approach. This research looks at how information could be shared while Shada's project looks at sharing the information securely, which is a necessary follow-on stage to this project.

2.5.3 Wireless Point of Care System (WPoCS)

This project was undertaken by Mohyuddin [52]. He proposed a VO framework centred on the patient, in the clinical environment to complement point of care functionalities without changing the current infrastructure [52, 53]. This is supported by wireless technologies at the point of care which provide better ways of accessing patient information so that it can be shared and used in decision making at the point of care [52, 53].

This current project also looks at VOs and how we can use them in a patient-centred approach. It is looking at having a VO across the different organisations involved in a single patient's treatment while Mohyuddin's project is focused on the ward point of care for a patient and how to provide required information at this point of care.

2.5.4 Facilitating Communication between General Practitioners (GPs) and Cancer Care Teams

This research was undertaken by Omnia Allam [54]. Omnia looked at the communication issues occurring between GPs and members of the cancer care teams [54, 55]. She created in her research the specification of a system which overcame many of the communication problems by providing a common EPR to supply the required information for all the healthcare providers involved [54, 55].

Omnia's research formed a foundation for this research. As she looked at the need for communication in integrated cancer care and the specific requirement of the GP and cancer care provider. We extend this to look at the communication among all care team members involved in cancer care across the different involved health care organisations. Moreover, we take this further to support care coordination along the treatment's ICP as the patient moves along the treatment pathway.

2.5.5 Educating Patients in Chronic Care

This research is undertaken by Kevin Butterworth [56]. Butterworth models current chronic illness patient education practice within tertiary and primary care, to move from an information provision model of patient education to a comprehensive individual focused learning model [56, 57, 58]. There is no direct connection between Butterworth's research and this research, however, at some stage, the WfMS could be used to identify and extract a patient's medical information needed for the individual's learning model at the current point in the care pathway.

2.5.6 Utilising Patient information to Focus Internet Searching for Cancer Patients

This research was undertaken by Asma Al-busaidi [59]. She looked at using a patient's medical information to help refine an internet search for cancer patients about their illness [59, 60]. Again there is no direct connection between Al-busaidi's research and this research, however, at some stage, the WfMS can be used to identify and extract a patient's medical information needed for the individual's search refinement related to their current treatment point.

2.6 Research Foundation

This research focused on the application of workflow technology to support the implementation of an ICP. The ICPs assume patient-centric care with all the necessary information about the patient being available along the care pathway. An ICP represents a series of treatment stages where at certain points a decision is made on the treatment progress. The decision could be: repeating current stage, moving to a particular stage, or simply following the anticipated treatment flow. The ICP is a workflow which takes account of the varied elements involved; including: treatment stages, logical sequence, decision points, information flow, and healthcare providers. For the different decision points within an ICP, the medical information required by the healthcare providers is different. Provision of this information is essential to support the healthcare providers in making informed decisions.

This research is based on the belief that team communication and care coordination are problems that are hindering implementation of IT systems to support the patient-centric delivery model. It assumes the cause of communication and coordination problems is difficulty in accessing the medical information held in legacy systems. It also assumes that a constraint within the domain is the need to keep legacy systems in operation in the original organisations, while

enhancing their functionalities to deliver appropriate data about a patient to the care team. These information systems cannot be changed across all healthcare organisations to create a new fully integrated system and their complete autonomy needs to be retained as they are serving staff in other organisations.

Chapter 3

Research

Overview

This chapter outlines and states the following: research background, research hypothesis, research driver, research aim, research achievements, and research scope.

3.1 Introduction

3.2 Research Background

CISs within the NHS are traditionally organisational-centred. They were originally designed to support the disease-centred healthcare delivery model followed earlier by hospital healthcare staff. These information systems are therefore mainly focused on the needs of the speciality they were built for. This means that CISs within the NHS are discrete and often very different systems and do not have a patient centric approach [61, 62, 63, 64, 65]

Healthcare providers within the NHS confirm that they work as a team with one another when they treat a shared patient. This includes not only healthcare providers within a single organisation or level of care but also across different organisations and care levels. A patient's treatment within the NHS follows the national guidelines for the diagnosed condition. The national guidelines define the best practice and aim to standardise the care process to ensure a delivery model fit for purpose. The clinical guidelines include the logic of the patients' treatment journey and are manually driven by the healthcare providers. Although each patient journey is unique, there is a logical sequence within the process of tasks that are followed by the care team. These are adjusted to the patient's situation which means they are not followed slavishly.

CISs currently in use are not able to and were not originally designed to support teamwork activities. Moreover, they don't support any sort of process formalisation. They lack information on the logic of the treatment and therefore are unable to undertake any actions to support the treatment flow and provide potential routing of the treatment process if adjustments are needed. They also lack information about the causes involved in reaching the current stage and the possible consequences.

Within a patient treatment pathway, each of the treatment stages could be either a step, a set of steps to accomplish a certain task, or a decision point. Processes representing a single step usually lead to a linear predicted flow while decision points are when the treatment flow is unpredictable and could take different routes. At any of these treatment stages, care team members handling these processes require a variety of information related to the patient from a single or multiple resource.

Care team members communicate with each other by exchanging medical information about their shared patients. Sources of the medical information could be manual or electronic. Moreover, clinicians always rely on patients as a source of information. Manual communication tools used in clinical settings include: patient chart, mail and fax letters, hand written notes, phone calls and face-to-face verbal communication. Electronic information can be accessible either through

single or multiple tabs within single or multiple screens. The screens also can be within single or multiple information systems which then use single or multiple databases.

Coordination is a primary element of the teamwork activities in a patient centric approach. It ensures continuity of care, dependencies control, followups and updates. Coordination in current CISs, is manually maintained by the healthcare providers at the different organisations. Moreover, the only forms of coordination activities currently used within the hospital systems are referral letters and responses to requests.

At any of the treatment stages, care team members handling the processes should communicate medical information to other team members and coordinate the care according to the guidelines being followed. Thus, they require appropriate information and actions at these treatment stages. Team communication and care coordination are key requirements of the patient-centric health-care delivery model. This project aims to facilitate these requirements, and will virtually connect the CISs within the healthcare domain in a seamless fashion.

This research investigates the use of workflow technology in the healthcare environment to support the team communication and care coordination needed for a patient-centric delivery model. It proposes the use of workflow technology as an independent layer to interact with the discrete distributed existing legacy systems.

It shows that the use of workflow technology in the healthcare domain can support seamless connection between the different parties involved in an ICP for a single patient. It also shows that the approach can evolve existing CIS to support the patient-centric needs. It can virtually integrated the required medical information from existing discrete legacy systems and present it in an appropriate format at the point of care as needed. This will be determined according to the active ICP logic.

The research also shows that the proposed approach can support team communication and care coordination among the multi-professional care team members according to the patient needs. Moreover, it gives support according to treatment needs at the different stages.

3.3 Research Hypothesis

The research hypothesis is:

“By mapping the Integrated Care Pathway (ICP) representing the national clinical guidelines that reflect a patient centric treatment pathway into a Workflow Management System (WfMS) or a Business Process Management (BPM) System in an independent layer, and incorporating its interface in an evolutionary development approach into existing Clinical Information Systems

(CISs), we can augment the functionalities of these systems to support team communication and care coordination among the multi-professional care team members working on a shared patient treatment journey(s) by formalising the treatment process, ensuring care continuity, filtering and gathering the information and pro-acting to changes. ”

The users of the proposed system are the members of the healthcare team. The functionalities proposed are:

- Formalising the treatment process is achieved through automatic routing of treatment processes. Firstly, by suggesting the next treatment stage according to the logic of the clinical guidelines in the ICP and the relevant factors affecting the flow. The driver of the routing suggestion is the patient's medical condition. This is shown to the healthcare team members, as the users of the system they act on the system's suggestions by accepting, rejecting, or suggesting a new route. Thus, the driver of the next treatment step is the user of the system helped by system suggestions. Secondly, by automating the steps of pre-defined tasks initiated/chosen by the user.

- Ensuring care continuity of patients especially when their treatment is undertaken by multiple departments/ organisations at distributed sites where team members work. Firstly, by automating the linkage between the multi-professional care team members to permit sharing of a patient's information. This may be among teams at the same level of care for different conditions. Secondly, by setting timers on certain processes to detect overdue requests and processes that need to be activated after a certain time. Thirdly, by automating the referral process across the multiple organisations and level of care.

- Filtering and gathering the information presented to the multi-professional care team members according to their need at the current point of care. Firstly, by gathering the information required by the user from the multiple resources available. This includes for example: notification of assessments or requested test results at a clinical decision point. Secondly, by filtering the following: treatment history, treatment milestones, order and time of treatments, and healthcare professionals involved in previous treatment decisions.

- Pro-acting to changes. This includes automatically detecting change triggers (embedded in the different stages), identifying involved care team members in the current multiple pathways followed by a patient, and managing a proposal to change by activating appropriate actions. This means CISs can be pro-active and examples of the actions that can be proposed include: referral, notification, alert, schedule, and setting timers.

3.4 Research Driver

The main driver of this research is the fact that use of e-health is expanding [66, 67, 68]. This is driven by the move toward the modern NHS and the adoption of the "patient-centric" approach. As the modern NHS is evolving as well as the technology, we are looking at how the requirements of the modern NHS can be met and how in the informatics support the perceived limitations can be addressed.

3.5 Research Aim

This proposal's ultimate goal is to ensure that the best informatics support is provided to the healthcare team. This will be achieved by empowering healthcare providers to make better informed medical decisions. The healthcare providers need to work with a patient centrally as a team and follow the national clinical guidelines for the patient's diagnosed condition. This is the core of what this proposal aims to support - Firstly, by supporting team communication and care coordination among the healthcare providers; and Secondly, by supporting the implementation of the clinical guidelines along a patient's treatment journey. This support will be through providing an adaptive and a proactive system that provides relevant, timely, and up-to-date medical information at the point of care using the information stored in silo legacy systems. This will improve a patient's care and satisfaction with the treatment, in addition to optimise the use of resources.

3.6 Research Achievements

The main achievements of this research are:

- Identifying the requirements and the potential benefits of supporting a case driven ICP in CISs and how to achieve this in a system.
- Proposing an approach to support the implementation of the ICP in CISs supporting a patient-centric delivery model.
- Identifying a specification of a WFMS to be used for the support of the patent's care.
- Implementing a proof-of-concept prototype of an ICP scenario in a WFMS.
- Mapping the coordination processes represented in an ICP into a WFMS.

- Investigating and demonstrating the support that a workflow technology approach can provide to the teamwork practice occurring along the shared patient's treatment pathway.

3.7 Research Scope

This research aims to present the concept of the proposal's approach and how it can support the decision making process. Accordingly, the scope is limited to the following:

- A focus on clinical information rather than management information. As our focus is on the decision making process and communication and coordination among the team and how they can be supported, the exclusion of the administration information will not have a direct affect on the concept of the ICP being used in informatics support.
- This research investigates a concept and how to incorporate it into a system. It does not look at the complete system. Therefore, technical issues associated with complete systems such as: training, human computer interaction, and security have been excluded. These technical issues don't affect the concept under research. Training for example is necessary for any new system adopted. However, since we are evolving existing systems that simply extend the current system's functionalities, some training will be required but it should not be major task and how it is achieved is outside the scope of this evaluation. Other aspects such as: human computer interaction and security can be studied as future work or as an extension to this project. Moreover, aspects such as: access, database, and information representation related to legacy systems have also been excluded. Since the research is proposing an independent tool, some of these aspects can be handled through wrappers and other similar tools to support end-point interactions.
- The choice of a breast cancer scenario to evaluate the approach as staff at Velindre NHS cancer centre are involved in this area of treatment. However, although we use a breast cancer scenario, the approach can be generalised to other types of cancer or indeed other areas where the treatment follows an ICP for the diesease.

Chapter 4

Approach to Research

Overview

This chapter introduces the scientific research methodology. It identifies the roadmap followed in the development of this project. An empirical research method was followed in this research. Within this empirical study, the proof of concept prototype was developed through a constructive study.

4.1 Introduction

In this research, we followed a scientific research methodology. The research involved both empirical and constructive studies. The main approach followed an empirical study route. This route investigated the current situation to determine the way forward and then most importantly evaluated the proposed approach to a solution, by interacting with the users, research community, and developers to refine this approach. Part of the research involved a constructive study, which used a software development methodology. This involved designing and building a system using WFMS as a prototype to present the proposed concept for the new approach so that the users could comment on the proposal. Iterative and incremental cycles were followed as we progressed the research. This resulted in continuous revision being conducted as the proposed system evolved.

The nature of this research required an empirical study. This is because the problem was not clearly defined at the start. Moreover, observation was required to fully understand the domain and therefore identify the problems that can be addressed. This meant that research approaches such as conceptual and exploratory were excluded. A conceptual research approach is appropriate when some abstract idea or theory is being used to develop a new concept and the objective is to develop a new concept or interpret one and the domain is well understood [69]. While an exploratory research approach is utilised when there is a hypothesis as the basis for the investigation and it is not appropriate when testing and observations are being used [69] and the objective is to explore a little known area [70].

4.2 Research Empirical Study

This research follows a *scientific method* as it is based on a hypothesis which the research aims to support by evidence [69, 71, 72]. This research is seen as an empirical study because it is mainly based on experience or observations. Observations of the user needs, current system behaviour and usage were made in the initial stage. This was followed by a concentration on the user's perspective in our approach.

The formal steps of this research were [73]:

- *identifying the research problem*: to set a defined research problem with aims and objectives.
- *reviewing the literature*: to understand the background and research foundations used in the domain.

- *specifying the purpose of the research*: to set the research hypothesis.
- *collecting data*: the data needed for the research experiments that will be undertaken needs to be identified and collected.
- *analysing and interpreting the data*: conducting the experiments and interpreting the findings.
- *reporting and evaluating the research*: to evaluate the outcomes of the experiments and therefore validate the hypothesis and understand its impact.

4.2.1 Identifying the Research Problem

The first stage is identifying the research problem. The problem was at first very broad and needed a lot of focussing by identifying more clearly the objectives. In order to focus the research problem, a literature survey was conducted with interaction with users occurring at appropriate points. This process went into a loop of continuous revision, between the problem, the literature, and user reaction, until a final focused problem emerged.

The initial problem was brought to our attention by the software development team at Velindre NHS Trust. The Velindre CIU team believed that there is lack of communication and coordination support among care team members and that the IT support systems could be altered to give better support for these activities. They then identified the need to support alerts within the current information system. The team also clarified that the inclusion of alerts within Canisc was part of their future plans.

This initial stage was followed by cycles of revisions driven by our increasing understanding of the domain from the literature findings and review of the current status. The key to identifying the research problem in this approach is understanding the causes of the broad problem and the limitations imposed by the domain. Causes of the communication and coordination problem are mainly related to the complexity of the domain and the care process. Limitations on the way forward include the need to keep legacy systems operating to retain an organisation's current IT systems and these users local autonomy while facilitating access to the medical information in them. It would be unrealistic to assume all the systems could be updated at the same time.

This was followed by the identification of the care pathway, as a common base for a care team's interactions. At this stage, it was decided to use the national clinical guidelines as a mean to understand and identify the different parties involved in the treatment process and their interactions. Moreover, it was decided to use the guidelines to identify the stages within the treatment flow requiring team communication and care coordination support, and identifying how these

stages can be supported. The possible requirements identified along the treatment pathway were then linked to the communication and coordination obstacles in the healthcare domain.

4.2.2 Reviewing the Literature

The literature survey was conducted to understand the current status in the healthcare domain. It was an activity aimed at refining the research problem and gaining a greater focus. When the research problem was identified, we did a focused literature survey on the final problem statement to relate our research to other work in the field and justify the decisions made with an awareness of related work.

The literature research approach undertaken started with a general observation of the healthcare system and communication and coordination problems in the healthcare domain (see chapter 5). This was followed by a search with a particular focus on teamwork and the challenges in the delivery of the ICP. This concluded that an ICP reflects a patient-centric flow (see chapter 5). We also looked at legacy systems, their limitations and current approaches being used to tackle these limitations. This confirmed that for some time legacy systems need to be kept while their interfaces evolve to support the requirements of a healthcare team in patient centric treatment. This was consolidated by positioning this research against current national and international health informatics projects (see chapter 6).

As part of gaining a better understanding of the healthcare domain and health informatics, the author had several discussion sessions with the CIU team at Velindre NHS Trust to link the literature with what is actually happening at the hospital and observe practically the way information systems at the hospital are used. This led to the need to investigate the different tools and technologies that can/are used to overcome similar problems. This review was conducted by considering the specifications of the ICP and the need to use existing CISs. This work suggested the use of workflow technology to address the research problem (see chapter 7).

4.2.3 Specifying the Purpose/ Hypothesis

This is the stage resulting from the problem identification (section 4.2.1) and literature review (section 4.2.2). Here after formalising the problem, understanding the domain and the capabilities of the suggested tool, we can clearly state the research hypothesis. This is to state the vision of what can be achieved using the suggested tool in the problem domain (as presented in section 3.3).

4.2.4 Collecting the Data

Data collection is also called the research experiment, this is when more thought is put into how the proposed approach can be assessed and evaluated. After stating the hypothesis, an intensive focused literature survey was undertaken to understand the current state of workflow technology, its different engines, and how it operates. This was followed by identifying the specifications of a workflow engine that could support the research problem (see chapter 8).

As part of our observation process, of the workflow technology and the different engines implementing it, a practical investigation was conducted. This was undertaken by downloading and running several open-source WFMSs to gain practical experience of different types of workflow system. This was an important stage in increasing understanding and helping us to classify the different engines. This resulted in an identification of the specifications of the engines that most suited the problem being addressed (see chapter 8). These engine specifications were identified based on the needs of the users along the ICP. The ICP represents the workflow implemented in the WFMS's engine.

Another part of the experiment is identifying different sources for the clinical guidelines. It was also found essential to have a specific scenario to be used as an exemplar to drive the research. A breast cancer scenario was selected for use in the demonstration, as the breast cancer scenario represent a good example of interactions in an ICP. This was followed by the identification of the critical stages within the scenario which need support (see section 10.2).

4.2.5 Analysing and Interpreting the Data

This is the stage when a decision is made on how the research can be evaluated to produce evidence to support or reject the hypothesis. Here thought is put into evaluating the proposal approach and what must be done in the evaluation. At this stage a decision was made on implementing a proof of concept prototype to achieve the following:

- Investigate and suggest a practical technique of mapping the ICP to WFMS (see chapters 9 and 10).
- Test the capabilities of the technology, and the support it can give to the scenario being followed as an exemplar (see chapter 11).
- Demonstrate the use of the technology. This will be used in the evaluation to allow users, technology experts, and developers to see what can be achieved (see chapter 12).

- Explore the challenges involved with the proposal and therefore draw constructive conclusions and recommendations on the way forward(see chapter 14).

The implementation of the proof of concept prototype is the constructive study of this research. For the constructive study a hybrid of software engineering methodologies was followed, this will be described in section 4.3. As a result of this stage the implications of the proposed approach became clear and are covered in chapter 11.

4.2.6 Reporting and Evaluation

Evaluation is a crucial stage of any project, and it is the heart of the empirical study. It is the stage which either proves and supports the hypothesis or rejects it. A lot of attention, time and effort was spent on this stage. The evaluation was conducted to assess different aspects of the proposed approach. These aspects are a:

- Usefulness evaluation by healthcare providers. This involved five one-to-one interviews with health care professionals who use the current information systems and made comments after a presentation of the proposed system.
- Technical evaluation by technology experts. This involved peer reviews by technology experts from several BPM communities.
- Setup evaluation by CIS developers. This involved an evaluation session with four experienced developers at the CIU at the Velindre NHS Trust who discussed the viability of taking this proposed system's concepts into a working system.

The evaluation results are presented and analysed in chapter 12. They are also used as a basis for the conclusions and recommendations made in chapter 14.

4.3 Project Constructive Study

From an application point of view, research can follow different approaches [70]. These depend on the time, purpose, or environment in which the research experiment is conducted [69]. Examples of research approaches include: longitudinal research, one-time research, laboratory research, clinical research, historical research, or decision-oriented research [69]. This research followed a constructive research approach which is commonly used in the computer science and information systems field [74]. The constructive study in this research is a practical application

which designed and built a system. The delivered system in our case is a prototype designed to examine the validity of the research question.

Most projects follow multiple software development techniques to achieve the required goal [13], and this project is not an exception. In the following, we will clarify the different methodologies used in the implementation stages and the reasons for selecting these approaches. The different activities within a software development process involve: planning, requirements identification, analysis and design, implementation, deployment, testing, and evaluation.

In this project a hybrid process model was followed. This consisted of iterative stages and an iteration process for continuous revision and refinement, as follows:

- The main stream followed an *incremental- iterative* methodology.
- Each of the increments within the incremental methodology went through an evolutionary *prototyping* stage to enhance them.
- At the end of a complete cycle of software development, a revision was made to the whole prototype which led to another cycle of *iterative- iterations*.

The following sections will introduce these different research methodologies and justify the reasons for the selection.

4.3.1 Process Iteration

Process iteration involves cycles of revision before a final project is delivered [13, 12]. The iteration cycle in our prototype methodology was a result of the flexible exploratory nature of this project. Therefore, methodologies that require linear fixed pre-defined requirements were excluded. In this research each of the main development stages was revised before moving to the next stage. The outcome of the stage was then evaluated to suggest the improvements to be made in the next cycle of development. The iterations within the development were a mixture of iterative and incremental cycles depending on the stage results and the development stage.

Incremental Model

An incremental model was suggested by Mills, in this model requirements do not have to be specified at the start and can evolve as parts of the system get developed. The advantage of this approach is that it reduces rework during the development [12]. Projects following this approach usually are divided into separate parts. Each part is usually developed completely before the next part starts its development cycle (see figure 4.1). The ensuing parts get integrated gradually to the first deliverable until a fully functioning system is achieved (see figure 4.2). Figure 4.2

represent each increment as a block. At the end of the development of each block, the following block gets developed to build on its predecessor. This process continues until all blocks have completed their development, to make up a complete package, representing the full system (see figure 4.2).

For this project, when it was decided to map the MoM ICP into the WFMS, we analysed the clinical pathway and identified the critical stages. This is when we decided to implement the prototype using multiple stages/increments, each representing an important stage within the clinical pathway. Once a stage is implemented and running fully, we move to implement the next stage and integrate it with the developing system. This led to a cycle of increments until the initially planned pathway was fully implemented.

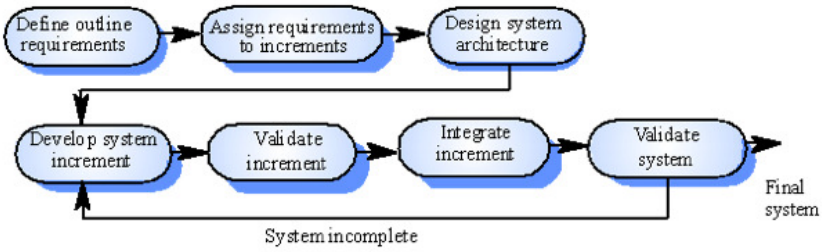

Figure 4.1: Incremental development [12].

Iterative Model

An iterative model is usually built on the defined requirements at the beginning of the development. A full system is usually delivered at the very beginning which gets evolved gradually into newer versions [13]. This process continues until a final version that fulfils the initially defined requirements is achieved. This is achieved by revising the requirements and therefore enhancing the functionalities [13]. An iterative cycle is followed to edit the resulting outcome of the iterations (see figure 4.2). Figure 4.2 shows the whole package developed at an early stage, representing the complete systems. The package consists of multiple blocks which get evolved along the development. The shaded block in figure 4.2 represent the part of the package that is refined at the different development stages.

The evolutionary prototyping model was followed in the process of developing each *increment*. In each evolutionary cycle, the implemented system and its interface were examined, and the stage undertaken again to incorporate any enhancement before moving to the next stage/*increment*.

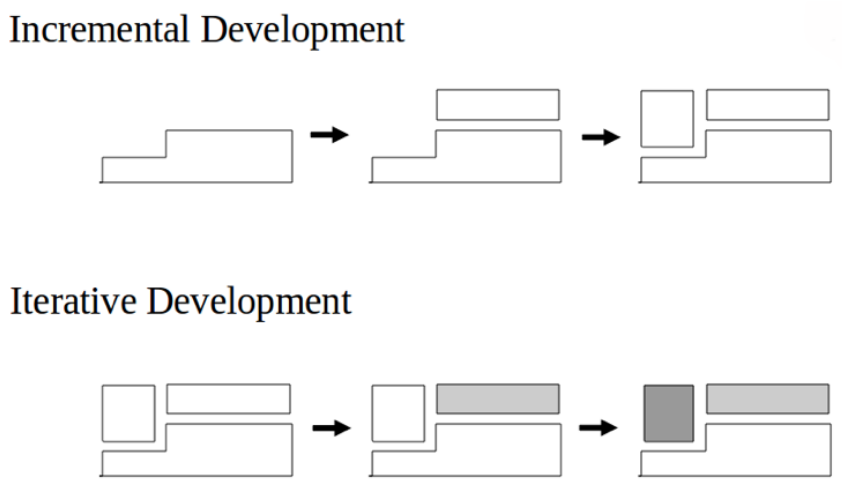

Figure 4.2: Incremental and Iterative models [13].

4.3.2 Evolutionary Prototyping Model

When using an evolutionary prototyping model, the system prototype is developed quickly to help show gaps within the earlier development stages. However, the distinction of this modelling process, compared with others, is that the specifications, requirements, and design go through repeated revisions at each stage and throughout the development process (see figure 4.3). In this approach the system requirements can be incomplete at the start which is totally acceptable in research projects [13, 12, 14]. The final version in a prototyping approach usually meets the requirements of the users as this has been given the highest priority throughout the development and was the driver of the development and the changes made to the requirements.

Throughout the implementation of the proof-of-concept prototype in this research, a single iterative cycle was conducted which created a prototype of the incremental model as a result of the revision stage conducted with the team members of the CIU at Velindre NHS Trust. This was discussed at the second meeting with the CIU team at Velindre, after the initial problem identification meeting. At this stage, the latest version of the prototyped was discussed. This is when the team suggested adding into the mapped ICP an additional part of the treatment to show the additional functionalities that could be supported at these stages. The pre-defined requirements were then re-visited and an iterative improvement cycle was applied to evolve the previously developed system.

4.3.3 Research Hybrid Model

In developing the project's prototype an *iteration-evolutionary approach* was undertaken. This involved iterations with a combination of incremental and iterative cycles. According to Cock-

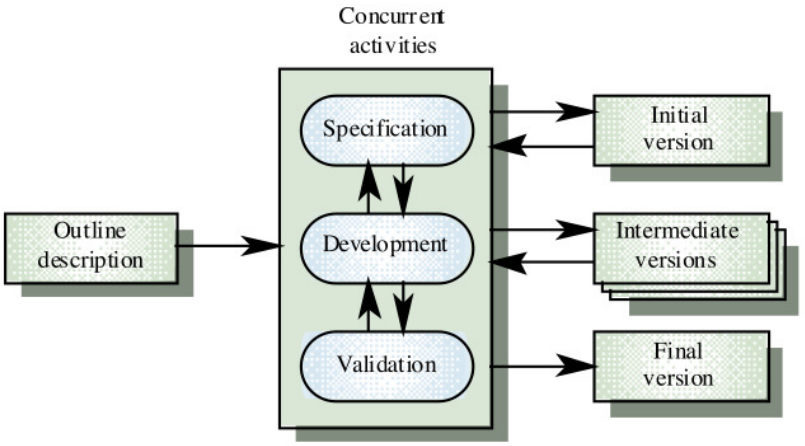

Figure 4.3: Evolutionary Model [12].

burn [14], each increment cycle leads to integration, while each iterative cycle also involves an examination of the current prototype. A set of any combination of integration and examinations can be followed when both models are used for the system development. Figure 4.4 shows an example of a possible combination of both models that can be used.

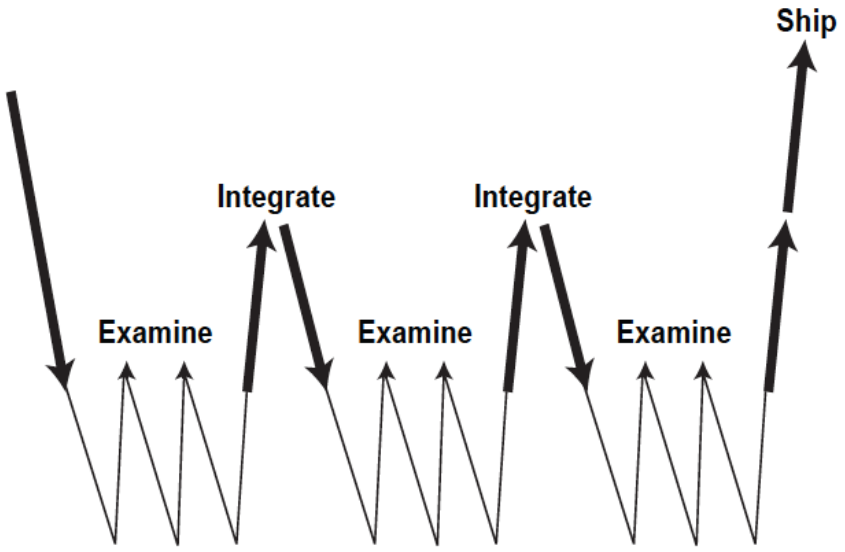

Figure 4.4: Putting Iterative and Incremental Development Together [14].

As this is a research project, continuous loops of revisions were conducted. This meant, linear development methodologies were not appropriate. Iterative approaches which ranged across: incremental, iterative, and prototyping were followed, as follows:

1. Define the overall requirements.

2. Divide the overall requirements into a set of increments. This is the first stage of the *incremental, iterative, and prototyping* cycles.
3. Define the requirements for each increment.
4. Implement a version for the first/current increment.
5. Revise the increment to satisfy its requirements.
6. Refine the requirement for the developed increment (if needed).
7. Improve the version of the developed increment (if needed).
8. Repeat step 5-7 until satisfied with the result. This is the last step of a *prototyping* cycle.
9. Repeat steps 4-8 until all increments defined in step 3 are implemented. This is the last step of the *Incremental* cycle.
10. Revise the the overall result against the overall requirements defined in step 1.
11. Refine/evolve the overall requirements and follow steps 2-11 again (if needed). This is the last step of the *iterative* cycle.

In our case we analysed the ICP of the breast cancer scenario and specified the stages within the flow that require support or attention. Each of these stages was considered as an increment. Examples of the stages include: referral, notification, alert, and setting timers (See section 10.2). Each of these increment were added to the flow in the order they appear in the ICP.

Each of the increments representing an important stage, was added to the flow.Then each went through an iterative loop for functionality and presentation enhancement. The referral, for example, was first added to the main stream to refer to an oncologist. This was followed by an improvement to select a specific oncologist which then got improved to also include a referral letter to the oncologist.

The resulting prototype was discussed with the CIU team at Velindre. They suggested the addition of the scheduling functionality in between treatment to allow a time gap. This inclusion required an evolutionary cycle to include this functionality in the flow stage when it was needed.

Chapter 5

Healthcare System

Overview

This chapter aims to explain the problem domain; the current situation and modernisation vision. Obstacles hindering the transition and guidelines to address these obstacles will also be explained. This is being presented to show the current situation as the environment which the research proposal is addressing. Understanding the process within the environment is essential as this is the process to be supported by the workflow system.

The chapter explains the healthcare system and its structure. It also presents the government plans to modernise the NHS across the UK, which is the underpinning initiator for this project. Moreover, related concepts to the emerging new NHS plans such as: patient-centric, ICP, and MDTs will be presented. Communication and coordination obstacles in the healthcare system and their related concerns in addition to approaches to tackle these issues will be discussed. This chapter concludes with a list of requirements needed to support team communication and care coordination in a patient-centric approach. These are considered in the following research and analysis of possible approaches.

5.1 Introduction

To understand the research problem fully, we give an overview of the current scene in the healthcare domain. This includes the healthcare system, the traditional healthcare delivery vision, and its modernisation plan. Concepts which have evolved as a result of the introduction of the modern NHS plan will be introduced, such as: patient-centric, ICPs, and MDTs. Communication and coordination obstacles and their related concerns within the healthcare system in addition to approaches to tackle these issues will be discussed.

5.2 Healthcare System

The NHS is the publicly funded healthcare system in the UK. It provides three levels of care to patients: primary, secondary and tertiary. These different levels involve many different organisations (e.g. Emergency and Urgent Care, NHS Trust, Care Trust, GP Surgeries, Pharmacies, Dental Practices, Opticians [75, 76]). Patients usually visit their GPs initially and are then referred on by their GPs to a general hospital for a second diagnosis when specialist care is needed. The healthcare system has its own characteristics, these are:

- *Complex organisational structure:* the organisational structure within the healthcare system has many and different components at different levels [77, 78]. These are located at different sites and often have different clinical systems. The different organisations within the three healthcare levels require effective inter-organisational as well as intra-organisational communication tools to ensure they allow exchange of medical information.

- *Many communication paths:* the number of communication channels in a healthcare setting is large and increases with the growing number of individuals involved in the system.

- *Different means of communication:* the multi-professional care team members use different means of communication to communicate, some use synchronous and others asynchronous communication tools. Synchronous communication tools are based on data exchange between communicating parties at the same site, such as: telephone calls and face-to-face chat [79]. Informal and formal asynchronous communication tools are based on archived data exchange between communicating parties at different sites, such as: e-mails and discharge summaries [79].

- *Multi-professional care team members:* individuals involved in the treatment process have

different expertise using different languages and terminologies as their standards to describe conditions.

- *Long treatment process:* the treatment process can and often does last as long as the patient lives.
- *Treatment process not determined from end to end:* each patient's treatment is different as many elements affect the treatment plan including; the current health state of the patient (medications and treatments undertaken), age, sex, medical history, response to treatment, and patient's choice. This requires flexibility in the support system.
- *Iterative processes:* the treatment processes go through iterations where special conditions should be checked and met before the flow of a treatment pathway continues.
- *Prioritised activities:* some activities are urgent and need quick responses. Here the traditional communication policies should be replaced with emergency communication policies to prevent any negative consequences that can affect patients due to delays [80, 81, 64].
- *Joint activities:* in a collaborative working environment, joint decision support tools such as electronic patient records and order entry systems are increasingly needed [79, 82]. The need for intelligent systems is always highlighted to support the collaboration in a complex healthcare environment that involves different individuals in different sites .
- *Sensitive data and information:* security is a very important element associated with medical data and information. Here secured data exchange between individuals, departments and organisations should be guaranteed. Moreover, the accuracy of the data is very important as any inaccuracy can cause adverse events to occur. Mistakes within the domain can be life threatening.

5.3 Modern NHS

There has been a move worldwide to modernise healthcare systems. Many strategies and projects have been presented and introduced for this purpose. Related research also has been intensively published to discuss and analyse this modernising vision, its implementation, and its implications. The UK NHS was formed in 1948, since then spending has increased throughout the years but not enough to modernise the entire healthcare service [83, 68]. In the late 1990's, the UK government decided to invest in the NHS in order to modernise and reform it for the 21st century. It was announced that this will be by being a healthcare service designed around the patient [83, 68].

The new plan aimed to meet patent's expectations for: improved techniques, better paid staff, less waiting times, better quality of patient-centred care, and improved healthcare centres and hospitals [83, 68]. This budget settlement also meant that the NHS was to grow by one third in size by 2005, by increasing the number of organisations and healthcare providers [83, 68]. The reform plan's aims included: reducing waiting times, improving healthcare service, and introducing new services to patients, such as [83, 68]: setting national standards, ensuring equality, improving collaboration between the social services and NHS, better contracts for GPs and hospital doctors as well as nurses and NHS staff, empowering patients, setting up public-private healthcare provider partnerships to give better use of facilities, and investment in staff and facilities.

The new NHS plans introduced new concepts, some of these concepts will be introduced in the following sections. The concepts covered are those affecting this research study.

5.3.1 Patient-Centric

For the last 50 years, a disease-centred delivery model has prevailed in medicine [83, 68], and healthcare systems were designed for this delivery model. However, recently, there has been strong support worldwide to change the healthcare delivery model from a disease-centred to a patient-centred approach, where care provision focuses on treating the whole patient rather than managing separate diseases. It is particularly valuable for the management of "difficult-to-treat" patients [84, 61]. The term patient-centric care used throughout this thesis refers to - a collaborative teamwork practice around the needs of a patient's care with all healthcare providers caring for a shared patient. In order for the healthcare providers to work as a team in this context, accurate, up to date and relevant medical information about the patient needs to be provided and shared fully at the point of care.

There is worldwide agreement on the importance and the need to provide a patient-centred care to patients [85]. Countries including the UK [68, 83], the United States [86, 87], Canada [88], Australia [89], Netherlands [66], Japan [67], and Saudi Arabia [90, 91] are among these adopting the patient-centred concept.

5.3.2 MDT

Depending on the diagnosis, the patient might be referred to a MDT multidisciplinary team [92], also called multidisciplinary medical teams and interdisciplinary teams. MDT meetings bring together specialists from different domains to discuss the management of patients with a given condition or disease. The MDT members plan the treatment of patients discussed in an MDT

meeting, however, they are not necessarily the team who actually treat this patient in clinics. The outcome of an MDT meeting is usually a consensus agreement on the treatment strategy that is informed by the combined experience of the team. MDT meetings also help share best practice among the professionals at the meeting.

The use of MDTs is worldwide, in that examples can be found in the UK [93, 94], the United States [95, 96], Canada [97], Australia [98, 99], Netherlands [100], Japan[101], and Saudi Arabia [90, 91].

5.3.3 ICP

Since the creation of the NHS in 1948 it was up to the healthcare authorities to decide the level of treatment to be provided to patients. In 1990, during the period of the internal market, it was down to the GP practice's choice, as competition between healthcare trusts to reduce cost and increase quality was encouraged by the government [102, 103, 104]. This changed in the late 1990s when the National Service Framework (NSF) [105] and NICE [1] were introduced to set national strategies and standards for treatments and patient care.

NSF is a national service which sets care quality requirements for major medical problems such as Cancer, Stroke, Mental Health, Diabetes, and Heart Diseases [105]. It also sets requirements for special groups such as children and older people. This is based on best evidence and is developed in partnership with healthcare professionals, patients, carers, managers, voluntary agencies and other experts [105].

Patient treatment is delivered through an ICP in a modern healthcare delivery model, where ICPs are "structured multidisciplinary care plans, which detail essential steps in the care of patients with a specific clinical problem" [106]. Clinical guidelines, also called clinical protocol, clinical practice guidelines, and medical guidelines, are based on best practice and are produced in consultation with health and care providers, patients, and the public. ICPs incorporate local and national guidelines into everyday practice to reduce variation in clinical practice and control the quality of care provided to patients across multi-disciplinary and multi-agency teams in different healthcare organisations [18]. Moreover, it has been shown that following guidelines improves efficiency and cost-effectiveness of care without adversely affecting the patient and their treatment [107, 108]. Guidelines help in changing the clinician's behaviour, and are extremely effective in helping clinicians agree on a treatment plan and options, and they also support the decision making process [108]. Examples of guidance on the ICPs used in the NHS in the UK can be found in the ICP National Library for Health [109] published by NICE [1], Scottish Intercollegiate Guidelines Network [18], as well as the recently released guidelines in the MoM [23]. Worldwide clinical guideline resources include: the US - National Guideline

Clearinghouse developed by the Agency for Healthcare Research and Quality (AHRQ) [19], and the Canadian - British Columbia Medical Guidelines are clinical guidelines developed by the Canadian Guidelines and Protocols Advisory Committee (GPAC) [20].

The treatment process for each patient is:

- unique: as the treatment process depends on case-specific decisions, which are made by interpreting patient-specific data according to medical knowledge as well as the available resources.
- complex: as the decision-making process depends on medical knowledge which includes medical guidelines of various kinds and evidence levels, as well as the individual experience of physicians [110].
- dynamic: as the treatment flow for a patient is unpredictable and many elements interact along its path.
- long: as it can last as long as the patient lives.

The ICP represents a treatment guideline for healthcare providers. However, a version of the ICP is created to suit the condition of each patient. This version is unique and only applicable for the particular patient for whom it was created.

5.4 Cancer care

Cancer care is considered to be a key model that will improve with a patient-centric delivery model [54]. It has a critical demanding journey in which team communication and care coordination plays a vital role. Figure 5.1 shows a sample of possible stages along a patient's treatment journey at the different healthcare organisations and across time for a patient diagnosed with cancer.

5.5 Communication and Coordination Challenge

The complexity of the healthcare system made controlling and monitoring the treatment process a challenge. The literature shows that efficient communication and coordination between clinicians has not yet been achieved [111, 112, 113, 114, 115]. A study of primary care adverse events, revealed that communication and coordination difficulties are the main causes of these adverse events [82, 65, 79], causing 98,000 deaths every year in the United States [81, 116, 117]

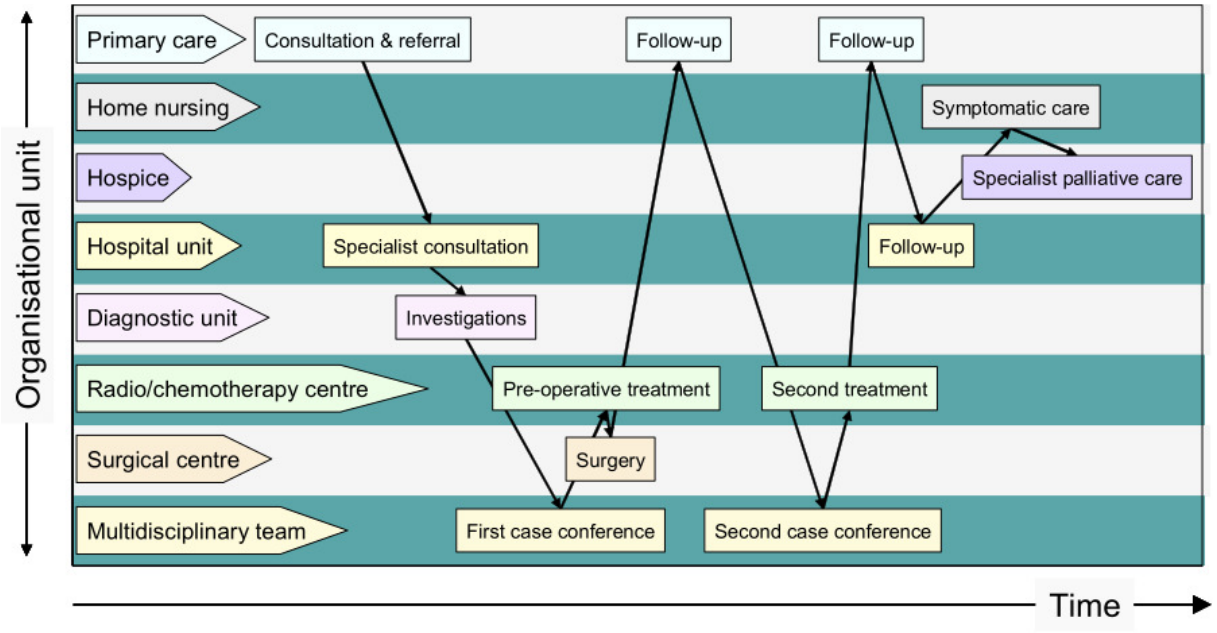

Figure 5.1: Sample of Cancer Care Pathway [15].

and approximately 850,000 errors in the United Kingdom [117]. Therefore, medical errors are considered the eighth leading cause of death among Americans [118]. Among these errors, it is reported that communication errors are twice as common as errors caused by inadequate clinical skills [82, 65, 79]. Moreover, a review of 14,000 in-hospital deaths showed that communication difficulties were the main cause of death [82, 65, 79].

In addition to patient safety concerns, the waste of time, effort and money caused by miscommunication are a major concern in the healthcare domain. A study in the Netherlands estimated that 300 million Euros is the annual wasted money due to medical errors as it causes 90,000 avoidable hospitalisations [118]. Furthermore, it has been estimated that the total cost of medical errors nationwide in US hospitals is between $17 billion and $29 billion per year (including the extra effects caused by those errors like losing income and disability) [81]. Consequently, communication in healthcare often raises concerns [64, 81, 116, 119, 120, 121]. In a survey of 12,000 adults in seven different countries [1], it was reported that only 45% to 61% of adults have primary care coordinating their care treatments, and that one in four in the U.S. reported coordination problems including duplication of tests and unavailability of records during visits to doctors [122].

[1] Australia, Canada, Germany, Netherlands, New Zealand, United Kingdom, and United States

5.5.1 Communication and Coordination Related Concerns

Communication and coordination related concerns are presented in the literature. These were also clearly stated in the NHS Plan, as follows:

1. Need for patient-centred care: this is a cause of frustration for both patients and staff [68]. Patients want more convenient services in which they can for example take actions on cancelled operations. While staff claim that the system is focused on the needs of the specific department or disease it is built for, rather than the patient's needs [68]. Thus, empowering patients and having information systems support the patient's treatment needs, are the tools required for patient-centred care.

2. Lack of national standards was also pointed out: for 50 years it has been left to individuals and authorities to decide on treatments [68]. This was changing with the introduction of the NSF and NICE, and is believed to be the foundation for improving communication and coordination interactions.

3. Delayed communications: leads to medical records being unavailable during visits to a doctor [80, 64, 81].

4. Lack of essential information being communicated [80, 81].

5. Information inconsistency [80].

6. Lack of support for wider distribution of information to other healthcare organisations [80, 64, 81].

7. Poor coordination between the NHS and other agencies: this resulted in three quarters of patients not getting the care they needed [68]. Ineffective coordination between activities leads to unnecessary duplication of the information provided and the tasks performed [80, 64, 81].

8. Lack of support and intervention: performance was not measurable due to the lack of reliable information for clinicians, managers and patients [68].

9. Poor linkage between related information such as prescriptions and diagnosis made it hard to share experiences, monitor, and learn from errors. It was highlighted clearly that: the NHS needs a system which spots problems early, takes actions swiftly and can act decisively [68].

5.5.2 Current Approaches to Tackle Communication and Coordination Challenges

As explained previously (see section 5.5 and 5.5.1), communication and coordination present major challenges in the healthcare domain. These challenges are currently addressed in many ways, such as:

- Synchronous coordination (such as face-to-face communication, telephone calls, and video conferencing) and asynchronous coordination (such as e-mails and voice mails). Despite the wide use of advanced network technology to facilitate asynchronous communication, most clinicians still rely on synchronous communication [79, 84] (e.g. 50% of information transfer in clinics happens face-to-face and only 10% occurs through clinical information systems [79]). This has an adverse impact on clinicians' time (e.g. it is reported that physicians in emergency rooms spend up to 90% of their time, exchanging patient information face-to-face [79]). Moreover, synchronous coordination can be inefficient and interruptible in ways that can cause errors [79, 84], while asynchronous coordination does not allow the acknowledgment of received information without a protocol [84].

- All on one site hosting focuses the treatment within one organisation. Although this approach is manageable in some situations, it supports only a limited number of patients and may not be feasible when applied in a situation, where there are a large number of patients. Thus, the scalability of solutions is not guaranteed.

- MDT coordinators: hiring manpower to ensure the availability of up-to-date clinical information during MDT meetings. This approach only provides a partial solution, since it only supports coordination in MDT meetings but not for the overall treatment process.

- Operation management tools, such as: Lean [123, 124] and Six Sigma [124, 125] are used for coordination. These work on physically changing the process implementation to improve quality and efficiency of the processing, and customer/patient satisfaction [123, 124, 125]. This approach does not support data archiving and requires input from the staff to suggest ways to improve the process.

- Improving the speed of information transfer: this includes moving from paper-based medical records to Electronic Medical Records (EMR), developing Health Information Networks (HIN) that facilitate information exchange between different departments and implementing National Health Information Networks (NHIN) (e.g. smart cards) [80]. However, none of these approaches focus on tackling coordination problems.

5.6 Communication and Coordination Suggested Solutions

In the literature, researchers have suggested different approaches to address healthcare communication and coordination problems.The suggestions include:

- Patient-centred approach: this approach can address healthcare communication and coordination problems. It has been demonstrated that it improves physicians' performance, patient satisfaction [61] and healthcare outcome [61, 126]. Also, it should lead to pooling of expertise and enhanced creativity in problem-solving [126]. The patient-centred approach can be achieved by a proper implementation of the ICP.

  This is a solution which helps support the first two concerns in section 5.5.1 of the need for patient-centric care and support for the implementation of clinical guidelines. It will also support the communication and coordination concerns listed in section 5.5.1.

- Computerisation, integration and automation: it has been shown that only computerised information systems allow a sufficiently rapid exchange of medical information within and between countries [127]. The need for EMR instead of paper-based and automated communication tools has been highlighted in the literature [128]. A study focussed on the worldwide withdrawal of Rofecoxib in 2004, identified the urgent need for a system that can handle such emergencies, as it is not a rare problem and it can happen again. This problem affected nearly 20 million people between 1997 and 1998 [128]. Also, it has been identified that improving the quality and decreasing the cost of care will not be achieved without integrated care and improvement in communication [129]. In the literature, there is agreement that integration is the appropriate approach to cost-effective treatment and improved decisions and processes in the patient-centred healthcare delivery model [130, 131, 132, 133].

  Computerisation directly resolves concerns related to: lack of support for essential information communication, information inconsistency, lack of support and intervention (see points 4, 5 and 8 in section 5.5.1). Integration has a direct affect on the lack of support for wider distribution of information, coordination between the NHS and other agencies, and linkage between related information (see points 6, 8 and 9 in section 5.5.1). Automation speeds up the process which can overcome existing delays within the healthcare system. Moreover, automation can be used to link related information in a way that is faster than manual linkage (see points 3 and 9 in section 5.5.1).

- Safety, error reduction and recovery systems and policies: the Institute of Medicine proposes a comprehensive approach towards reducing and managing adverse events, including the establishment of a national focus on patient safety, the creation of a mandatory

reporting system, raising standards and expectations for safety improvements at a national level, and creating safety systems in health care organisations [134]. In the US, the fatal accident rate of 0.077 accidents per 100,000 in 1990 was reduced to 0.009 per 100,000 in 2004, as a result of the implementation of system-level error-reducing policies. Error disclosure is widely highlighted in the literature, and it is suggested that disclosure of system errors is generally more important than disclosure of individual errors because root cause analysis may yield information that facilitates the creation of a resilient and fault-tolerant system [135]. This highlights the need for a flexible support system as the treatment process is dynamic and unpredictable. System flexibility is defined as: "the ability of a system to respond to potential internal or external changes affecting its value delivery, in a timely and cost-effective manner" [136]. In practical terms, it is "being able to implement several alternative behaviours or react to change of the environment during operation" [137].

The literature shows that flexibility is a complex, multi-dimensional, and hard to capture concept [138]. Safety, error reduction and recovery systems will help support communicating essential information and support the linkage between related information (see points 4 and 9 in section 5.5.1). Stating policies and standards will also help support the patient-centric and lack of national standards concerns (see points 1 and 2 in section 5.5.1).

5.7 Discussion

The new collaborative model for treatment being adopted worldwide to provide a healthcare service around patients, necessitates adequate support for team communication and care co-ordination among the care team members. The ICP within the patient centric model outlines the possible stages in the treatment of a medical condition. Implementing these clinical guidelines is part of the patient-centric requirements. Communication and coordination difficulties has been widely recognised in the literature. These difficulties include the need for standards and patient centred care; information not communicated, delayed or inconsistent; lack of connection between the different NHS organisation and also related agencies; and linking of information and its use for intervention. Suggested solutions have also been discussed in the literature. These begin with the need to implement patient centred care, integrate and automate information systems, and support safety, error reduction, and raising standards. These form the basis of the current scene to be considered when a research solution is proposed.

Chapter 6

Clinical Information Systems

Overview

This chapter aims to explain the information systems used within the problem domain; how these currently operate and the vision on how they should operate. Some of the projects planned and underdevelopment to improve these information systems and provide the required support will also be introduced. These will be linked back to the communication and coordination concerns discussed in section 5.5.1 and the suggested solutions in section 5.6.

This chapter describes the informatics side of a healthcare system. The legacy CISs in use are presented as these must interact with the proposed dynamic workflow system aimed at unlocking the information within their silo databases and ensure its availability at the point of care in new systems. Also, IT national and international projects to modernise and improve these CISs will be discussed. This will be followed by a gap analysis of the current scene. This is necessary to discuss current attempts to resolve limitations within the existing CISs to distinguish and position this research with other work conducted in this field.

6.1 Introduction

Informatics and the use of IT is evolving in the healthcare domain. The following sections introduce current legacy CISs and their operation according to the purpose they were originally designed to support. It also presents the NHS modernisation plans for information systems, and national and international projects in place to modernise the existing systems. The limitations of these projects will also be discussed. Finally, a discussion of the requirements for the CIS to support practice will be presented and linked back to the suggested solution discussed in section 5.6.

6.2 Clinical Information System (CIS)

A CIS is an information system that *capture clinical data to support more efficient and effective decision making and clinical care delivery* [139]. Current CISs were designed to support a disease-centred approach and therefore are unable to cope fully with the new requirements of the patient-centred delivery model. These CISs were mainly designed for administrative purposes. The clinical information has been included but still in a disease-centred fashion. This means it is not designed to support the treatment of patients or the communication and coordination needs of the multi-professional care team members. CISs within the different departments and organisations are discrete and heterogeneous.

Data stored within the legacy CISs are directly related to the speciality it is built for. Patient's medical data are separately stored in the different information systems within the healthcare organisations. A patient's medical information is fragmented among the different databases of the different departments or organisations involved in the treatment of the patient. In this way many CISs are organisational centred. Moreover, information within the different systems is static and only retrievable when it is requested by the healthcare providers using the system.

This structure was totally appropriate when the healthcare delivery model was disease-centred. However, the change to patient-focused care requires the implementation of the three C's: communication, continuity of care, and concordance [61]. Moreover, for patient-centred care, a systems that supports dynamic processes and effective communication and collaboration between healthcare providers has become essential [140, 62]. This is to support the treatment and aid the decision making process along the treatment pathway. Therefore, a number of recommendations have been made by public and private authorities about the changes needed (see section 5.5).

6.3 Modern CISs

Modernising information systems in hospitals is a core part of the UK NHS plan. The scene was clearly described when it was said to be *a 1940s system in a 21st century world* [68, 83]. Following the Modern NHS plan, in early 2001, the Department of Health (DoH) released a document detailing the IT systems modernisation plan [141]. The Secretary of State for Health, Alan Milburn's message highlighted the importance of IT in this change, as [141]: "The better capture, management and use of information - analysed, communicated and shared through modern systems and networks - is central to managing change and modernising the front- line delivery of care, treatment and services to patients. It is central to improving the day to day working and skills of staff. It is about improving the day to day working skills of staff. It is about improving the very nature of care itself - information, communication and understanding."

A separate budget was set for IT development. From 1999 to 2004 the total spendings in investment in IT was £747 million. The plan was to have a national IT system which improved the capture, management and use of information. The need highlighted was for an infrastructure that was robust, flexible, secure, and standardised.

A summary of the reform plan of healthcare IT systems includes the following selected points [141]:

- The need to support patient-centred care and services. This builds on and updates the Information for Health [142] information strategy for the NHS.
- The need to support a co-ordinated service across all systems.
- Support for personalised information and IT systems to meet the needs of patients and healthcare providers.
- The need to redesign the care system to include other services involved in health care. This aims to deliver preventative care and self-care as well as providing primary, secondary and specialist care. It was also clarified that this requires a networked NHS.
- The need to fulfil the stakeholders' requirement for information services (e.g. NHS Direct), electronic records, and national or local applications to help them take informed decisions. It was clarified that this requires the development of infrastructure and standards.
- The need to implement standards once they are agreed is facilitated if there is a standard infrastructure.
- The need to deliver services electronically to the user has become essential.

Part of the investment plan in facilities involved having an up-to-date information technology system underpinning. At this stage, the NHS was already investing £200 million in modernising IT systems, and an extra £250 million was to be invested in 2003/2004 [83, 68]. This IT investment aimed to provide patients with the following facilities [83, 68]: electronic booking for appointments, patient access to their own medical records, electronic prescription system, GP practices connected to the NHSnet, and local health services with telemedicine facilities.

The staff also benefited from the IT investment by having [83, 68]: easy access to an up-to-date and accurate patient record, an ability to submit test requests, being able to refer patients, book appointments, and access state-of-art information on treatments and best practice.

At the organisational level, the new IT systems would improve efficiency, help monitor performance and practice, and extract performance indicators [83, 68].

The modernisation plan of CISs is a worldwide movement and Saudi Arabia is not an exception. The Saudi Arabian Ministry of Health released in 2010, an "e-Health" strategy plan for modernising the information systems used in healthcare [91, 90]. This strategy included plans for: EMR, TeleMedicine, an electronic administrative and financial system, Health Knowledge Management, and monitoring systems, such as dash boards.

6.4 International/ National Projects

A number of recommendations have been made by public and private authorities about the changes needed (section 5.5.1). Therefore, a number of national projects are currently running in the UK and worldwide aiming to modernise CISs. Informatics has been widely used in the healthcare domain with an emphasis on the implementation of standards and providing access to knowledge resources, as well as the use of ICT to provide improved access to patient data including EPRs (e.g. [22]), knowledge management systems (e.g. [23]), triage systems (e.g. [143]), assessment systems (e.g. [144]), prescribing systems (e.g. [21]), and test ordering and result systems [145].

Projects have been undertaken on a variety of levels, from very specific systems targeted for use in a single hospital or service, to national projects intended for national or even international implementation. There are too many projects to discuss them all in detail, but some examples include:

- In Europe: the Good European Health Record project [146] aimed at developing an architecture for sharing electronic health records across Europe.

- In Canada: the Canada Health Infoway [147] funds a multitude of projects ranging from drug information systems to developing interoperable electronic patient records for public health surveillance.

- In the United States: private companies, including Google ™and WebMD [148], have focused on improving the patient experience through the use of healthcare ICT.

- Universally: Google Health [149] attempts to provide a universal patient record while supporting patient empowerment by allowing the patient to control his or her medical data (recently it has been discontinued), while the WebMD website [148] provides an interactive patient information service.

- In the UK: examples of projects aiming to implement the NHS plan include: CfH [21], which is the English national project, and the Welsh project, IHC [22]. UK projects include:

  - *Shared and unified records accessible at any location*. The unified EMR, the WCP [43, 150] developed as an IHC project is an example of a project aimed at information exchange with predefined policies to support the communication aspects. Also in Scotland, the Scottish emergency care record which makes key aspects of a patient's record available to out of hours services is another example [18].

  - *Integrated medical records for information sharing*. Supporting the integration of medical records to insure information sharing between care team members. Projects in this area include: SCR - introduced by CfH [151] and the Individual Health care record (IHR) - introduced by IHC [152].

  - *Developed clinical guidelines and standards*. This is being realised by developing and making guidelines and standards available through the NICE [1] and the MoM [23]. MoM is a knowledge management tool currently used by some NHS trusts in Wales and England to support clinical decision making. MoM is a web-based visual representation of clinical guidelines to be followed when treating a patient. They have been confirmed by evidence. It includes policies and guidelines [145, 23]. MoM is used as a communication tool and has been implemented in some systems to support automatic decision support or recommendations for action and some systems have integrated it into the clinical environment [145].

  - *Managed prescriptions*. E-prescription is a management system for prescribed medications. It was introduced by CfH [153, 154, 21] to focus on the prescription process either within a single department or across the departmental boundaries. It manages medication and any prescription therapies prescribed electronically. The process

managed within E-prescription starts at the prescribing and continues to supply and administration [155].

6.5 Limitations/Gaps in these projects

While the projects introduced in section 6.4 are an important first step, there is still more work to be done. For example:

- Shared patient records support the treatment process in terms of provision of patient information and medications prescribed. However, they do not actively indicate to practitioners that relevant information is available, nor do they consider the individual information requirements of practitioners with different specialties or the dynamic communication requirements of care teams working collaboratively.

- Decision support and knowledge management systems support coordination between different tasks or processes by managing their sequence. This is suitable for patients following the anticipated treatment pathway. However, patients often follow a non-predicted care pathway. As each patient is unique, changes to the treatment plan can happen at any time. This requires support for dynamic team allocation and the management of changes along the care pathway, which is an extremely dynamic process.

- Projects considering support for care teams usually emphasise that there is a formal MDT. An MDT usually consists of clinicians from a range of specialties related to a specific diagnosis. They often, however, do not include members of the allied health professions (physiotherapies, for example) or nurses, and almost never include GPs.

- Most of the mentioned projects in section 6.4 speed up the process by supporting information sharing, clinical decision making, and managing prescriptions. However, these projects are not set to support important timing factors affecting clinical visits, medications, dependencies and care continuity. Timing and other factors such as order dependencies play a vital role in the treatment process and therefore need to be supported within the developed systems.

- Safety error reduction and recovery systems have not been included on a large scale for any projects covered in 6.4 and are needed if the systems are to cover a full treatment journey. Safety projects on a small scale have been introduced such as medication projects to check prescribed medications for conflict which is very useful but is not included in many projects.

6.6 Discussion

It has been recommended that team communication and care coordination can be supported by having a system that is patient-centred, computerised, integrated, automated, and with reduced and recoverable errors (see section 5.6). For the system to be patient-centred, it has to be flexible enough to adapt to each patient's specific case. Computerised and integrated systems are required to support the basic information sharing needs for team communication. Moreover, automated systems according to the standards presented by the clinical guidelines are required for a pro-active system that supports the treatment needs of each case and therefore coordinate care. Moreover, factors that interfere with the treatment process such as the time, order, and dependencies should also be included and supported by these systems. Finally, errors need to be reduced and recovered within the automated process.

Using workflow technology and having it interact with existing legacy systems aims to change the way these systems operate. The use of WFMSs aims to interact with the distributed heterogeneous systems, access the data stored within these systems, link and process this data, and as a result identify the appropriate actions to be taken. The actions are decided according to the current status of each unique case across the different systems. This changes the use of the data stored in the silo system from passive to active in the patient's treatment process.

Chapter 7

Virtual Integration of Information for CISs

Overview

Different technologies and techniques are used to integrate independent systems. An overview of these different technologies and techniques are presented in this chapter. Moreover, a justification of the choices of these systems made in the development of this research will be given. This includes choosing the development methodology to be evolutionary, the approach to be achieved through a VO, and the main tool to be using a workflow technology. Finally, we will analyse the different usages of workflow technology in the healthcare domain and explain how these are different from the use proposed in this research.

This is based on previous discussions presented in chapter 5 and 6 which identified the fact that information systems in healthcare are discrete. Thus, to support team communication and care coordination in a patient-centric care approach requires integration of the discrete systems. These legacy systems cannot be changed and therefore, an evolutionary methodology has to be followed. Integration of heterogeneous systems is impossible when the systems are discrete and their autonomy must be retained. However a virtual integration of the data will satisfy the requirements of the users for this data in the domain. This integration is achieved at the business level to satisfy the user requirement of using workflow technology as a wrapping tool for the discrete CISs to preserve their autonomy.

7.1 Introduction

A review of the literature showed there is agreement on the need for systems integration as the solution to providing cost-effective and improved decision making in healthcare delivery and providing processes supporting the patient-centred healthcare delivery model [132, 130, 133, 131]. In this research, the system integration techniques used across departments and organisations to integrate information systems were investigated. The requirement is to integrate the independent information systems used at different departments which are located across multiple sites. Integration can be achieved by forcing it physically through hardware at the technology level or by using soft-techniques which wrap the multiple systems at the business or application level. This research proposes the use of workflow technology as a tool to achieve a business level integration of the heterogeneous distributed CISs which retains their autonomy and allows them to continue in use within their organisation.

In this research we chose an evolutionary development methodology, as it allowed the existing legacy information systems to be kept but enables these systems to exchange appropriate information with users of other systems. We also aim to build a VO, incorporating multiple healthcare organisations and professionals, around a patient to fulfil the needs of the care team treating a patient. Different technologies have been used within the healthcare domain to integrate different healthcare systems and manage the treatment process of a patient. Some of these technologies are currently used and others were only researched and never used in a treatment environment. Examples of these systems will be given in this chapter.

7.2 Development Methodology and Concept

It was decided that an evolutionary development approach should be used as the framework for development. Moreover, it was clear at the start that we should aim to support the interactions along the patient's treatment pathway by constructing a VO around each patient's needs. Consequently, a virtual integration technique for the integration to the integration of the CISs is required, if legacy systems are to be evolved and a VO approach is to be followed. These choices will be explained in the following sections.

7.2.1 Evolutionary Approach

It was decided to adopt a pragmatic approach that aimed to evolve existing systems rather than propose a new system [156]. Adopting an evolutionary approach keeps the current legacy systems running but enhances their operation. This maintains the users local autonomy for the

current systems. Moreover, evolutionary approaches are more suited to implementation when consideration is given to the different constraints, such as financial, resources and time. In addition, this proposal is in-line with the Welsh national project, IHC [22], which uses an evolutionary approach (see section 7.4).

7.2.2 VO

A VO setting "...consist of networks of workers and organisational units, linked by information and communication technologies (ICT), which will flexibly co-ordinate their activities, combine their skills and resources in order to achieve common goals but without very much by way of traditional hierarchical modes of central direction or supervision." [4]. A VO changes the essence of the organisation and management of the daily operation [157] by making these daily operations within and across the different organisations operate as being in a single system.

This research uses the concept of VOs to better support communication and coordination between healthcare practitioners working as a care team across the healthcare organisations. A care team within these organisations will be treated as a type of VO, as it allows the implementation of a patient centric approach. This will allow distributed teams across organisational boundaries to communicate and coordinate the shared patient's care *virtually* [158]. Moreover, the complexity, heterogeneity, and distribution of the legacy CISs that will be involved in the VO, also suggest that physical enforcement of a patient-centric system is a challenge.

7.3 Systems Integration Approaches

Healthcare systems have special characteristics that make the adoption of IT into the domain a complicated process [159, 78]. Many trials have been undertaken but yet the success stories are fewer than failures [160, 78]. The literature covers many studies, views, recommendations and projects explaining the challenges for these healthcare system and therefore defining the domain requirements for the IT used in it , these include: security, standards, flexibility, timing and safety requirements (see chapter 5.6).

Systems integration is done at three different levels: inter-organisational integration at the business level, enterprise application integration at the application level and middleware integration at the technology level [16] (see figure 7.1). All of these layers should be considered when integrating systems [16]. At the business level, business engineering is required to standardise the business rules. The application level operates as an interpreter/middleware between the

business rules and the technology. The technology is the detail level, it defines the information and communication infrastructure [16], examples of these include: Common Object Request Broker Architecture (CORBA) [161] and Distributed Component Object Model (DCOM) [162]. The choice usually depends on the tool used at the application level. CORBA, is defined by the Object Management Group (OMG) [161] to allow software components written in different languages to operate together. DCOM allows software component co-operation among Microsoft® software components [162]. Integration is required to ensure that medical inform-

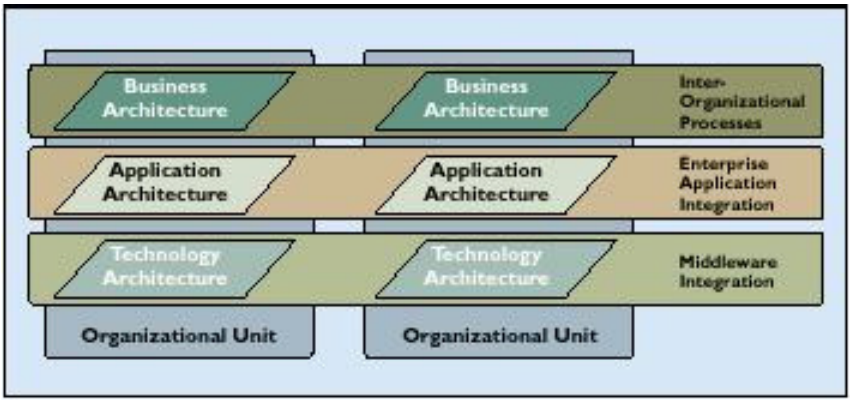

Figure 7.1: Integration Layers [16].

ation is available to the healthcare providers at the medical decision points occurring in the care pathway. Therefore, a tool to gather the required medical information and ensure its availability when needed will satisfy this need. This is called a *virtual integration of data*, as the different data are collected from multiple distributed resources and then presented "as if" they are physically integrated into a single record. Moreover, since the legacy systems providing the data are heterogeneous, integration at the technology level will not be possible.

For this research, the integration will be conducted at the business and the application level. Integration at the business level will be according to the ICP needs. Using the ICP, the rules are defined in a stage. Accordingly, information requirements at the different stages along the treatment pathway will be identified. At the application level, these requirements can be satisfied, by implementing an additional WFMS application, representing the ICP. This WFMS understands the requirements of each stage within the treatment flow. Thus integration at the application level, integrates the interface of the WFMS, that collects the data, with the interface of the legacy systems according to the ICP rules.

The focus of the research is thus on the application level and the tools that can provide the appropriate application integration. This integration can take different forms. These can be internal using Enterprise Application Integration (EAI) [163] and/or external using Business-to-Business (B2B) application integration through the web [164].

Different integration tools support different integration concepts or technologies. These concepts and technologies include Object Oriented (OO), Component Based Development (CBD) [165], EAI [163], B2B [164], Business Activity Monitoring (BAM) [166] and the support of portals.

The main application integration tools in this area include: Inter-Organisational Communication Network (IOCN) [118], National Healthcare Information System (NHIS) [118], Service Oriented Architecture (SOA) [167], Enterprise Resource Planning (ERP) [168], Workflow Management (WFM) [168], BPM [168] and smart card [80, 169]. Each of these has well known usage and limitations in practice as follows:

- **IOCN and NHIS**; are mainly used to coordinate geographically distributed organisations. They support cheaper and improved quality of service [80], and data exchange [118]. However, they involve long term processes and raise cultural, financial, technical, political, organisational, and ethical challenges to manage macro level changes [118]. A study in the USA, in 2005, estimated that the cost of a US NHIS would be $156 billion in capital investment for 5 years, for acquiring functionalities and inter-operability [170]. To set an ICON or a NHIS, usually a new information system is needed in the working environment. These need to be homogenous and originally designed for this purpose. However, if an IOCN or a NHIS is to be built to include existing information systems, an integration at the technical level is required. Usually this is only possible for homogeneous systems.

  For the CISs, if this approach is to be used, information systems across all health organisations need to be replaced with new ones simultaneously. This is because current legacy systems are heterogeneous and originally designed to stand-alone and support different purposes.

  For this research, we are looking for an approach to support linkage between CISs and gather the medical information systems within these systems at the different treatment stages. This means the involvement of the multiple CISs at the different organisations is an essential part of this research. This requires evolutionary approaches due to the large scale of the project as revolutionary approaches to replace existing systems with new ones is unrealistic and would be very expensive.

- **SOA**; is mainly used to deliver services that are reusable across organisations, applications, channels and user groups [167]. It supports information sharing and interoperability between applications, departments and organisations. It is a location transparent protocol and platform independent, loosely coupled, flexible and agile [167]. A SOA approach is mainly used for an environment that is mainly designed to provide re-usable services that

can be written and enhanced as time passes. These are distributed and accessible remotely by systems.

For the CISs, if this approach is to be used, these services represent specific applications used along the treatment flow that are reusable across the multiple organisations. An example is an application for analysing x-ray images or laboratory tests; which can be accessed and used by multiple healthcare organisations. These services can be improved and enhanced at any time.

For this research, we are looking for an approach to support linkage between CISs and gather the medical information systems within these systems at the different treatment stages. This means the main stages within this environment involve the applications within the CISs used at these different treatment stages. These application are disease-centred information systems. These are not services. Moreover, medical information within these CISs is accumulative and is never replaced with new altered data. These information are the medical history of a patient.

- **ERP**; is mainly used to manage business process, integrate data and applications, and improve visibility [168] It is also data-centric [168]. Limitations of the ERP include: being domain specific, need for homogeneous environments, require data conversions, and top-down approaches are used in systems implementation [168].

  In the healthcare domain, applications are mainly designed for different purposes and to stand-alone at the different healthcare departments. These systems were not designed to operate together and therefore they are heterogeneous. This means, the ERP approach can be used at departmental or organisational scale in a completely new system.

  For this research, we aim to involve the multiple applications at the healthcare organisations. This require the replacement of all these systems across the healthcare organisations simultaneously, if ERP is to be used. This is unfeasible and expensive.

- **WFM and BPM**; are mainly used to manage business process, integrate data and applications, and improve visibility. It is ad-hoc and supports domain independence, process-centric, heterogeneous and autonomous environments. It supports a bottom-up approach in systems implementation [168]. However, WFM and BPM may require data conversions [168] if different systems to be linked.

  For CISs, this approach can build on legacy systems. This is because it supports an evolutionary development approach and it can operate with heterogenous systems. This approach is also process-centric, which allows the operation to be controlled down to applications within the information systems as part of the process.

  For this research, we look at the application level of detail as well as the need to support

an evolutionary approach for linking heterogeneous systems. This is enforced by the need to conduct the approach across the healthcare organisations and retain autonomy for the users using these systems. This also means that the improvement can be done gradually which increases the success rate and controls the cost.

- **Smart Card**; is mainly used for its mobility [169] to store patient information. It records information and can be used as a key to encrypt internet access to information [80]. Limitations of smart cards include: needs a reader with the same standards, can be expensive to increase security, and some are slower in performance than traditional software [168].

  For CISs, this approach can be used to store medical information as patients receive medical care. It is a way of having a mobile medical information repository with the patients. Despite the limitations of this approach, technically and financially, it can support the decision making process by having the medical information available to the healthcare provider who needs it. However, for this research, the aim is not only providing accessibility to medical information, but also to take account of the current treatment stage and provide the required information at these stages. This cannot be done using smart cards.

7.3.1 Discussion

In table 7.1, a comparison between the different integration technologies in-terms of the support they provide is presented. The table compares the support given by the technology to communication, coordination, patient centric treatment through ICPs, and evolutionary prototyping.

Comparison Aspect	**IOCN/ NHIS**	**SOA**	**ERP**	**WFM/ BPM**	**Smart Card**
Communication	✓	✓	✓	✓	✓
Coordination	Partially	✓	✓	✓	Partially
Patient-Centric via ICP	X	X	✓	✓	Partially
Evolutionary Prototyping	X	✓	X	✓	✓

Table 7.1: Comparison between Integration technologies.
Key: a '✓'means supported, 'X'means not supported and 'Partially'means limited support for this aspect.

Communication can be supported by all the technologies, while coordination is supported by all the technologies either fully or partially (i.e. no explicit support for coordination is supported but it can be implemented). In terms of the support for the patient-centric care through following an ICP, only ERP and WFM/BPM can support this aspect. This is achieved by supporting the treatment stages and the progression between stages as determined by a patient's current

state. Evolutionary prototyping is the last element compared. It shows whether the technology could be evolved to retain local autonomy or whether new systems need to replace these systems which have the same facility. This tables shows that only an approach based on WFM/BPM will be able to meet all the aspects.

Examples of these approaches/tools which require technology integration were excluded. This is because legacy systems are heterogeneous which means that technology integration is extremely difficult and in some cases impossible. Tools falling in this category are: IOCN, NHIS, and ERP. Moreover, as the main challenge in this research is the distribution of CISs, tools that are not mainly meant for distributed systems were excluded. Although SOA supports information exchange in a loosely-couple, domain-independent environment, its strength is in its inter-operability rather than distribution. SOA mainly focuses on providing services that can be enhanced and the data can be over written when replaced. Medical data within the healthcare domain does not change and it is accumulative which requires a tool that brings the data to a potential user rather than a service. Therefore, SOA was excluded in the selection. Smart cards were also excluded as they are only suited to the provision of medical information which limits the functionality that can be provided using this approach. This limited the choice of technology to WFM and BPM.

7.4 Selection Process

By studying the characteristics of healthcare systems and the limitations inherent in the implementation of ICPs, we identified that integration at the application level, automation, process management as well as bottom-up implementation are the main requirements for the system. WFM and BPM seemed to provide appropriate support for the distribution and heterogeneity aspects, as these tools offer:

- Domain independence, which widens the choice of systems [168].
- Process-centric, which is appropriate for the main part of the patient's clinical pathway which defines its processes by diagnosis and treatment.
- Support for distribution.
- Support for heterogeneous and autonomous environments - the usual situation in healthcare systems.
- Bottom-up system implementations. This fits well with the decision to evolve existing systems rather than propose a new system [156].

Further investigation showed that BPMS is a significant extension of WFMS, offering more sophisticated build-time and run-time diagnostic capabilities and wider capabilities for EAI and B2B integration [171]. Thus, WFM and BPM are used interchangeably throughout this research. This is because when we refer to WFMS it is as Business WFMS with specific specifications (for a fuller explanation, see section 8.2). In practical terms, we will be considering a software system that supports the identified problem domain and the project's goals will determine, whether the decision moves toward BPM or WFM. These tools were chosen, as they:

- provide tools and techniques to manage and control the entire treatment pathway. Basically, an ICP can be mapped to a workflow, by a mapping in which: processes represent diagnoses and treatments, paths represent the flow of treatments, routing decisions represent the clinical decisions on treatment and diagnosis (which we refer to as the change points) and finally the multi-professionals represent the different roles acting in the system.
- provide the facility to track and trace each case in a treatment pathway separately.
- can be run as an EAI platform which ties together the applications and manages the overall process, as well as being a hidden embedded engine inside the separate application systems to evolve the system process [172].
- enable evolutionary implementation to facilitate evolving the current CISs rather than wasting resources in developing new systems.
- have been shown to support distributed work units [173, 174].
- are flexible in supporting dynamic processes but limited to pre-defined logic. This means the tool is adaptive to the individual patients along their treatment pathway.

7.5 Workflow Technology in Healthcare

Workflow technology has been widely used in the healthcare domain. Projects presented in the literature include:

- **Managing End-To-End OpeRation (METEOR) system [32, 175]:** WFMS is used as a tracking system of children's immunisation. It tracks immunisation and supports interaction between Connecticut Healthcare Research Foundation, healthcare organisations in the area, and user organisations (such as schools and social services). It also sends alerts within the system, works as a reminder and generates reports for the state. METEOR

was implemented at the Large Scale Distributed Information Systems (LSDIS) unit at the University of Georgia, Athens, GA, USA.

- **Woflan 2.0 diagnosis tool [33]:** is used as a catalog for definitions of diagnosis. This catalog can be put into production at a later stage. It is used by the engine of a workflow process definition to find and correct errors in diagnosis. Woflan 2.0 was implemented by the Department of Technology Management, Eindhoven University of Technology, Netherlands.

- **AGENTWORK system [34]:** a WFMS that supports a rule-based approach for dynamic and automatic adaptation to exceptions. It uses temporal estimates to determine future exceptions and predict suitable adaption. This is to minimise the user interruption along the flow process. AGENTWORK demonstrates its usage using a drug administration system. This includes the drug and dosage and shows how the system handles exceptions within the flow. AGENTWORK was implemented by the Department of Computer Science, University of Leipzig, Germany.

- **PruHealth BPM [35]:** is software launched in South Africa and the US to extend the health insurance service that can be provided. The aim of the BPM extension of PruHealth is to improve the process for managing appointments with partners, tracking usage, and preparing corporate invoices in addition to automating the process for receiving, validating, reconciling, and routing electronic claims for assessment. It encourages customers to look after their health and be rewarded for their efforts by collecting vitality points according to their activities.

- **Prescribing Information and Communications System (PICS) [176]:** is developed by the team at the University Hospital Birmingham. The system reminds the staff to give patients in the ward their medications. It uses a rule-based system which can be customised by the different staff roles according to their needs. We suspect it is a WFMS. Recently on the BBC, it was announced that using this system can prevent 16,000 deaths a year caused by missed medications [177].

- **SIEMENS^{TM} BPM Medical Solutions [178, 36]:** SIEMENS^{TM} provides system solutions for aspects of healthcare. These are used across the world for complete solutions as well as services and consulting. A BPM tool has been used in some of their solutions. Examples are:

  - *Bed management [179]* system. This is a WFMS to implement the tasks associated with bed placement. It supports online bed requests, work-lists, and an on-line screen for bed status. It also interacts with different communication tools including e-mails, pagers and telephones. This increases efficiency in bed turnover, and

resource utilisation. Cape Fear Valley Health hospital in California, USA [180] is one of users of the SIEMENS™ Bed Management solution. They found the system a very useful tool which helped automate the bed allocation process and therefore increased the efficiency of bed usage in the organisation [179].

- *Soarian Quality Measure [181]:* is a WFMS tool that provides quality management data and measures. It is used by the different users including clinicians and hospital executives to view, understand and interpret the different quality indicators. Denver Health and Hospital Authority in Colorado, USA [182] is a Soarian Quality Measures customer who confirms that the system provides quality indicators which can help improve quality of care [181]. Reading Hospital and Medical Centre in Pennsylvania, USA [183] is also a system user who believes that the system reduces the dependency on manual quality measuring techniques, and so improves accuracy and speed in calculating the measures[181].
- *Soarian Financials [184]:* is used for finances. This includes contracts, a master person index, and a claims index and editor. It supports informed decision making, and creates more efficient business practice. The University Hospitals Case Medical Centre in Cleveland, Ohio, USA [185] is one of the customers of the SIEMENS™ Soarian Financials who found it improves operational efficiency and effectiveness, and reduces errors and rework [184].

Other researchers have also proposed different usages of WFMS/BPM technology in the healthcare domain. These usages include: medical data analysis [186], medical data access control [187], exception handling [188], advance drug trial verification of business rules [189], and alerts in mobile healthcare applications [190]. There are other proposals such as phones and voice mails [191].

7.5.1 Computerisation of Workflows and Guidelines in Healthcare

A number of researchers have looked explicitly at process modelling and the computerisation of workflows and clinical guidelines [192, 198, 199, 200, 193, 194, 195, 196, 197]. Examples of these researches include:

- {M} [1] Muscholl [198, 199] proposes an architectural model to support a standardised reference model for clinical guidelines and interchange among distributed CISs. The {G} Guideline Interchange Format (GLIF) [200] and workflow reference model published by

[1] This code is used in table 7.2 to identify the row referring to this research in the table

WFMC [201] are similar projects to Muscholl, in that they aim to unify the rules among multiple systems by designing a suitable architectural model. These projects demonstrated the benefits of having an automated common reference model in this domain. However, they did not go beyond the model and discuss how practically the model could be implemented.

- {K} Knape et al. [193], focus on the need to facilitate the use of clinical guidelines. This research proposed an approach which transforms narrative clinical guidelines into a UML model, which then could be translated into an XMI (XML Metadata Interchange) representation, which can be used to build appropriate information systems. This research shows the need to have guidelines attached to clinical decision systems for adaptive support. However, it does not look practically at how this approach could be implemented. Similarly, {P} Peleg and Samson [194], propose a template which could be used to translate narrative guidelines to produce a representation which could be used electronically to create suitable information systems.

- {Ma} Mans et al. [195], propose a framework called Proclet to model the gynaecological oncology care process. They compare the proposed framework with other modelling techniques and present how it advances this support to real-life scenarios. The research compares the modelling techniques in-terms of their granularity and concurrency support for different interactions. Again, this is a modelling approach which does not describe an implementation approach.

- {A} Alexandrou et al. [196], propose a prototype which supports real-time adoption of the healthcare processes. It comprises a process execution engine assisted by a semantic info-structure. Although this research uses similar tools to those proposed in our approach including: clinical guidelines and workflow technology, the focus is different. In our research we focus on supporting the communication and coordination among care team members as an important goal in the implementation of the treatment process. Alexandrou's prototype [196] focuses on supporting continuous change in the treatment process as its main goal.

- {H} Huser et al. [197], use an open-source WFMS to support clinical decision making based on clinical guidelines. This research uses similar tools to those suggested by us but focuses on different aspects of the treatment process. In our approach we look at the support for communication and coordination along the treatment pathway. This means we look at decision points but unlike Huser's approach where this is the focus, in our work it is part of the process being implemented.

In order to position our work against these different approaches, we need to look at their support for: communication, coordination, ICPs, and workflows. These are the basic elements of our research and are the difference between their approaches and the approach we propose. Table 7.2 analyses the support for these different elements for the system discussed here.

Approaches	Communication	Coordination	ICP	Workflow	Implementation
{M} [198, 199]	✓	✓	✓	X	X
{G} [200]	✓	✓	✓	X	X
{K} [193]	✓	✓	✓	X	X
{p} [194]	X	✓	X	✓	X
{Ma} [195]	✓	✓	✓	X	X
{A} [196]	-	-	✓	✓	X
{H} [197]	-	-	✓	✓	X

Table 7.2: Analysis of Different Approaches.
Key: a '✓'means facility, 'X'means not facility and '- 'means not mentioned as a goal.

7.5.2 Discussion

Projects proposed in the literature which use workflow technology in the healthcare domain, mainly support a very focused task which is a stand-alone solution. Although they promote flexibility and adaptability as key benefits, the functionality they promote are very limited and are to be used at a single department or organisation. These projects are mainly proposing administrative tools which do not consider the support for patient-centric care. These are clearly distinguished as being different from the concept proposed in this research where the system is aimed at supporting the care team's work as the patient proceeds along an ICP.

The different projects that use workflow technology confirm the capabilities of such a tool and the benefits it provides to the processes implemented. These projects confirm its flexibility, adaptability, scaleability as well as its ability to automate processes, handle exceptions, and interact with humans and machines.

Table 7.2, shows that even projects that focus on computerisation of workflows and clinical guidelines do not actually take their approaches beyond the models or simply do not address the uses which were the focus of this research, namely the support for team communication and care coordination. A systematic survey on computerisation of workflows, guidelines, and care pathways published in 2012 [192], identified 108 different research projects in this area. It classifies the different approaches as:

- Electronic healthcare record integration,
- Clinical workflow integration and point of care, and
- System implementations: knowledge models, software, and architecture.

Our approach focuses on the second and third of these areas. We studied the clinical workflow integration and the support it could provide for decisions being made at the point of care, as well as creating an architecture coping with existing legacy systems.

In terms of Implementation, none of the projects that implements clinical guidelines into a workflow engine focuses on support for the treatment process by supporting team communication and care coordination. while in terms of architecture, none of the projects using workflow technology addressed the need for independent tools that interact with legacy systems. Moreover, none identified the resulting system as a tool that evolves these systems and enhances their functionalities. The vision of constructing a VO around the patient needs for patient-centric care is also novel.

Chapter 8

Workflow: Terminology and Concept

Overview

In chapter 7, workflow technology was selected as a suitable tool to support the research problem specified in chapter 6. Literature review showed that there are different workflow types and therefore different types of system are available. This chapter presents the study undertaken to identify the specification of the workflow system type that gives the best support for the problem domain. Moreover, a selection process was conducted to choose a WFMS for the proof-of-concept prototype.

8.1 Introduction

The following sections describe workflow technology. It explains related terminologies, workflow types, type of flows, patterns, and WFMS types. This will be followed by an introduction to different WFMSs and a comparison between them. This concludes with a list of the characteristics of a WFMS's engine that best suit the problem domain. According to the specified characteristics, a system is then selected to be used in implementing a prototype to meet the project's aims.

8.2 Workflow Terminology

Some of the terminologies and concepts associated with workflow technology will be briefly introduced in the following sections and also the relationships between the different terminologies will be presented in figure 8.1.

8.2.1 Workflow

A workflow is the sequence of steps or processes from initiation to completion through which a piece of work is accomplished. The steps can be industrial or administrative or any other type of process. The WFMC defines workflow as:

"The automation of business process, in whole or part, during which documents, information, or tasks are passed from one participant to another for action, according to a set of procedural rules" [2].

8.2.2 WFMS

Initially, the pattern and design of a workflow was coded into applications to execute the business flow logic of an organisation. With the evolution of the computer, information and object-oriented technologies, nowadays WFMSs have been widely implemented to support distributed work units through use of a workflow engine [174, 173]. The WFMC defines a WFMS as:

"A system that defines, creates and manages the execution of workflows through the use of software, running on one or more workflow engines, which is able to interpret the process definition, interact with workflow participants and, where required, invoke the use of IT tools and applications" [2].

8.2.3 Business Process

According to [202], the activities in organisations can be: material processes where physically humans move things from one place to another to perform an action; Information processes where techniques of data processing are used in a networked environment for valuable information processing; and/or business processes, where roles and acts get involved in the process. In practice, business processes usually get implemented in information processes with some sort of data processing. Information processes are then implemented as material processes where manual processes can be involved.

Business processes generally can be described as the flow of procedures or activities that are undertaken to perform a certain task or service. There can be one or more activity(s) in a business process but they are usually restricted to a certain role in the organisation and each role is restricted to specific actions. Moreover, activities in a business process usually require an input which gets processed through a method to produce an output [2, 174, 202, 203].

8.2.4 Process Definition

A process definition is linked to pre-defined roles of the business process flow which sustain and support the execution of the workflow logic by a WFMS. It also includes accurate information about routing conditions, inputs, and outputs as well as authorised users, data to be used, and the invoked IT resources of every single activity in the workflow [2, 174, 204].

8.2.5 Activity (Process)

Activity in a workflow is the piece of work that forms a logical step to perform the business objective. It can be either a manual or automated step and can use a resource such as data, web services and/or a computer application [2].

8.2.6 Instance

An instance is a representation of a single enactment of a case [2]. It can be an instance of a process or an activity within a process. It also includes its linked data which can be internal or external variables. These variables define the state and value of an instance. Each instance represents a unique case which is executed and controlled separately [2].

8.2.7 Discussion

In this project the workflow terminology represented in figure 8.1 is mapped as follows:

- The ICP represents the *business process*, it defines the general guidelines which should be followed in the treatment path of a patient. These general guidelines are managed by a *workflow management system*.

- Within the clinical guidelines there is more details of the treatment stages which are included in the *process definition*. For each patient, a unique version of the process definition is created. These stages represent what actually happens in the *process instances*. These are managed by a WFMS.

- Each of these treatment stages are undertaken as different steps in the workflow, each of which represents an *activity*.

- Activities within the treatment flow can represent a *manual* or an *automated* activity. When an activity is activated for a certain patient, it creates an *activity instance* of the patient's process instance.

- An activity instance which is a single step within the treatment journey of a patient can represent a *work item* that is allocated to a workflow participant or an *invoked application* which can be a legacy system or an automated tool as appropriate.

8.3 Workflow Types

There is no specific classification of workflow types. Some researchers classify workflow types according to the application domain, as administrative, productive, collaborative and ad-hoc [205, 17, 206]. Another classification of workflows, used by some researchers, is according to the flexibility they offer in presenting the organisation's processes. Figure 8.2, shows the workflow continuum according to flexibility where it varies from ad hoc workflows with unstructured information and passes through to processes (unique path for each situation), to standard workflow where the process is structured [17]. Other researchers classify workflows from an implementation point of view according to its process orientation as follows:

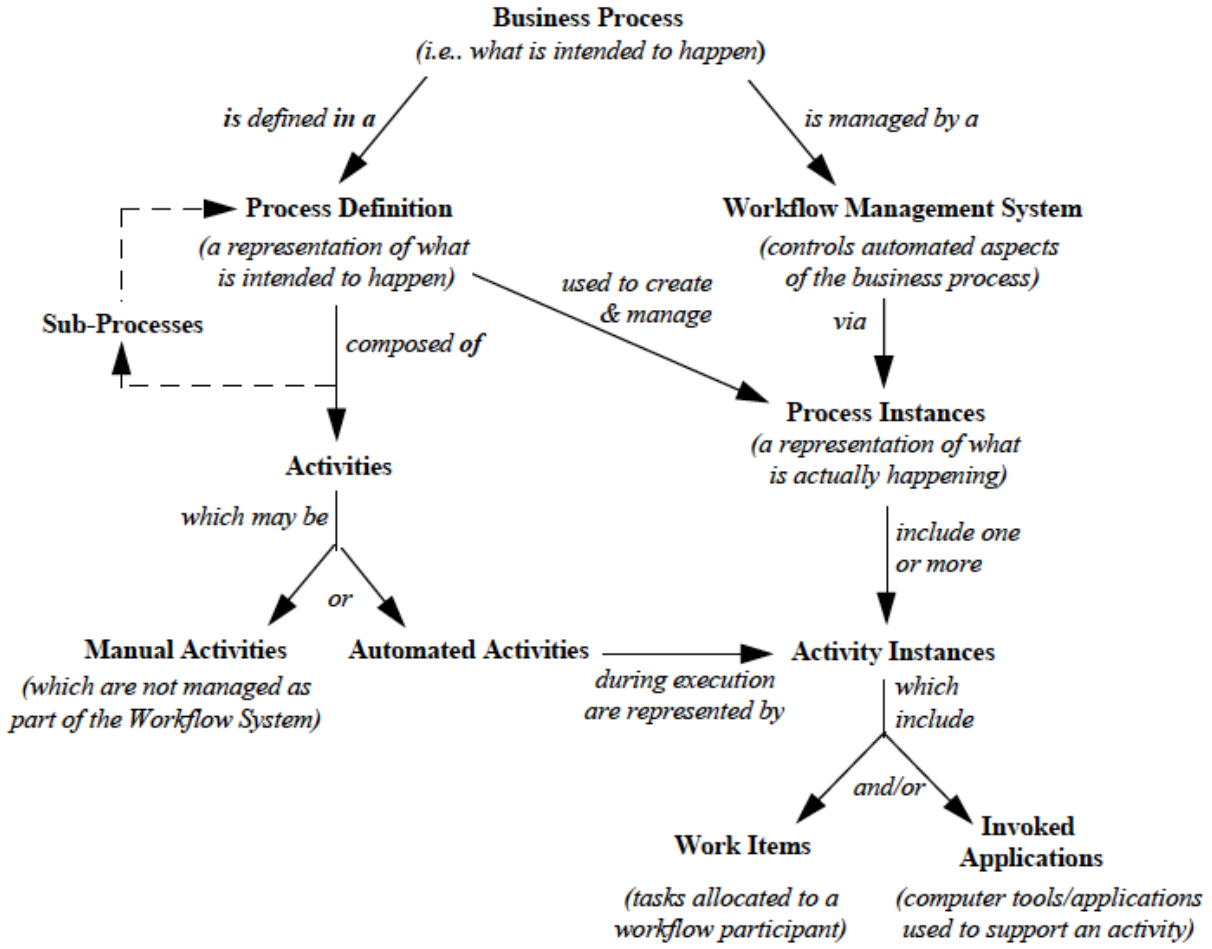

Figure 8.1: The relationship between basic workflow terminologies [2].

8.3.1 Activity-based Workflow (Activity-Oriented)

In activity-based workflows, the centre of the processes is the activities. To perform a certain business process a number of activities have to be processed and after executing a process the next process will run according to the process definition. Each process in this type can be restricted to a certain role and can be manual or automated [203, 205, 207].

8.3.2 Communication-based Workflow (Entity-Oriented)

In communication-based workflows, the main concern is the commitment between the processes [203, 205]. It is about what the processes require from each other in terms of data and its state. The process receives the data as an input, processes it and produces an output which will be used by the next process. All the processes in this type are centred on data moving between

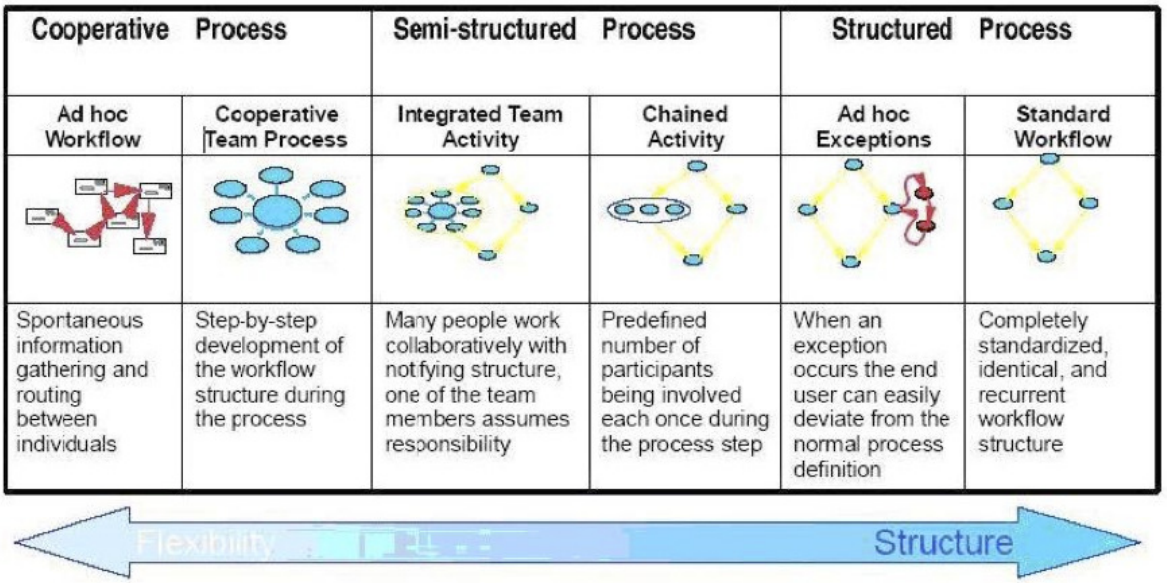

Figure 8.2: Workflow Continuums [17] .

processes, and the final data or information required comes from the last process in chain [207].

8.3.3 Discussion

If the process is to be classified according to figure 8.2, the ICP can be represented as an *integrated team activity* in a *semi-structured process* if a healthcare provider (such as a GP) is taking responsibility for notifying the other involved healthcare providers. The ICP can also be represented as an *ad hoc workflow* in a *cooperative process* if the flow is to be completely flexible.

The ICP represented as a business process is what needs to be managed by the WFMS. This will be via the treatment stages which represent the process instances. The activities within the treatment stages are mainly actions that need to be processed to support the working practice of the healthcare provider. This will also include invoking applications, performing automatic actions, or allocating task(s) to user(s). This means the main stages of the ICP are activities and therefore an activity-based engine is required. Although, human interaction is also a core part of this process, the different activities are not mainly concerned with passing information from one to the other. However, these activities aim to allocate and gather the information available in the different systems and ensure their availability at the point of care to the user.

8.4 Types of Flows

According to Dickson " (a) flow is a directed relationship that transmits an event from a source activity to a sink activity between the business partners" [208]. He also classified the flows in a large scale B2B information system as five elementary flows namely: control, data, semantic, exception and security [208].

The security and exception flows, are flows which occur for either security or exception reasons. Here, we also distinguish between the expected exceptions, which the system covers in its process definition and the un-expected exceptions which the implementer did not consider (usually technical problems) [208]. The control, data and semantic flows are explained briefly in the following sections:

8.4.1 Control Flow

Many researchers in workflow systems consider control flow and mention it in their reports [209, 206, 208]. In WFMSs the control flow maintains the workflow logic [208]. It determines which process is to be processed next and executes it. In addition, the control flow checks the pre-defined business rules and according to the current state it moves to the next process. Mohan sees the use of control flow as very similar to a programming language where pre- and post- conditions as well as dependencies and other external issues control the flow of tasks [17].

Control-flow in the healthcare scenario is required to maintain the treatment progress. These controls should be according to the national clinical guidelines, represented in ICPs. It is the driver of the flow according to the given elements which is unique to each patient. The control flow in the healthcare scenario is needed to support the decision making process without taking over the control. This is important as the decision making process should always be by the system user or the healthcare provider. However, control-flows can drive the automation of manual processes which does not require user interaction.

8.4.2 Data Flow

Data flow is also considered by many researchers in workflow systems [209, 17, 208]. It is concerned mainly with the circulation of the data around the different processes to produce the final processed data [208]. The focus here is the data - what data is received and what data should be produced. The passing of the data can be by value or reference and in both cases data security and perseverance storage management should be considered [17].

Data-flow is also required in the healthcare scenario to pass patient related information; as a value or a reference. This is to relate all the activities to a particular patient as the treatment progresses. It aims to provide a context to the flow, so as to associate activities to patients and to keep track of these stages. The data flow can be used to identify a patient's medical information within the legacy systems and retrieve this data as well as to record changes as the patient's care progresses.

8.4.3 Semantic Flow

Semantic flow is a high level concern as it abstracts the relationships among the information that passes in a workflow system [208]. It is at a high level in the hierarchy of the workflow processes as it helps understanding of the overall processes but does not include any of the details involved in the processing. This element is used to give a meaning to the workflow process. This is through linking roles and actions to the overall processes and the active instance.

Semantic flow is directly linked to the treatment stage processing. This needs to be included to relate the treatment stage to the ICP being followed. The use of semantic flow is essential when managing the treatment of patients following multiple ICPs, such as a patient following the breast cancer and the diabetes ICPs. Here we need to link each stage to the treatment it supports. This is then used with the data flow to retrieve information from legacy systems as well as record the treatment progress. The semantic flow helps pull meaningful information to be used by the team members for informed medical decisions, such as:

- medical problems a patient has,
- healthcare providers involved in each of these medical problems, and
- current and next treatment stage in each of a patients medical problem.

8.5 Workflow Patterns

The area of workflow patterns was an initiative by Will van der Aalst, a professor intensively researching workflow management, and Arthur ter Hofstede in 1999 [210, 211]. Its main aim is to provide a conceptual foundation for process technology [210]. It provides a tool to evaluate different perspectives that occur in a workflow system according to the needs of the application it models. It also can be used as guidance for the design and development of WFMSs. The

different perspectives in workflow systems are, control flow, data, resource and exception handling [210]. Patterns describe the permitted flow of these different perspectives e.g. sequence, parallel split, synchronisation, and exclusive choice. [210, 212].

A variety of workflow patterns are required to implement an ICP. Parallel processing is required when a patient follows multiple ICPs. Within a single ICP, an example of a parallel pattern would be a number of tests that can be taken simultaneously before a clinical decision is made. An example of a split pattern, is a decision point where a number of alternative paths could be taken according to the decision made. Synchronisation is needed when meeting a condition is required before processing the next step. An example of this, is a delay of a certain number of days between two treatments. The flow of data and controls is required in different directions and there is a need to take different perspectives to drive the flow of these patterns. The implementation of the different patterns if it is not supported by the WFMS implementation within the tools should be allowed by other means.

8.6 WFMSs Types

There are a considerable number of open source WFMSs as well as commercial ones. By looking at the different features and usages of WFMSs, we see that they can be classified into two types - scientific and business [213, 214].

8.6.1 Scientific workflow

Scientific workflow is a virtual representation of a scientific experiment and these are usually modelled to analyse scientific data. They are widely accepted in bioinformatics [215] and cheminformatics [216] where they were introduced in the early 2000s. Most of the scientific workflows are communication-based and data-driven. They mainly concentrate on what data the next process requires from the current process, and then the data is sent to the next process according to pre-defined algorithms which prepare it for the next stage [217, 218].

8.6.2 Business Workflow

Business workflow is a virtual representation of tasks that represent a business process. These tasks can be applications, human decisions, and/or automatic activities. Its origins started in 1970 when paper-based tasks started to move to computer-based implementation. Most business workflows are activity-based and control-driven. They mainly involve different actions that can

be taken with a control flow. The system decides on the next route to be taken according to pre-defined algorithms.

A business workflow is needed to support an ICP. An activity-based WFMS is required to support treatment stages and their linkage in the ICP, as it involves human interactions along the process pathway and access according to defined roles for the next stage.

8.6.3 Summary of Required Characteristics

The following is a summary of the required characteristics in the WFMS to support the ICP:

- *Activity- based Workflow*: where the focus of the process is the activities. In healthcare systems all the processes or the stages the patient goes through for treatment should be modelled in the workflow management system. These different activities are assembled as the main blocks of the system in the pathway.

- *Control Flow*: this is usually coupled with activity-based workflows. In the workflow system representing a healthcare system the flow between the different activities will be the main control elements, they will examine the current state of the patient treatment and use this to decide what should be the next path according to pre-defined rules.

- *Data Flow*: this is needed to relate each case to the patient. This is very important as information referencing the patient record should be associated along the treatments flow to relate the running process to the patient, to achieve a patient-centric approach.

- *Workflow Patterns*: these are required in healthcare system and should be provided by the workflow management system. Otherwise it will not be possible to implement this aspect.

- *Business Workflow*: this is required to model the large number of processes in a healthcare system. Human interaction with the system is necessary in healthcare systems where different care team professionals interact with the system and support the decision making and as a result the routing within the pathway. Also assigning activities to different roles or sometimes identified members within that role, is associated with the human interaction. This is also a major element that must be supported in a healthcare system as it supports security and privacy. Also, setting timers to do alerts and activate activities is a factor that should be considered and is often a major factor in a healthcare system.

8.7 WFM

There are a huge number of WFMSs available. Some of these are commercial like: WebSphere MQ Workflow [219], TIBCO [220, 221], Ultimus [222], COSA BPM [223] and Alia Systems [24]. Others are open-source or research prototype workflow management systems like: Kepler [224], Taverna [225], Triana [226], JBPM [227], Werkflow [228] and OSWorkflow [229].

8.7.1 WFMSs

In order to choose a WFMS for this project, a study of the available workflow systems had to be done. In this section some of the WFMSs considered will be introduced and a comparison between them will be presented. The comparison will give the basis for choosing the WFMS that best suits the healthcare systems domain we are considering. The following is a brief description of the systems considered in this research. These were considered as tools that can be used to implement a proof-of-concept prototype, customised to the needs of the ICP.

Kepler

Kepler [224] is an open-source WFMS. It was developed at the University of California [230], USA. Kepler is funded by many institutes, including the US National Science Foundation [231], the US Department of Energy [232] and by the US Defense Advanced Research Projects (DARPA) [233]. Its main aim is to allow scientists to build scientific workflows and execute them. Kepler's engine is based on distributed computing techniques [224]. Kepler was included in the comparison because it is well used in the US and also it is an open-source software system easy to access and try.

Taverna

Taverna [225] is an open-source WFMS. It was developed by a team from the University of Manchester [234] and the European Bioinformatics Institute (EBI) [235] led by Tom Oinn. Taverna is funded by the Open Middleware Infrastructure Institute UK (OMII-UK) [236] and my Grid node [237]. Its main aim is to assist scientists to use workflows and distributed computer technology [225]. Taverna was chosen because it is well used in the UK and also because it is an open-source software system.

Triana

Triana [226] is an open-source WFMS. It was developed by Cardiff University [238] and funded by GridOneD [239] and GridLab [240]. Its main aim is to provide a tool to build and analyse programs based on workflow technology [226]. Triana was chosen because it is open-source software and is built by our colleagues at the school. This means a lot of technical and theoretical support can be provided by the developers as this team is local in our research school.

Stateframe

Stateframe [24] is a commercial WFMS. It is developed and funded by a privately owned UK-based company, Alia Systems Ltd [24]. Its main aim is to provide a tool to build business process workflow systems [24]. Currently called a BPM solution since its functionalities have been extended over the years. It also provides the facility to control and manage each case separately. Alia was chosen as the author had pervious experience with the tool during her MSc project [241] and its providers had/ will provide the required support during the development.

JBOSS (JBPM)

JBPM [227] is an open-source WFMS created by community developers. Its main aim is to provide a tool to model business processes that takes account of and coordinates the inputs between people, applications and services in a workflow application [227]. JBPM was chosen because it is open-source software and because it models business processes and supports distributed technology. This is different from what the other chosen systems do, as it is the only open-source business WFMS.

8.7.2 Comparison between WFMSs

A comparison between the different WFMSs was undertaken in order to choose the most suitable for the healthcare system under consideration. In order to do the comparison, the different software systems were installed and tested. The Digital Enterprise Research Institute (DERI) [242] identified, in a technical report, the different aspects for comparison of workflow systems. The key aspects mentioned in the report were investigated in each of these WFMSs. These different aspects are: organisational, availability, portability, functional, operational, behavioural, informational, and security.

The different aspects are important in different stages in the process of installing, implementing and running the system. Some of these aspects are considered by the developers while others are considered by the users and the rest are of the organisational system requirements. These include the requirements of the ICP and its implementation.

Organisational Aspects

The organisational aspect is a key aspect which defines the responsibilities in a workflow system [242]. It considers system requirements and how they should operate. Elements such as human involvement and setting timers are considered in this aspect. It is one of the important aspects that should be considered when choosing a workflow management system for a certain application.

Human interaction is a vital element of the ICP. The human interactions are conducted by the healthcare providers who operate within the system as they care for their patients. There actions mainly include undertaking medical decisions, retrieving and recording data. Setting timers is also an important aspect at some stages within the treatment flow, which has time constraints. It is beneficial to ensure care continuity of patients and control follow-ups. Table 8.1 compares these aspects between the different WFMS.

Organisational Aspect	Kepler	Taverna	Triana	Stateframe	jBPM
Human interaction			✓	✓	✓
Setting timers				✓	✓

Table 8.1: Organisational aspects of different WFMSs.

Availability Aspects

The availability aspects are mainly defined by the environmental perspective. When we discuss the availability aspects we find it a matter for the developers. These covers ease of installation, need of computing background and need of coding. It is also an organisational matter when we discuss the cost.

The availability aspects are not directly related to the requirements of the ICP and its implementation. Table 8.2 compares the availability aspects in the different WFMSs.

Availability Aspect	Kepler	Taverna	Triana	Stateframe	jBPM
Open source	✓	✓	✓		✓
Can be used by users with limited computing background	✓	✓	✓		
Can be used by users with limited technical resources and support	✓	✓			
Ease of installing the software	✓	✓	✓		
No coding required	✓	✓	✓		

Table 8.2: Availability aspects of different WFMSs.

Portability Aspects

The portability aspect is also defined by the environmental perspective. It is an issue that matters to the users and the organisation in terms of what is required to run the system at the user's end.

These aspects do not directly relate to the requirements of the ICP and its implementation. However, these are technical issues which are significant. When comparing this aspect, all systems were able to run on any operating system such as PC, Mac and Unix except Stateframe and jBPM.

Functional Aspects

The functional aspects are one of the aspects which defines what can be done in the workflow [242]. It covers the functionalities that are provided by the WFMS including the level of complexity the system supports, the ability to combine the system with distributed technology, the availability of a library and finally if it supports logical conditions and iterations. Developers need to make sure of the availability of functionality that meets their requirements for the system to be developed, and the ability to customise existing processes or build new ones if aspects are missing.

The functional aspects that are required are mainly dependent on the requirements of the implementation of the ICP. These aspects represent the functionalities that are provided by the WFMS during the implementation of the system. The choice is then made according to the importance of each of these functional aspects to the treatment flow progress. Aspects that are required by the ICP and not supported should be implementable by other means into the selected system. Table 8.3 compares the functional aspects in the different WFMSs.

Functional Aspect	Kepler	Taverna	Triana	Stateframe	jBPM
Construct complex analysis	✓	✓	✓	✓	✓
Based on distributed computing techniques	✓	✓	✓		
Ability to combine with web services	✓	✓	✓		✓
Locate services on local machine	✓	✓	✓		
Locate services on remote machines	✓	✓	✓		
Extend existing component	✓	✓		✓	✓
Library available	✓		✓		✓
Ease of use interface	✓	✓	✓	✓	
Ability to build hierarchal workflow	✓	✓		✓	✓
Ability to progress individual objects				✓	
Include iteration	✓	✓	✓	✓	✓
Include logical conditions	✓	✓	✓	✓	✓
Support Rapid Application Development (RAD)			✓	✓	

Table 8.3: Functional aspects of different WFMSs.

Operational Aspects

The operational aspect is a key aspect which defines the workflow operations [242]. It covers the capabilities of the system and includes database access, level of visibility, results representation and the ability to monitor the progress of the processes. These aspects are important to the users of the system and some are organisational/environmental requirements like the database connection.

The operational aspects that are required are also dependent on the requirements of the implementation of the ICP. These actually present the functionalities that the system will support once implemented. The choice is then made according to the importance of each of these operational aspects to the treatment flow progress. Aspects that are required by the ICP and not supported should be implementable by other means into the used system. Table 8.4 compares these aspects among the different WFMSs.

Behavioural Aspects

Behavioural aspect is another key aspect. It mainly defines the process perspective; the different activities, their execution order and whether they are atomic or composed [242]. It represents the type of workflow and what it is centred around - communication or activity (see section 8.3). Therefore, it is mostly dependant on the business rules representing the tasks supported.

Operational Aspect	Kepler	Taverna	Triana	Stateframe	jBPM
Access external data	✓	✓	✓	✓	✓
Run on user's data	✓	✓	✓	✓	✓
Use different kind of data	✓	✓	✓		
Ease of transport and track data		✓		✓	✓
Use backing hardware of remote components	✓	✓	✓	✓	
Case management				✓	✓
Ability to monitor the progress of the processes		✓		✓	✓
Run on web client				✓	✓
Guide user through steps				✓	✓
Visibility of model	✓	✓	✓	✓	
Change visibility level		✓			
Present the result in textual format	✓	✓	✓		
Present the result in non-textual format	✓	✓	✓		
Save result as text	✓	✓	✓		
Save result as image	✓	✓	✓		
Save result as XML		✓			

Table 8.4: Operational aspects of different WFMSs.

This feature has been fully discussed in sections 8.3. Moreover, the need for an activity based system to support the implementation of the ICP has been clearly stated in section 8.6.3. Table 8.5 shows the support for communication, activity, and OO approaches in the different systems.

Behavioural Aspect	Kepler	Taverna	Triana	Stateframe	jBPM
Communication-based	✓	✓	✓		
Activity-based				✓	✓
Object-oriented	✓	✓	✓	✓	✓

Table 8.5: Behavioural aspects of different WFMSs.

Informational Aspects

The informational aspect is a key aspect which defines the data and data flow perspective. It looks at the different flows that can be passing between activities in a workflow system (see section 2.1.3). The informational aspect and the behavioural aspect are very closely related in that usually data flow is coupled with communication- based systems while control flow is tied with activity- based workflow systems.

The informational aspects have been discussed in section 8.4. Also the need for data and control flow to support the implementation of the ICP has been clearly stated in section 8.6.3. The informational aspects are compared among the different systems in table 8.6.

Informational Aspect	Kepler	Taverna	Triana	Stateframe	jBPM
Data flow	✓	✓	✓		
Control flow		✓		✓	✓

Table 8.6: Informational aspects of different WFMSs.

Security Aspects

The security aspect depends on the organisational needs. Security can be a dominant requirement for some systems while it is not even an issue to be considered in others. One of the ways of securing the system is setting rules to be met for access to the system where each task could be restricted to certain rules and even roles within those rules.

This is a very important feature that is associated with the business- workflows, as they allow human interaction. Here the roles and rules as well as the security constraints in term of access are identified. This is an important aspect required for the implementation of the ICP as at the different stages along the treatment, different healthcare providers get involved. Moreover, information along the treatment progress are targeted to a certain role and should be viewed only by this person. This is in addition to the multiple system across the multiple organisations that are involved and therefore the security constraints that need to be placed. The availability aspects to support security settings, rules and roles is shown in table 8.7.

Security Aspect	Kepler	Taverna	Triana	Stateframe	jBPM
Rules and roles				✓	✓
Security				✓	✓

Table 8.7: Security aspects of different WFMSs.

8.8 System Choice

We specified in section 8.6.3 the required characteristics in the WFMS to support the ICP. We then compared different WFMSs in different aspects in section 8.7.2. At this stage, we need to select a WFMS to use in the implementation of the proof-of-concept prototype.

According to sections 8.6.3 and 8.7.2, we need a WFMS that supports the behavioural aspect, is activity-based, the informational aspect to be data and control driven, and the functional aspect to support workflow patterns. Consequently, the paradigm is of a business workflow supporting human interaction and setting timers as organisational aspects and supporting roles and rules as well as security as security aspects.

Stateframe and jBPM are the only systems within the studied WFMSs that support activity-based (see table 8.5). These systems also support the control flow in addition to Taverna (see table 8.6). Data flow is supported by Kepler, Taverna, and Triana only (see table 8.6). This means none of the systems are activity-based, data and control driven. However, Stateframe and jBPM can manually support data-flow. This limits our choice to Stateframe and jBPM when comparing the behavioural and informational aspects.

In the comparison of the functional aspects (in section 8.6.3), workflow patterns were discussed. These include constructing complex analysis, building hierarchal workflow, including iterations, and including logical conditions. These were all supported equally by all the systems except Triana which did not support building a hierarchal workflow (see table 8.3). This is particularly important to ease the implementation of the complex process in ICPs. Functional aspects concerned with locating and using services are not one of the main requirements of this project. Aspects such as the ability to progress individual objects and the support for RAD are important. Table 8.3 shows that only Stateframe supports these features. This makes Stateframe preferable at the functional level.

Finally, we stated in section 8.6.3 that we need a business workflow. This is to support human interaction and security constraints. Table 8.1 and table 8.7 shows that Stateframe and jBPM are the only systems that support these two aspects combined.

The Choice of a WFMS

At this stage, the choice is limited to Stateframe [24] and jBPM [227]. As they are both business process workflow management systems, there are a lot of similarities between them. They are similar in the type of workflow and the type of flow, in that both are activity-based and support control-flows. Data-flows are needed but can be included manually when implementing the process.

One of the major differences between them is that jBPM is open-source, while Stateframe is a commercial software product. Here the trade off between commercial and open-source software arises. In this comparison between these two approaches, issues such as cost, flexibility, security, end user support, compatibility and integration are considered [243]. The main issues

related to our project are the cost and the support provided. Here Stateframe is preferred over jBPM because of the support provided from its vendors in setting and operating the system.

The second major difference between Stateframe and jBPM is the visual interface provided in Stateframe, which increases its usability by supporting building and designing workflows. Although jBPM does provide a library which can be used by the developers. Having the supportive interface in Stateframe saves time and effort and reduces the errors that can occur during the implementation process. This also makes Stateframe preferable over jBPM.

The third major difference is the support for distributed technology, which is the ability to combine with web services. jBPM supports distributed technology, while Stateframe only supports the use of backing hardware for remote components. This covers part of the advantages of web services. Hence jBPM is preferable over Stateframe on this point.

Moreover, Stateframe supports extra functionalities which jBPM does not have for progressing individual objects and supporting RAD of new components.

Finally, JBOSS will provide installation and technical support through its online forum while Stateframe developers will support the installation and give the technical support in person.

By looking at the identified factors needing to be considered when making the choice of the WFMS to be used, we found that the advantages that will be gained from using Stateframe are more than those gained by using jBPM. Therefore, Stateframe was chosen to implement the proof of concept prototype for this project.

Chapter 9

Architecture of Proposal System

Overview

This chapter explains the architecture of the proposed system, WffICP. The architecture will position the proposed system against the current CISs and show how the CIS's functionalities could be evolved. This will be followed by explaining the architecture of WFMS used in the project. Finally, the technical details of how the proposed system works will be presented.

9.1 Introduction

This research does not propose a new system to replace existing CISs but a tool which works with these systems to evolve and extend/enhance the functionalities they provide. In this chapter, a clarification of how the proposed WffICP system will be adjusted to the structure of the existing CISs will be presented. Moreover, the architecture of the workflow engine and how it will operate will be presented. This chapter will put this research in the context of how it interacts with the current state of the healthcare domain.

9.2 Fitting Proposal with Existing Healthcare Information Systems

One of the biggest challenges in the healthcare domain, is the fact that legacy CISs within the different departments and across the healthcare organisations are heterogeneous and contain valuable information still needed in patient care. Therefore, the proposed solution is independent of the underlying information systems and their structure (i.e. unified patient record or organisational/departmental centred patient record are not assumed or proposed). This is important as replacing legacy CISs is another challenge, due to the risk and cost it involves in addition to the political barriers [48]. Consequently, this proposal suggests adopting an evolutionary framework which enhances existing systems so that they support the team communication and care coordination. This is achieved by implementing a separate independent WFM based system which has interfaces which allow integration with the interface of existing CISs.

The proposed WffICP system acts as a central hub to the heterogeneous systems (see figure 9.1). This means it is not connected into the CISs but used to capture and forward information from and to each of these systems, while linking the captured information to create a fuller record for a patient. Therefore, it can inter-operate with different systems independent of their underlying structure, provided a wrapper is provided. The WffICP system will act as a middle layer which lies between the user interface layer and the CIS's interface layer (see figure 9.2). The WFMS is independent of the CIS's interface layer as it should be able to interact with any interface currently used, whether the CIS deals with a unified electronic patient record or a departmental patient record (see figure 9.2) although a wrapper may need to be written for a CIS not previously linked.

At run time, the users will interact directly with the user interface of WffICP which forms the first layer in the structure of the proposed system. The user interface will then send the request to the WffICP's engine which will record the related information about the patient's treatment,

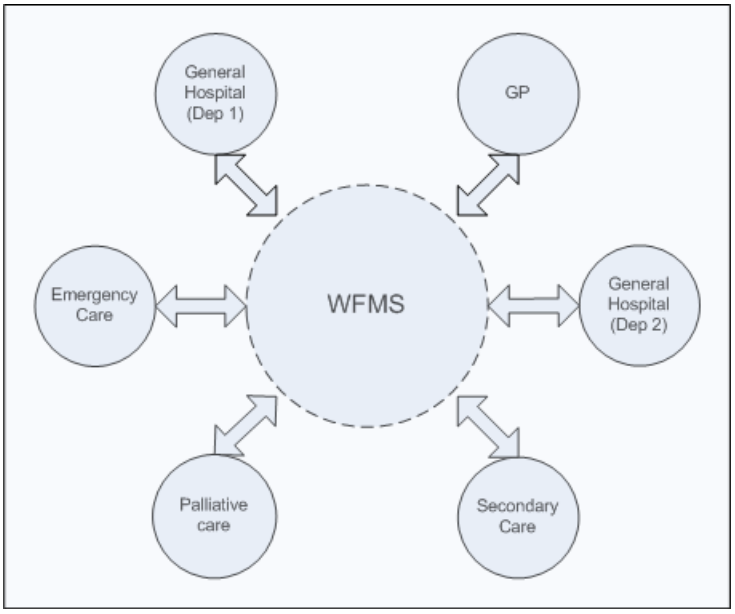

Figure 9.1: Positioning WFMS to Other Systems.

link it to the patient, look for triggers and their appropriate actions (if any). If an action is linked to the request within the WFMS's database, the WFMS will run the appropriate action otherwise the WffICP system will pass the user's request to the interface layer to deal with the request.

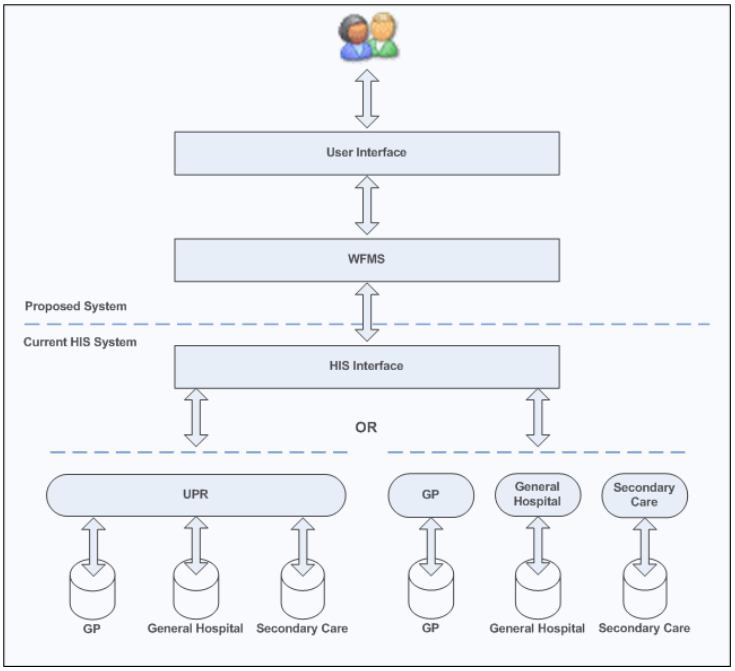

Figure 9.2: Proposal System's Architecture.
Code: UPR- Unified Patient Record

9.3 Architecture of the WFMS

The WffICP layer (see figure 9.2) consists of a WFMS engine and a WFMS engine's database. The engine usually implements the logic of the flow in the process map which uses the stored information in the WFMS's process server database as User Data Properties (UDP). The UDP process server database consists of tables of data about the processes, cases and all flow related data (see figure 9.3). Each process map consists of one or more processes and each process can be linked to one or more actions. Processes can also be linked to an interface of a CIS which is linked to its own database.

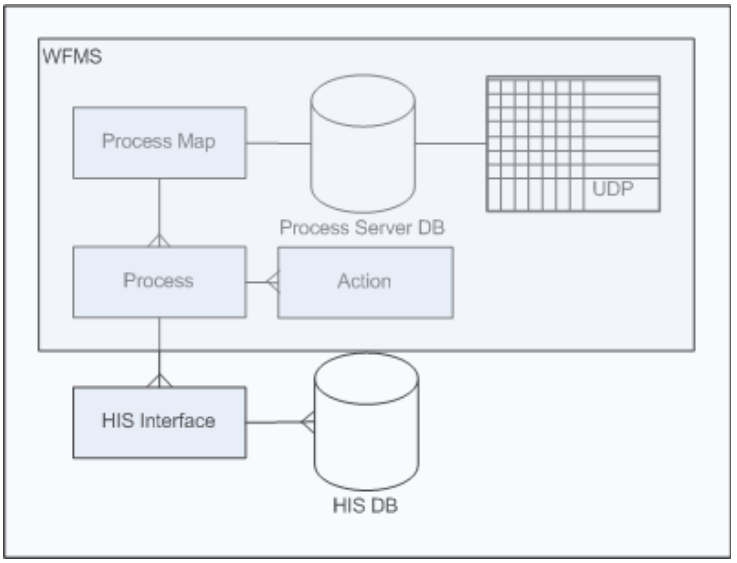

Figure 9.3: Physical Architecture of WFMS layer.

We add to this architecture a stand-alone database for the WffICP system's specific data. The WffICP's data describes the scenario's specific needs including: link roles to patients, trigger and action related information.

9.4 Architecture of Stateframe

Stateframe is the BPM toolkit used in this research to develop the proof of concept prototype. Stateframe 4.0 is built on the .NET platform for the Microsoft Windows Environment. The Stateframe engine's architecture is shown in figure 9.4 [24]. This engine interacts with an underlying UDP storing the logic flow information. Figure 9.4 shows the components of Stateframe's engine and how it is customised. The architecture includes:

- *Stateframe Engine* implemented as a .NET object which can be installed on one or more servers and/or clients run against a shared UDP.
- *Application Programming Interface (API)* which has methods for the three main objects: case, process object, and activity. There is a separate API for the organisation components.
- *Reusable Components* these are held externally to the system to make it usable and ease the customisation.
- *Automation Agents* working asynchronously as hidden users for task automation, not necessarily as a direct reaction to a user's input.
- *Time Keeper* (also called overdue scanner) which synchronises the processes and ensures continuity of the flow.
- *Security Client* maintains the groups, users, rules, and roles.
- *Process Mapping* tool uses Microsoft Visio with a custom template. The mapped maps are dynamically stored in Stateframe's database.
- *Administration Tools* deal with the UDP configuration, versioning and case investigations.
- *Code Generation* tool is used to interpret the map into code which can be run by the user.
- *Web Client* this is provided through a web based ASP.net client. It is an interface through which a user can access the following:
  - *Intray* of the user with awaiting tasks
  - *Case Viewer* of progress
  - *Activity Frame*
  - *Case Search*

9.5 How Stateframe Work

This section explains how the WFMS/Stateframe system operates. The process to map the workflow logic into the system, what happens when a process is activated, and how actions are activated. This links back to the architecture of the WFMS engine (figure 9.4) and to the components in the physical architecture in figure 9.3.

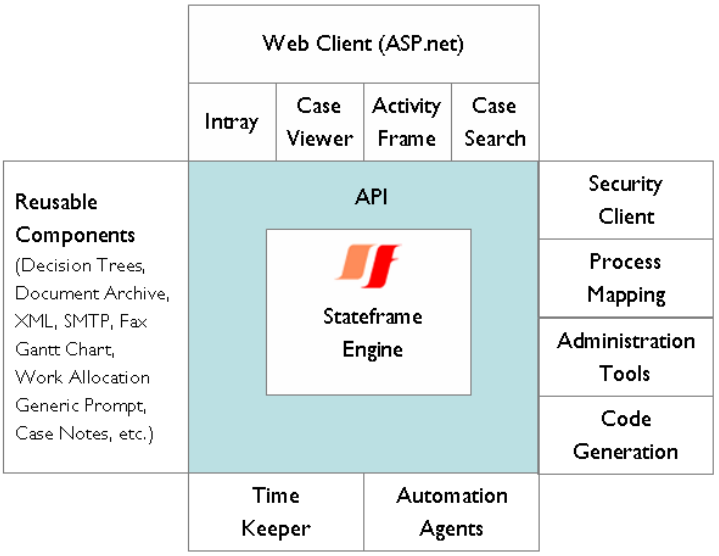

Figure 9.4: Stateframe's Engine.

9.5.1 Process Map

To map the processes into the workflow engine, the logic needs to be mapped into the process map. This will automatically be translated into a *web client* (figure 9.4) page using the *code generator*. It will also be mapped automatically to the workflow engine's database UDP which in this stage will contain information about the processes flow logic. *Security* and *administration* information settings should be assigned to each process. *Security* will involve authorising organisations, roles, and/or users to deal with case information, while *administration* involves authorising users to deal with the workflow engine's settings at the administration level. A process undertaken by a certain role will be associated with its role to be linked later to the case in progress. Moreover, processes within the logic that might involve this action will be coded to call the action appropriately. The application's case specific information will be stored in the WffICP database.

In the healthcare scenario, the logic will be the clinical guidelines, as given in an ICP representing the treatment flow. This is mapped into the system through the process mapping tool. The process mapping tool will dynamically translate the information about the process map into the UDP. Stages within the treatment journey involving a care team professional will be associated with the person to keep a track of the carers involved in the treatment process of the patient. At some points in the treatment flow an action may be needed. At these points, the logic of the action will be programmed to ensure the actions execute as expected.

9.5.2 Active Process

When a process is activated, the process connects to the workflow engine's UDP to read the case information and its related actions. This might also involve a scan into the healthcare information system's related database (see figure 9.3) to collect additional details about the case. Moreover, if the process is associated with a role, the system links the role and the professional to the patient and keeps a record of this linkage. Processes can be either a web client page, automatic agent, and/or reusable components. Web client pages provide the users with access to their own intray which shows their received messages and awaiting tasks. Users also can view and search their cases. Automatic agents are usually not visible to the users as being automatic it is a hidden process that performs a certain task without the need for a user's input.

In the healthcare scenario, at the different treatment stages some actions might be required to support a patient's care coordination. At each treatment stage, the system fetches the required actions. This action can be directly related to the treatment stage or related to a combination of the treatment stage and the treatment history , which requires access to the healthcare information system's related database. Moreover, some treatment stages, such as clinics and tests must be run by an appropriate care team professional member. In this case, the system adds the profession and the exact care team professional to the patient's related part in the WffICP's database. Other stages of the treatment process, such as referrals and scheduling can be done automatically through the automatic agents.

9.5.3 Active Policy

When a policy trigger is activated, the system identifies the appropriate action to be processed and the affected professional role (if any). In this case the system takes actions with consideration of the involved roles and the exact professional, as appropriate. Policies can start also when a trigger of an automatic agent or a time keeper is activated. Actions can be either an automatic process or a prompt which requests a user's input. These usually affect the routing flow direction.

In the healthcare scenario, policies such as referrals, notifications and alerts will need to be sent to a particular role or professional. These will be identified in the patient related data. Some of these actions such as a referral will most probably be initiated by a healthcare professional, while others such as alerts might start automatically due to a change happening in the flow or the data. Overdue tasks can start a policy without being initiated by a healthcare professional, as a reminder of tasks or messages that have not yet been selected or processed and in some cases this is the result of a waiting time set initially by a healthcare professional being exceeded.

Chapter 10

Implementation and Design of WffICP

Overview

This chapter introduces the selected scenario, breast cancer diagnostic and treatment options. This is followed by an identification of the stages within the selected scenario that need support. The mapping process of the scenario into the selected WFMS (Stateframe) will also be explained. This will include the process of mapping processes and activities as well as defining process objects and cases. Furthermore, the coding that is incorporated into the system and how the system is programmed to meet the ICPs requirements will be clarified.

10.1 Introduction

To demonstrate the ideas behind this research and the capabilities of the proposed system, a proof of concept prototype was implemented. The clinical guidelines for "diagnostic of a breast cancer clinic" and a "selection of the treatment options" were used as a scenario to build the prototype using the Stateframe System [24].This chapter details the implementation stages of the prototype. This includes the scenario selection, process mapping, coding, and finally discussion of the resulting system. The prototype is used later to test and demonstrate the functionalities that can be achieved by mapping the ICP into a workflow engine (see chapter 11). The prototype is then used during the evaluation process to assess its usefulness and to show the possibility of adopting the ideas in the healthcare environment (see chapter 12).

10.2 Scenario Selection

Prostate, Lung, and Breast cancer ICPs from MoM were investigated to understand the overall treatment processes and to decide on the most suitable ICP for implementation in the prototype. When looking at all three cancer treatments, we realised that there is a lot of commonality in the stages of these treatment processes. These occur in the referral process, MDT involvement, assessments and diagnosis, treatment options, and palliative care involvement. These are identified in the stages in the ICPs in figures 10.1, 10.2, and 10.3 which represent stages of prostate cancer care, 10.4 , 10.5, 10.6, and 10.7 which represent stages in lung cancer care, and 10.8, 10.9, and 10.10 which represent stages in breast cancer care. The common aspects include:

- Figures 10.1, 10.4, and 10.8 show the referral process in prostate, lung and breast cancer ICPs respectively.
  - Common stages among all three treatment ICPs are the standard procedures prior and after the clinical presentation (stages 1-5 in all three ICPs and stage 6 in prostate and breast cancer ICPs).
  - The referral process is classified according to the urgency in all cancer treatments. However, the urgent and non-urgent referrals are differently processed in the different ICPs- stages 10-13 in prostate cancer ICP, stages 7-16 in lung cancer ICP, and stages 8-18 in breast cancer ICP.
  - In prostate and lung cancer ICPs, differential diagnosis is considered before a referral is processed (stage 8 in prostate cancer ICP and stage 6 in lung cancer ICP).

- All three ICPs involve an MDT at a certain stage. However, the order in which the MDT is involved is different among all three cancer ICPs.
  - In the prostate cancer ICP, an MDT is involved in the early stages to decide on the urgency of the referral - stage 8 in prostate cancer ICP (figure 10.1).
  - In the lung cancer ICP, the patient is referred to an MDT depending on the urgency - stages 9,12, and 16 in lung cancer ICP (figure 10.4).
  - In the breast cancer ICP, the patient is referred to the MDT at a later stage (in comparison to other cancer treatments) as it follows the diagnostic stage - stage 11 in breast cancer ICP (figure 10.9).
- The assessment and diagnosis of all three cancer treatments are presented in figures 10.2, 10.5, and 10.9.
  - Imaging is part of the assessment and diagnosis in all cancer ICPs - stage 9 in prostate cancer ICP (figure 10.2), stage 5 in lung cancer ICP (figure 10.5), and stage 8 in breast cancer ICP (figure 10.9).
  - Core biopsy is done for prostate and breast cancer ICPs - stage 12 in prostate cancer ICP (figure 10.2), and stage 11 in breast cancer ICP (figure 10.9).
  - Other assessments are different in the different treatments - e.g. stages 7-17 in lung cancer ICP (figure 10.5) .
- Treatment options in all three cancer treatments are presented in figures 10.3, 10.6, 10.7, and 10.10.
  - All three cancer treatments could include chemotherapy - stage 15 in prostate cancer ICP (figure 10.3), stage 8 in lung cancer ICP (figure 10.6), and stage 12 in breast cancer ICP (figure 10.10).
  - Surgery is an option in lung and breast cancer but not in prostate - stage 11 in lung cancer ICP (figure 10.6), and stage 13 in breast cancer ICP (figure 10.10).
  - The rest of the treatment options vary from one treatment to the other e.g. hormone therapy is only offered for prostate cancer - stage 13 in prostate cancer ICP (figure 10.3).
- Finally, palliative care is involved at the final treatment stages in all three treatments - stage 19 in prostate cancer ICP (figure 10.3), stage 4 in lung cancer ICP (figure 10.7) and stage 24 in breast cancer ICP (figure 10.10).

The examples presented above, show that the similarity in the treatment processes is between all three or two of the treatment pathways. Moreover, these examples show that the order in most cases changes as each of the treatments require. However, the general stages along the treatment is similar with some changes in the details within each . These common processes in the treatment patterns of all cancer treatments was also confirmed in the literature [15] (see figure 5.1). However, a specific cancer ICP scenario had to be selected for further detailed study as only one was to be used in the implementation.

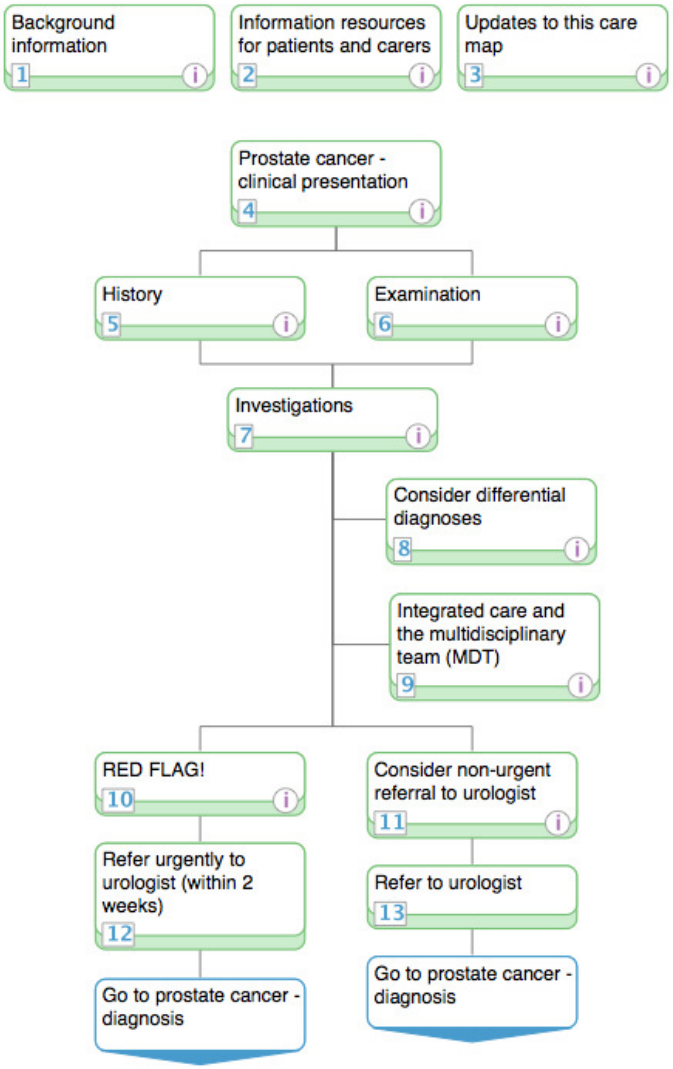

Figure 10.1: ICP - Prostate Cancer (Referral).

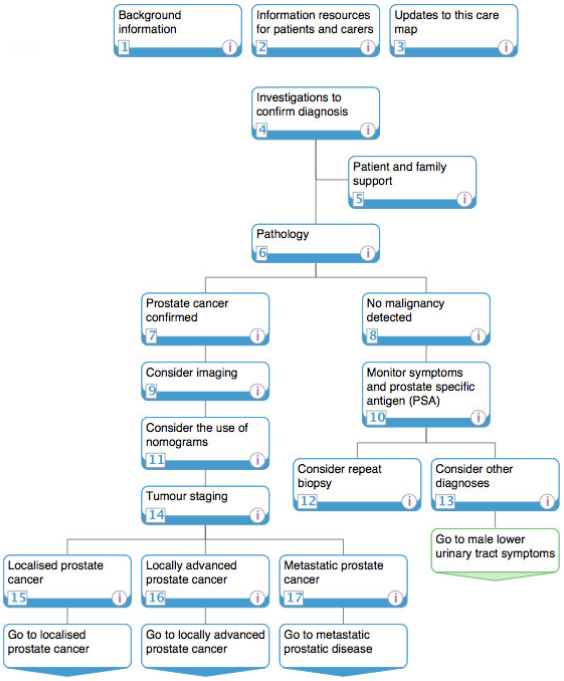

Figure 10.2: ICP - Prostate Cancer (Assessments and Diagnosis).

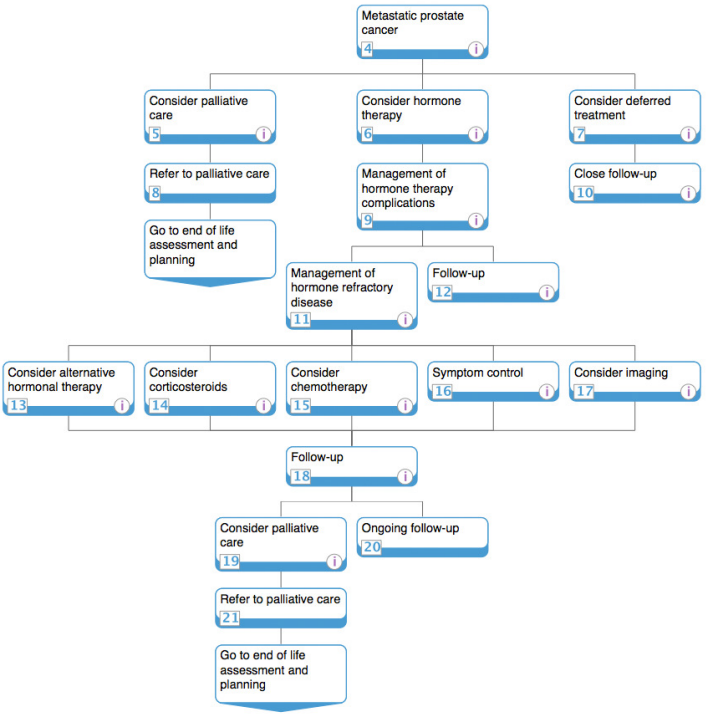

Figure 10.3: ICP - Prostate Cancer (Treatment Options).

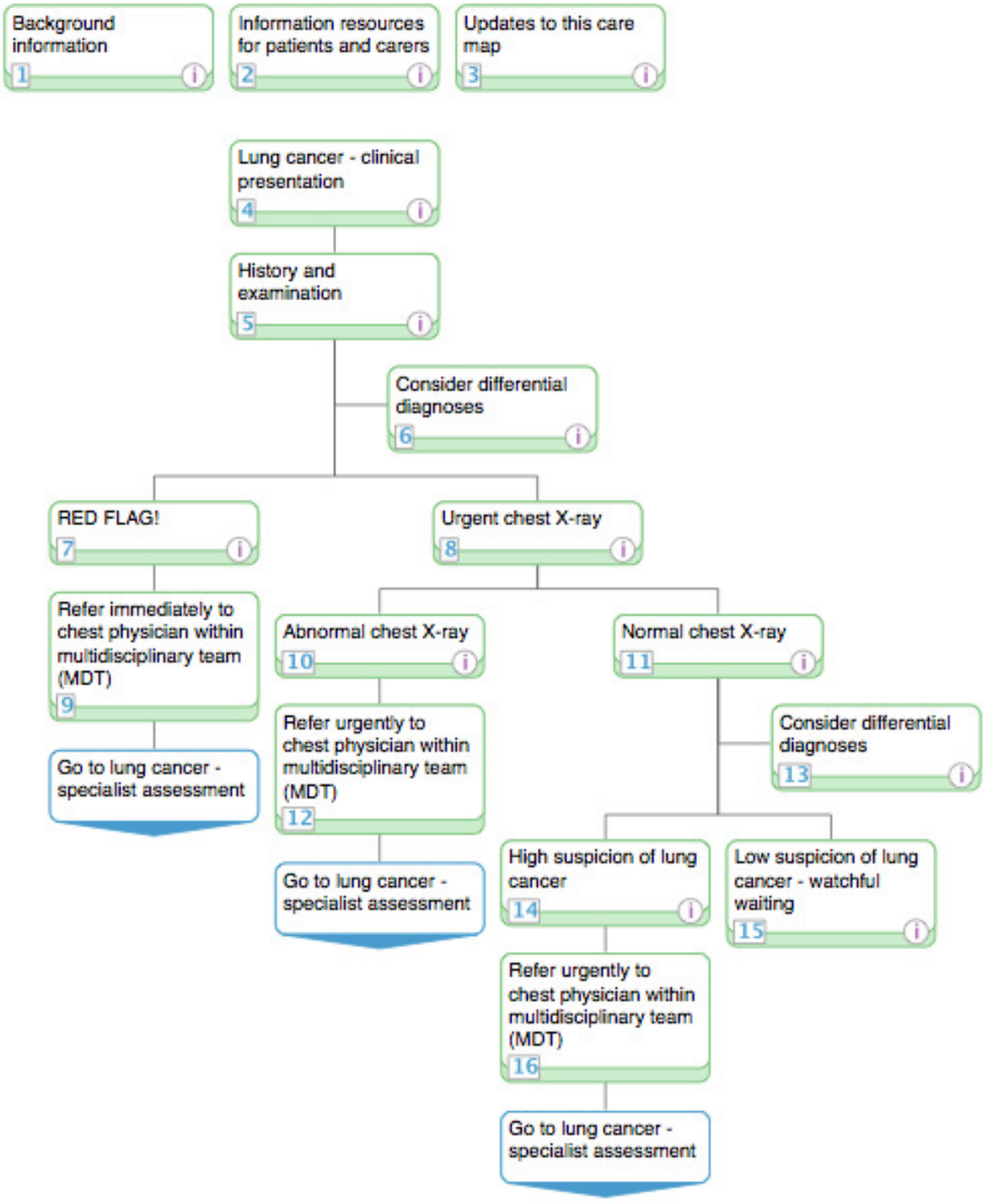

Figure 10.4: ICP - Lung Cancer (Referral).

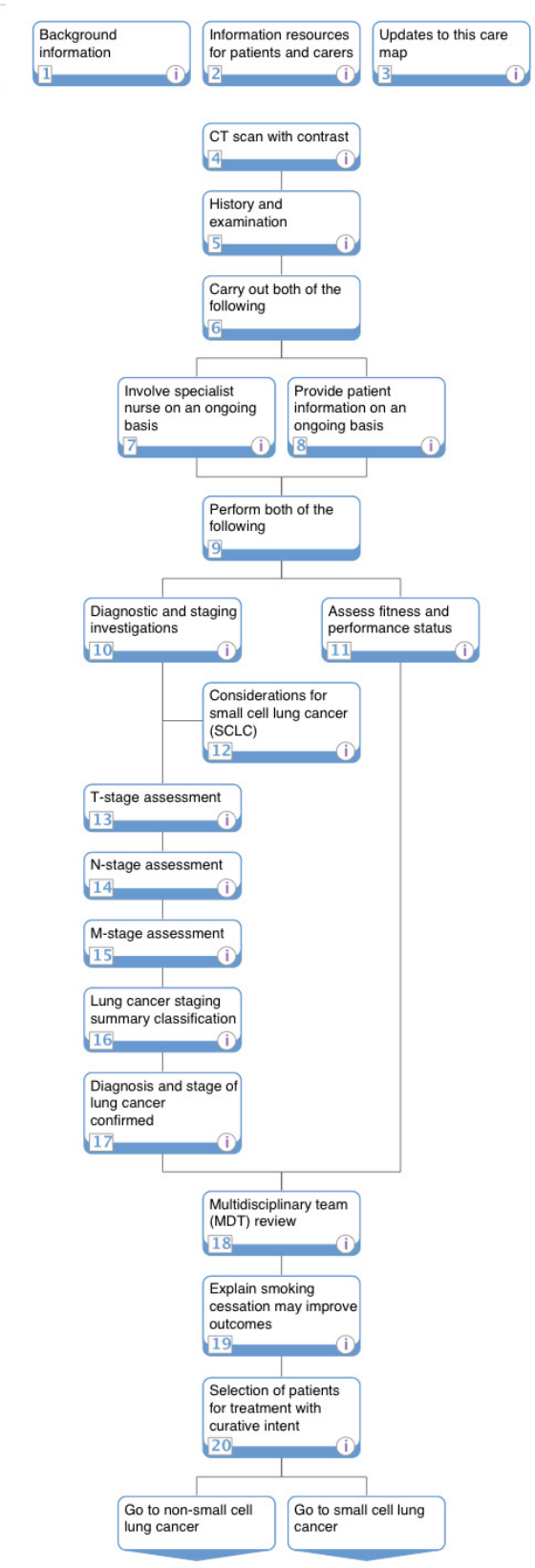

Figure 10.5: ICP - Lung Cancer (Assessments and Diagnosis).

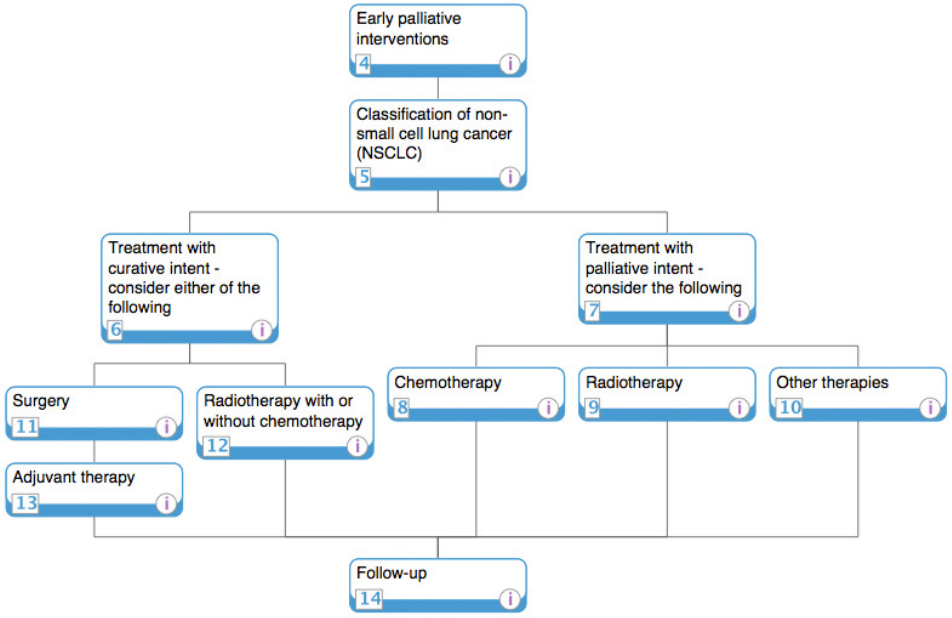

Figure 10.6: ICP - Lung Cancer (Treatment Options).

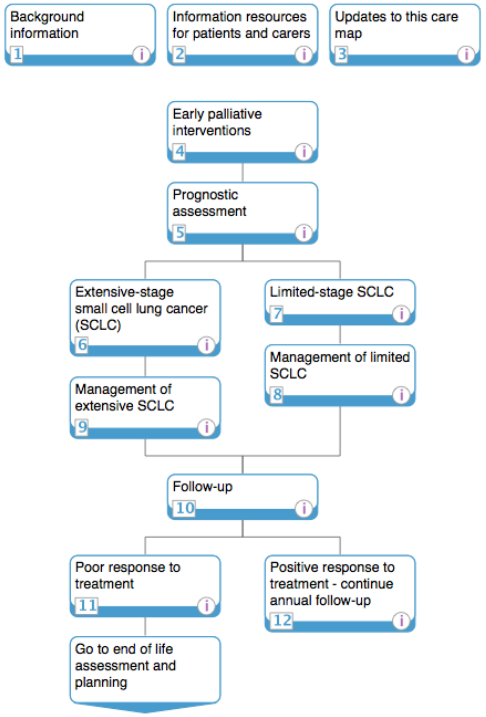

Figure 10.7: ICP - Lung Cancer (Treatment Options (2)).

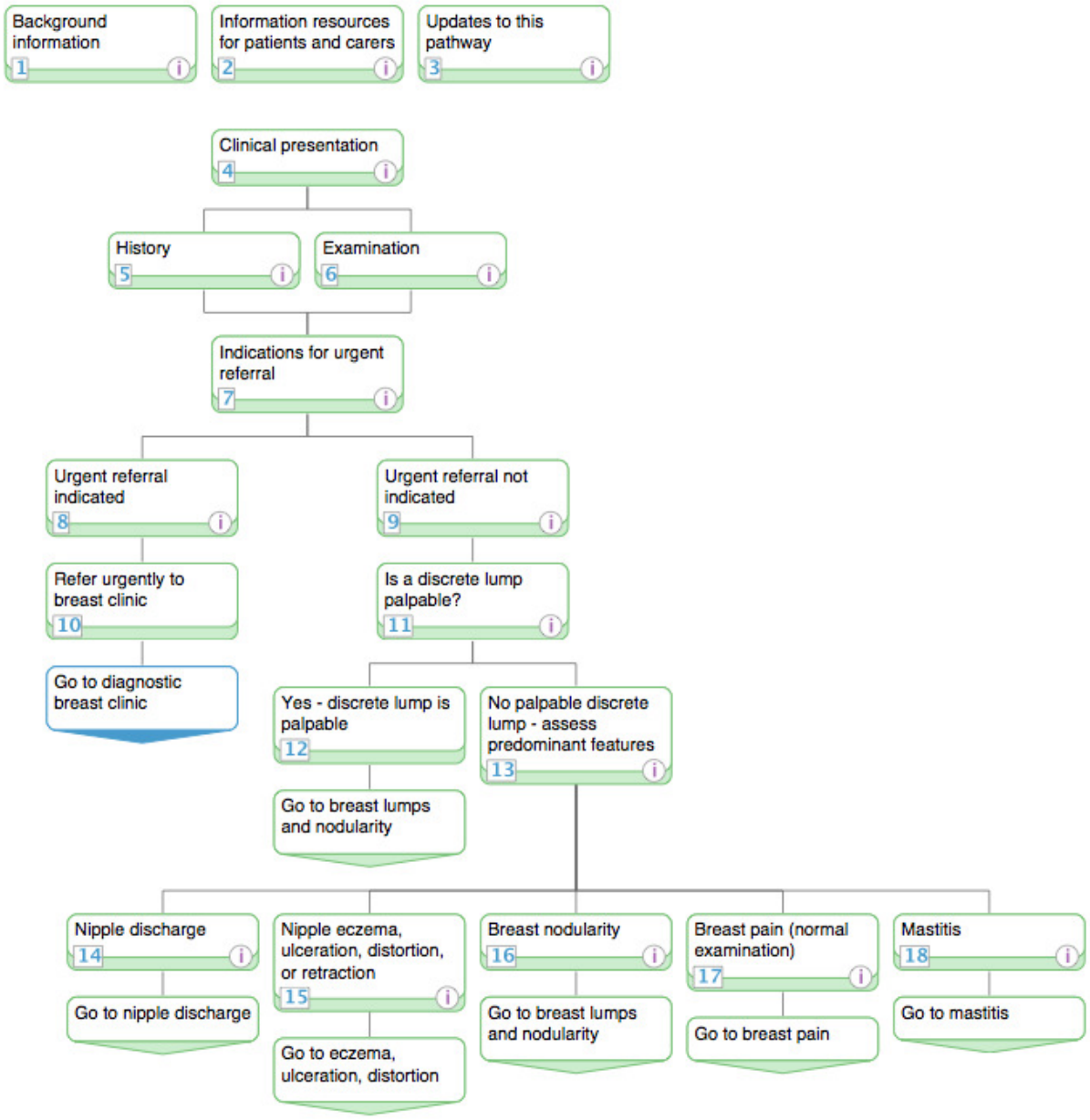

Figure 10.8: ICP - Breast Cancer (Referral).

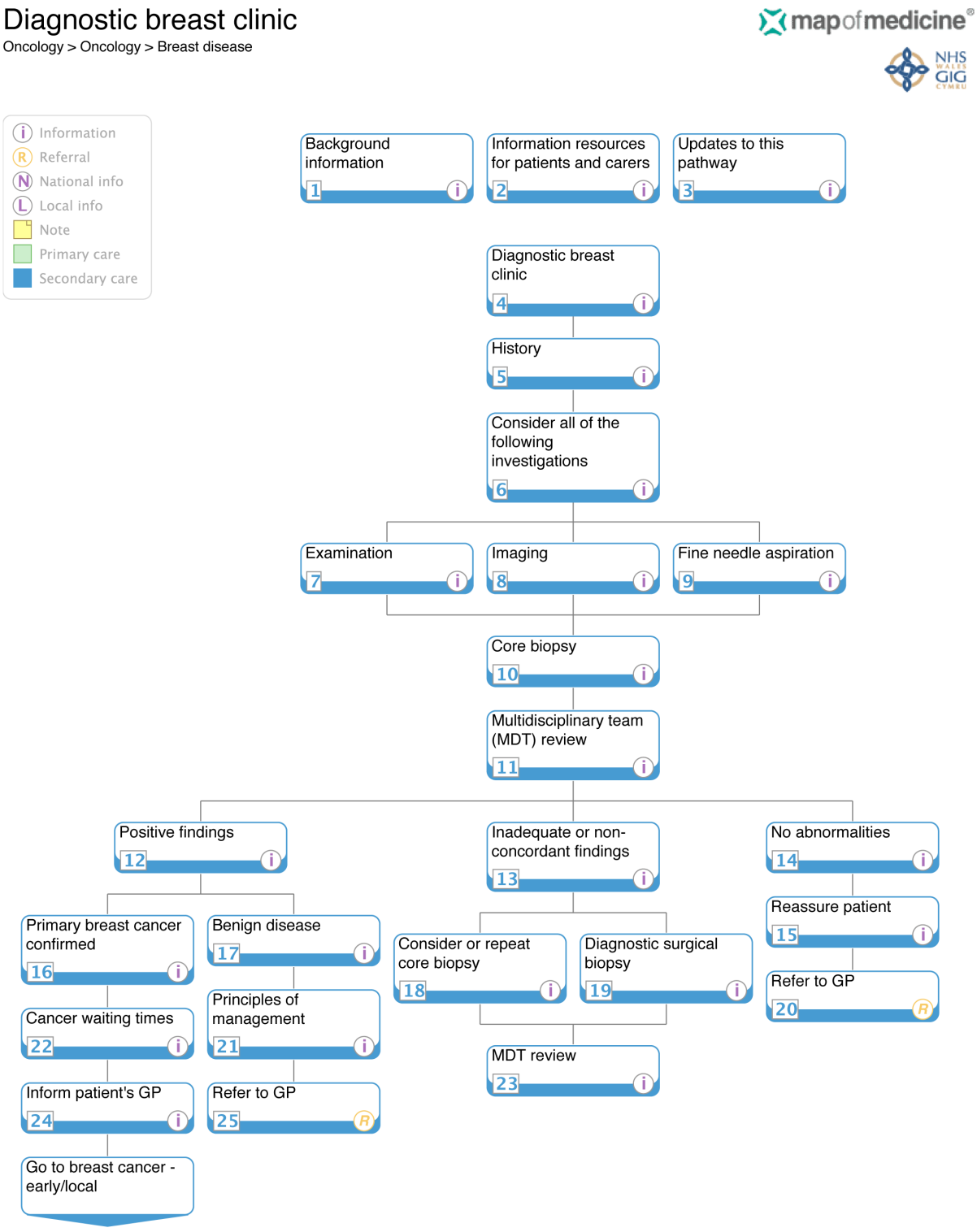

Figure 10.9: ICP - Breast Cancer (Assessment and Diagnosis).

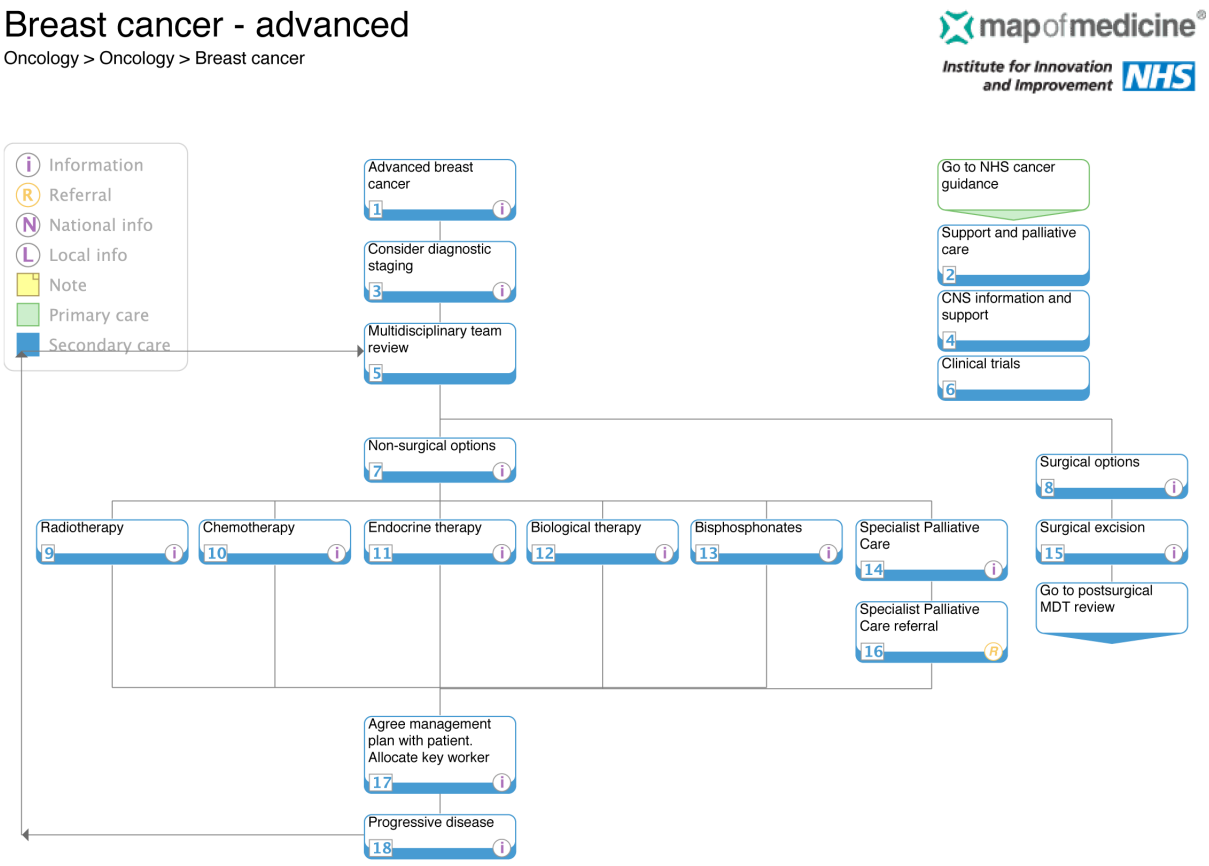

Figure 10.10: ICP - Breast Cancer Treatment Options.

10.2.1 Breast Cancer ICP

The diagnostic breast cancer clinical guidelines were selected as the scenario to be used in the proof of concept prototype. This choice was made for the following reasons: first, there is great deal of information about cancer and its clinical guidelines online which makes understanding the treatment process a lot easier. Second, the process is complex enough to show the challenges involved in the treatment delivery, as it involves interaction among different systems, organisations and care team professionals. For these reasons cancer is recognised as a scenario for demonstrating the integrated care approach by the NSF [54]. Finally, the cooperation between Cardiff School of Computer Science & Informatics [244] and the CIU at Velindre NHS cancer centre [41]. The choice of a cancer treatment from initial diagnosis through to treatment was recommended by the CIU staff.

The guidelines of the diagnostic breast cancer clinic and the treatment choices used in the implementation of the prototype are taken from the MoM [23]. This guideline shows the different

stages of the treatment process and they have an attached document explaining the details about the organisations involved, information required, roles involved, flow logic and any constraints [245, 246]. Using this information a good sense and understanding of the treatment process being followed was achieved.

Figure 10.9 shows the map of medicine guidelines for a diagnostic breast clinic [245]. Along the treatment journey multiple organisations and multi-professional care team members are involved. Treatment option guidelines are represented in figure 10.10 [246]. This is followed by patients with breast cancer confirmed and who have progressed in the treatment process to treatment options. Figure 10.11 shows an altered version of figure 10.9 combined with figure 10.10. This shows the full treatment pathway of a patient progressing from the diagnostic of breast cancer stage to undertaking treatment.

The scenario represented in figure 10.9 and 10.11, starts at the point, where a GP suspects a patient has Cancer and therefore refers the patient to a surgeon oncologist. The Surgeon Oncologist then checks the patient's history and requests some assessments such as: (examination, imaging, fine needle aspiration, and core biopsy). The results of these test will then be reviewed at an MDT meeting to decide whether there are no abnormalities, more tests needed, or positive findings. In the case of no abnormalities, the patient will be reassured and the patient will be discharged to primary care. In the case of more tests are needed, the MDT will decide whether a surgical or core biopsy is needed before the patient is reviewed again in an MDT meeting. In the case of a positive finding, the reviewers will decide whether it is benign or cancer confirmed. If a benign disease is confirmed the patient will be educated on the principles of management of this condition and the patient will be discharged to primary care. If Breast cancer is confirmed, the GP will be informed. This will be followed by a number of stages until the patient reaches a point where a decision is made on the treatment options represented in figure 10.10 and 10.11. Patients can then have surgery or undertake non-surgical options such as radiotherapy or chemotherapy.

The flow in figure 10.11, is a combination of the flows in [245] and [246]. By looking at the associated documentation in these references and other information in the literature, we can identify stages, where there is a need for care coordination among the different care professionals involved in this flow. These stages are identified on the combined map in figure 10.11, as follows:

- *Referral* from the GP to the surgeon oncologist. This will be initiated by the GP, performed by the primary care nurse and sent by the administration at the GP surgery. Then the referral will be picked-up by the administration at the secondary unit scheduled on the secondary care system and picked up by the breast cancer nurse to be processed by the surgeon oncologist.

- *Notification* to MDT reviewers about the outcome of the triple assessment results and clinical examination notes have to be gathered and be available before the MDT meeting. This will be forwarded by the breast cancer nurse, haematologist, radiologist, and pathologist from the stored information in the secondary care records, held in the haematology laboratory system, the radiology system and the pathology system. This information will be gathered by the MDT coordinator so that it can be discussed at the MDT team meeting, consisting of a surgeon oncologist, radiologist, pathologist, clinical and medical oncologist, and a nurse.

- *Alert* of a patient diagnosed with breast cancer and the process of informing the patient's GP. This will be initiated by the surgeon oncologist, performed by the breast cancer nurse and sent by the administrator at the secondary care unit to the GP surgery. Then the message will be picked-up by the administrator at the GP surgery, scheduled by the primary care nurse to inform the GP and used to update the patient's record in the GP surgery system.

- *Alert* of the patient undertaking chemotherapy or radiotherapy. This is used to avoid any conflict. This is usually managed and controlled by the clinical oncologist using available information about the patient's medical and treatment history and the medical information gained from the patient.

- *Schedule* required if the patient is under both chemotherapy and radiotherapy. There is a requirement for a minimum of two weeks delay between these two treatments. This is also managed and controlled by the clinical oncologist using available information about the patient's medical and treatment history, and the medical information gained from the patient.

- *Timer* this is required to refer patients to their oncologist after recovering from a surgical operation. There is usually a specified waiting time after surgery for recovery before a patient is reviewed. The patient is then seen at a post-surgical MDT to agree on the treatment plan after surgery. This will be requested by the surgeon oncologist, performed by the nurse and picked up by the MDT reviewers.

Figure 10.11 shows a simple flow with no complications which is not the usual case as most patients have further complications. Patients do not usually follow the anticipated care pathway and each patient flow is unique as many elements interact and affect its progress. Although this is a simple flow, support is required at several stages along the treatment pathway. These demonstrate the concept which can be applied in a more complex cases.

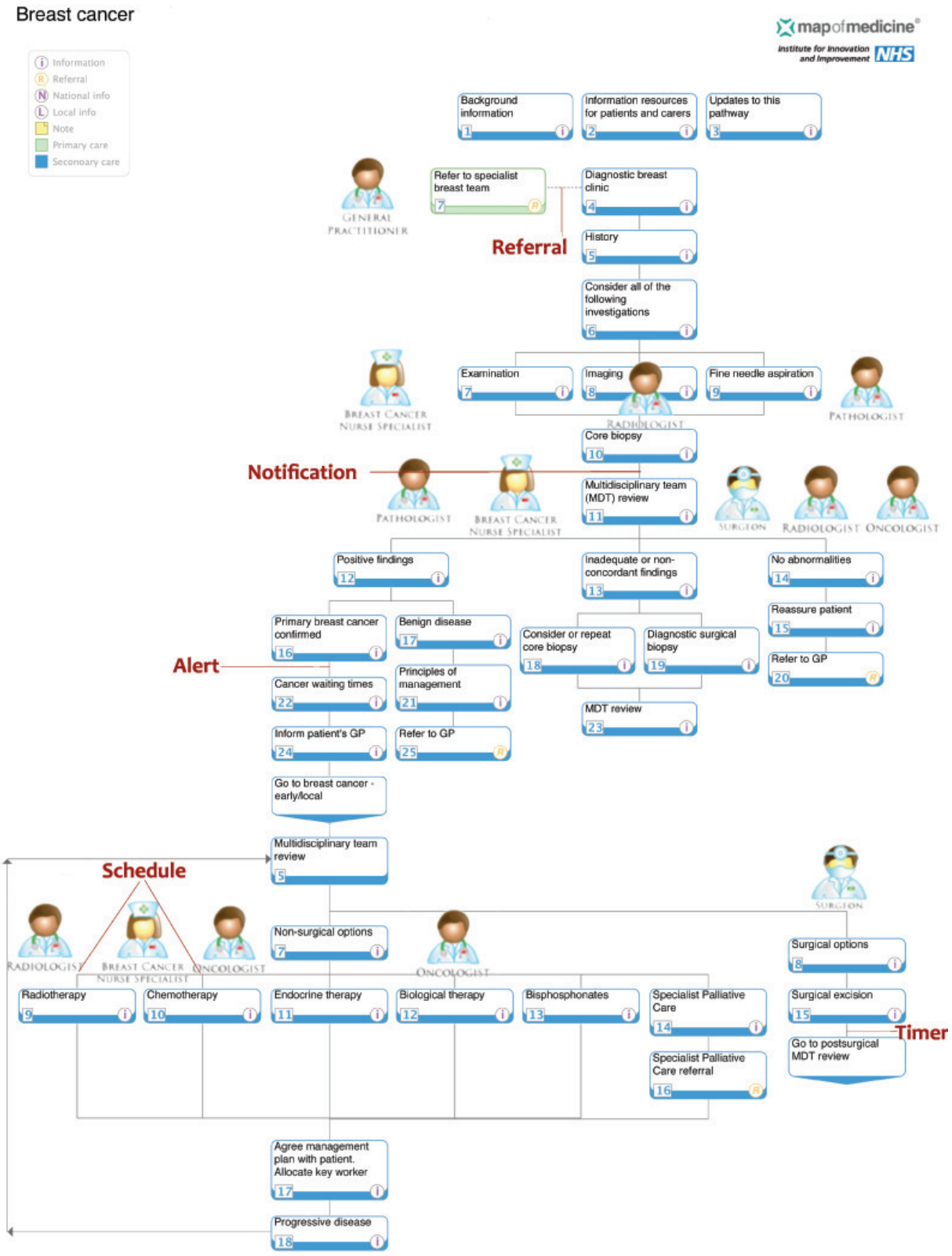

Figure 10.11: Breast Cancer Diagnostic and Treatment.

10.3 Process Mapping

The next step after selecting the scenario for the demonstration and the identification of the stages within the scenario that need support, is to map the scenario into the chosen WFMS. We chose to use Stateframe from Alia Systems Ltd. [24]. The process mapping is done through the tools provided by Stateframe and each process map consists of several elements. The process mapping also involves coding at some stage along the care pathway. The following section will introduce the mapping tools, the process map elements and the coding involved.

10.3.1 Process Mapping Tools

Alia Systems support a process designer and a user data properties tool for process mapping process, as follows:

Process Designer Tool

A process designer tool is provided with the Stateframe system. Within Stateframe the mapper uses Microsoft® Visio [247] with a customised template. This tool provides a visual representation of the logic. Moreover, it links the logic designed on the process designer tool dynamically to the system's engine.

UDP

Data about the flow logic, rules, users and cases which have been processed and are processing on the system is stored in the process server database which is organised using the UDP. This is part of Stateframe's architecture and it stores all the map related information to be used at execution time. This data is also used at runtime to manage the processing of individual cases.

10.3.2 Process Map Elements

The process map within Stateframe consists of processes, activities, process objects, and the actual case in-progress. These elements are:

Process

The actual workflow map of the clinical guidelines is a set of stages. A process can be a representation of a full disease treatment or a specific task or a stage within the treatment guidelines. When a clinical guideline is divided into multiple processes representing its tasks or stages, these can be then internally (within the map) linked to represent and support the full treatment of the disease. Repeated tasks along the treatment pathway can be mapped as separate processes to be called as often as required by the treatment progress.

In this project the whole treatment journey represented in figure 10.11 was mapped into a single process. The scale of the project is small and therefore it did not require splitting the treatment guidelines into separate processes. However, to improve the visibility of the processes and for a more organised manageable mapping, the map is divided into separate sheets. Sheets are organised to represent different roles or locations a patient gets referred to, along the treatment pathway. Examples of these roles and locations are: MDT, Oncologist, Surgeon, Radiology and Secondary Care. Figure 10.12, 10.13, and 10.14 show the parts of the process maps representing the first stages of the diagnosis of breast cancer to which the Radiologist and MDT processes map respectively. These steps are linked internally to each other and the rest of the sheets to sustain the flow of the treatment according to the clinical guidelines.

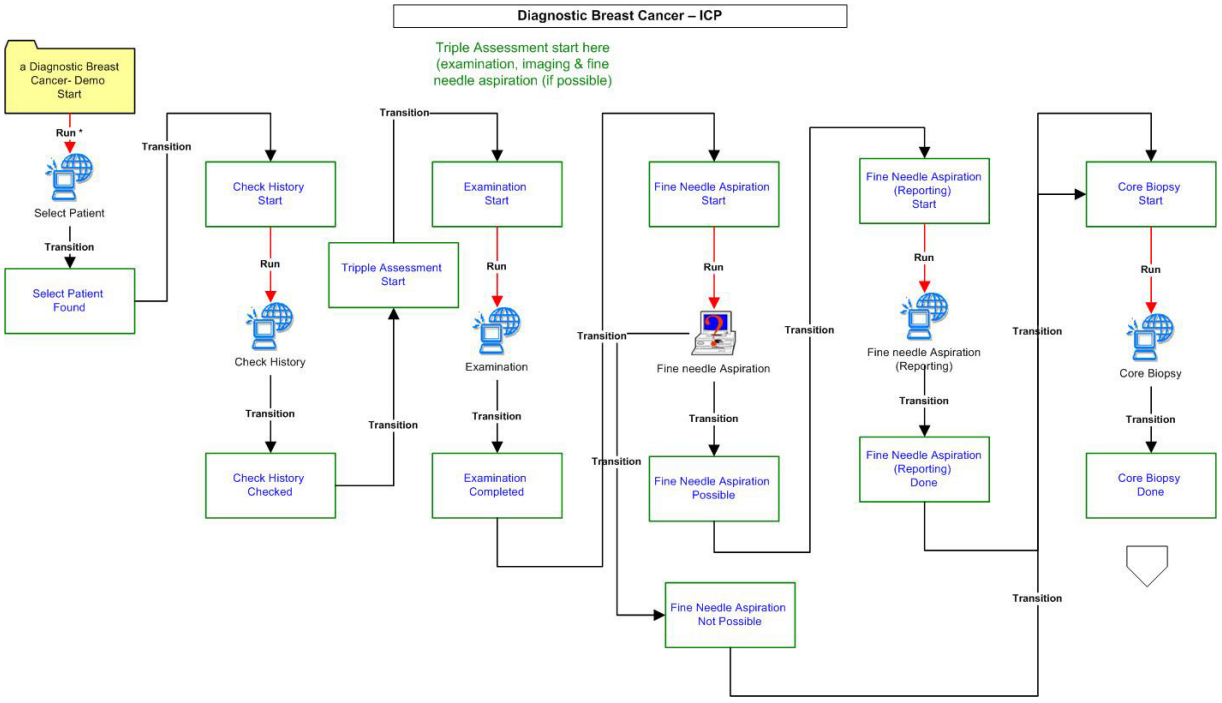

Figure 10.12: Diagnostic Breast Cancer Process Map (Start).

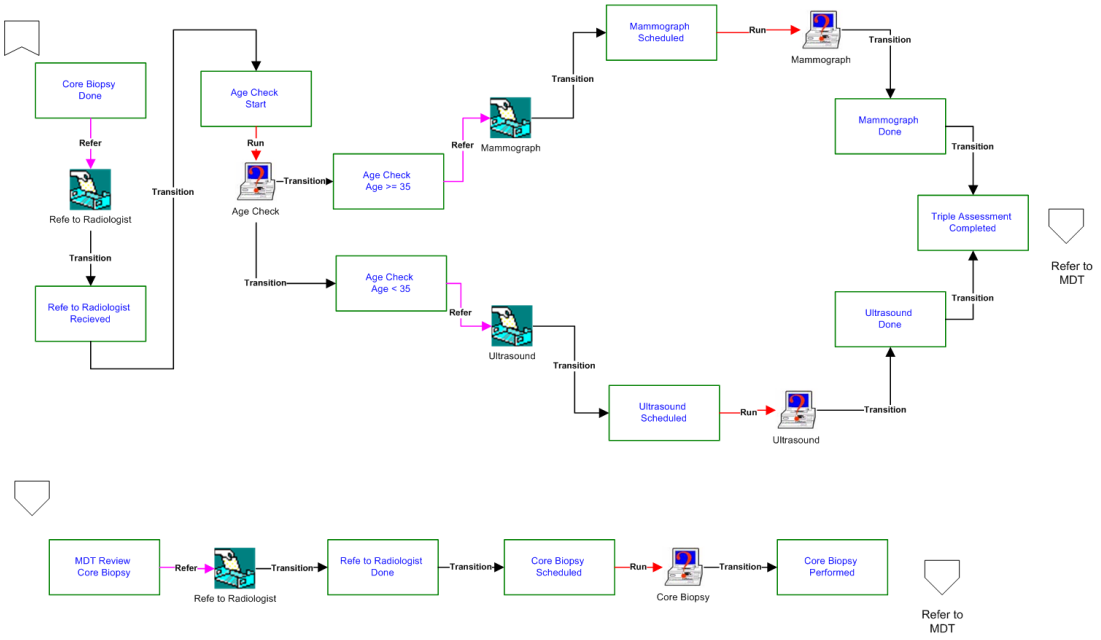

Figure 10.13: Radiologist Process Map.

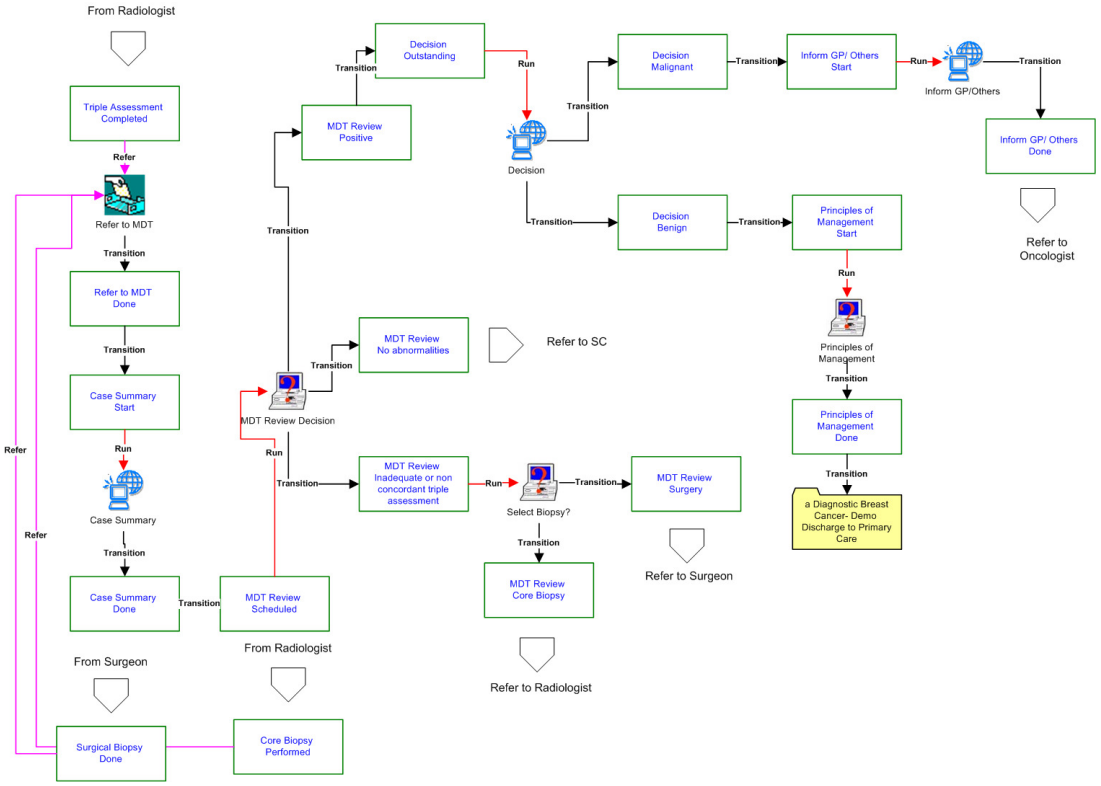

Figure 10.14: MDTs Process Map.

Activity

Each step in the clinical guidelines is represented as one or more workflow activities. Activities represent tasks which provide productivity gains, and accomplish something, throughout the process flow. An activity can be any of the following:

- A *prompt*: This is usually used to indicate the need for a user's manual decision. The properties of the prompt activity are specified in the property's window as shown in figure 10.15.
- A *referral*: This is an automated step which specifies the role and the specific user (if any) to which the case should be referred. Setting referral attributes is done through specified property windows, see figure 10.16.
- An *ASP activity* (decision support tool): This displays relevant information to the user and their decision is expected as input to the currently running/active task. The code of the interface and its embedded logic is linked to the activity using the ASP properties window (see figure 10.17).
- An *automated step*: This is where no user interaction is required for its completion. Moreover, system users might not be aware that automated steps are in-process until its consequences become visible. This includes subsets of tasks, and integration to application and/or data that runs as one set to accomplish something (e.g. Calculate age). The automated activity is similar to the ASP activity, since in both the module attribute will link the activity to the underlying code (see figure 10.17).

In this project, each stage within the treatment flow for breast cancer diagnostic and its treatment was represented in at least one activity. The choice of the type of delivery depends on the nature of the task. Figure 10.12 shows the mapping of the triple assessments performed at clinics, these actions are: examination, fine needle aspiration and core biopsy (processes 4, 6 and 7 in figure 10.11). The activity of these stages within the process map in figure 10.12 are represented in ASP pages. However, within the map each of these process objects should be linked to the specific CIS used for this purpose. Within the map, a prompt is used at simple decision points, where the user needs to decide whether fine needle aspiration is possible within the available resources at the hospital or not. Referrals to Radiology are shown in figure 10.8. The referral can be either to a specific user or to a role within an organisation/department where it will get processed by the first available professional who is suitably qualified. Referrals can be sent between departments in a single organisation or across multiple organisations. A referral usually involves sending a message to the inbox of a user or role in a specific department.

The module in the ASP activity's property window (figure 10.17), connects to a file containing the code programmed to derive any logic including accessing any data or application that the security rules allow. Here data relating to a patient's medical condition can be fetched and processed as needed. The code can be run as a departmental application to fulfil the actions required at the current stage.

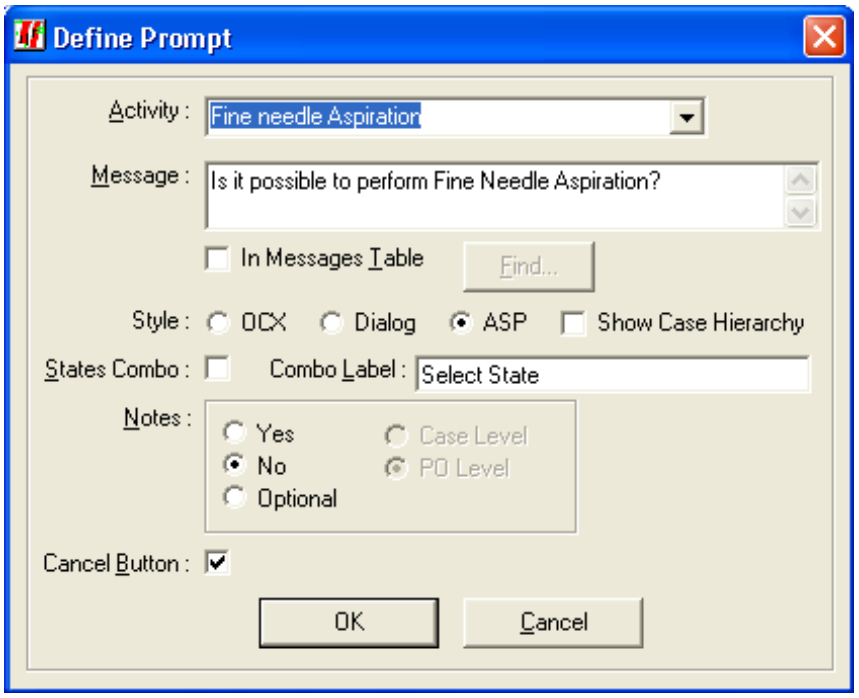

Figure 10.15: Prompt Properties.

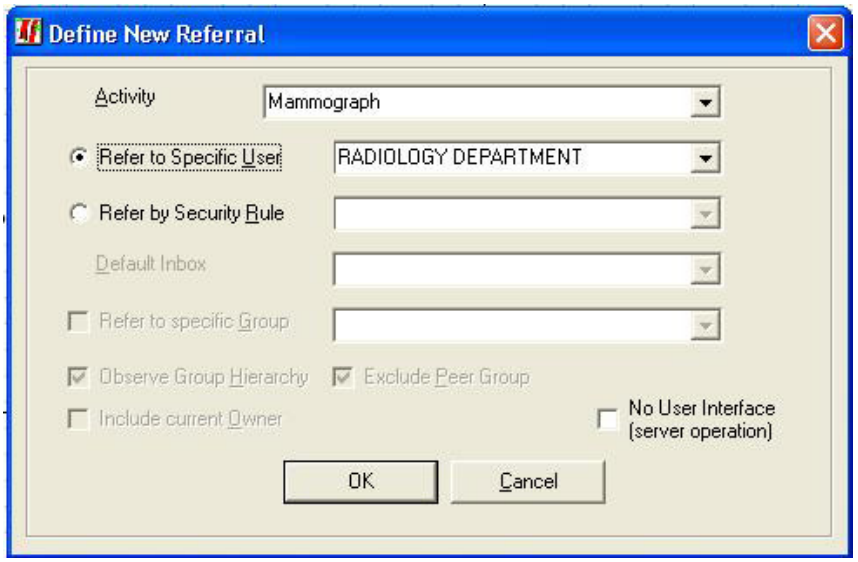

Figure 10.16: Referral Properties.

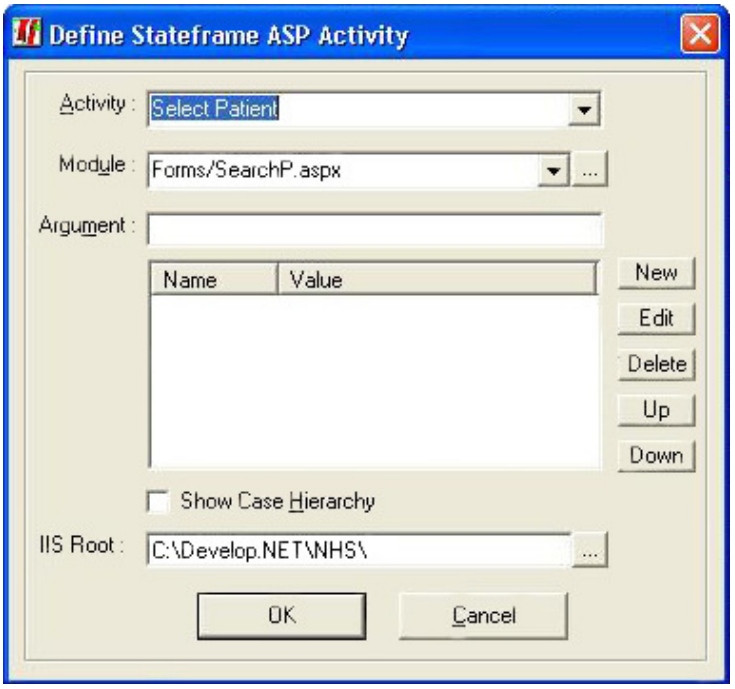

Figure 10.17: ASP Activity Properties.

Process Object

Process objects provides the facility to control and audit a case according to its state. A process object state identifies the state of the case. As a state-driven engine, the actual driver of the flow is the case process object state representing the patient's status or condition at certain points of the treatment. Process objects can change the state of another object, initiate an activity or simply state a condition. Activities on the other hand change the state of the process object, that initiated them. This is usually defined before and after each activity by showing the initial state of the process object and the resulting state after processing a task. Moreover, for each process object, attributes can be identified. This includes its process, process object name, process object state, visibility, arguments, turnaround (timing), priority, security or administration rule, and any descriptive icon, which shows the state of the object (see figure 10.18).

In this project, process object states represent either treatment flow progress or a patient's condition. Examples of process objects representing treatment flow progress include: examination start, or examination completed (see figure 10.12). When the object state initiates an activity it should identify its state before and after it is processed. The patient condition states are also used as process objects in the process map, such as MDT review decision of malignant, benign or no abnormality (see figure 10.18).

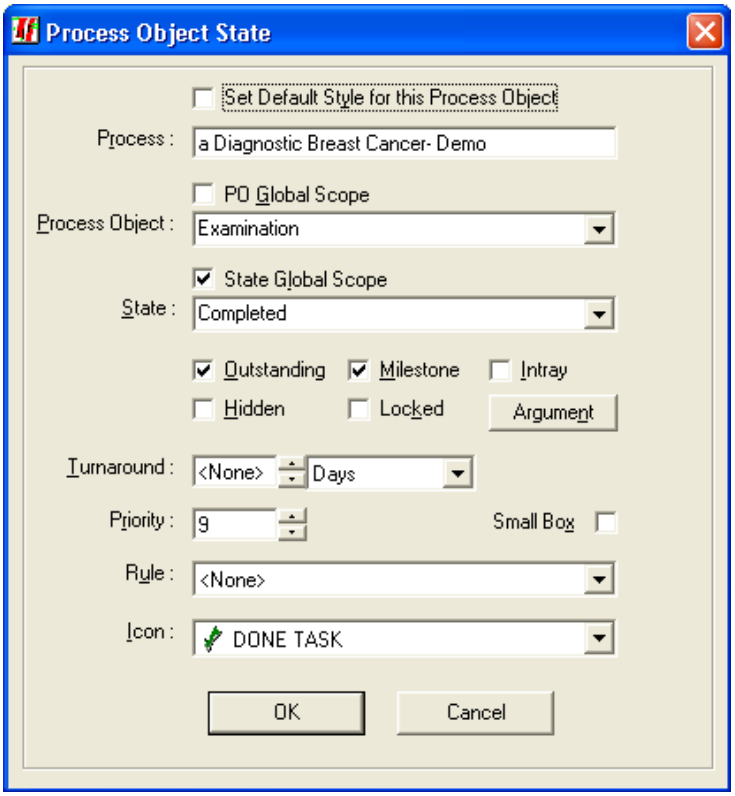

Figure 10.18: Process Object Properties.

Case

The case is the actual patient-specific scenario in progress. Each case represents a single patient treatment flow. For each patient the treatment pathway is unique and is processed by considering a patient's health condition and the available resources. The case hierarchy at run time usually shows the treatment history, the progress, the state/status and the roles or users involved in the different stages. The visibility of the different treatment stages (activities and process objects) are pre-stated in the process mapping stage by the developers. These are the check boxes in the process object properties window (figure 10.18). However, each care team professional can customise the level of detail they would like to see about the case, i.e show a summary, show hidden states or a fuller report (see figure 10.19).

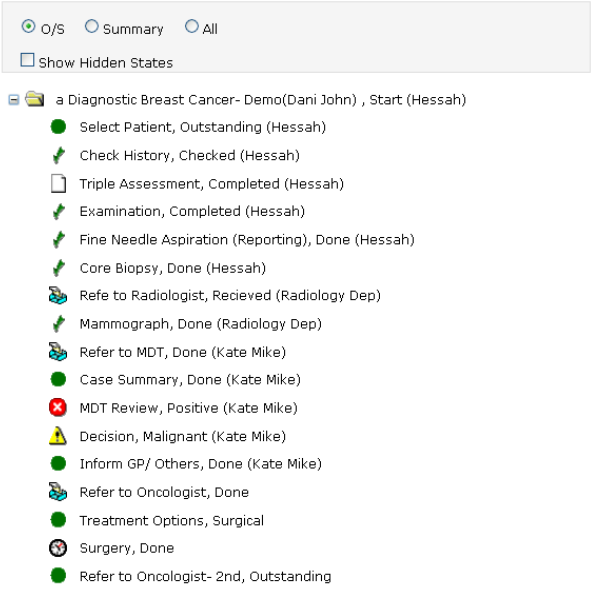

Figure 10.19: Case Hierarchy.

10.3.3 Coding

The system is implemented as a web application. VB.NET was used to design the web pages interface. C# is the language used to code the activities. It was used to code the logic for a simple database access through to a more complicated routing logic. An example of database access is fetching the triple assessment results to be viewed at an MDT meeting. Examples of a more complicated routing logic include setting a timer to execute referral after a two week recovery period following surgery.

A stand-alone database was created using a SQL server to store information about cases and the professionals involved in the treatment of each case. The database created is completely independent of the UDP (section 10.3.1), data repository linked to the WFMS's engine. This is a realistic anonymised subset of Canisc, which has been used for testing purposes in a number of health informatics projects at Cardiff School of Computer Science & Informatics. The most recent project using it is Skilton's [48] project which created a view of the database. This view consisted of a subset of the database with more realistic names. The original database consist of 355 tables and 7304 rows with unintelligible character string names (see figure 10.20). For this project we used Skilton's view presented in 10.21. This is a subset of Canisc database which included the data we required.

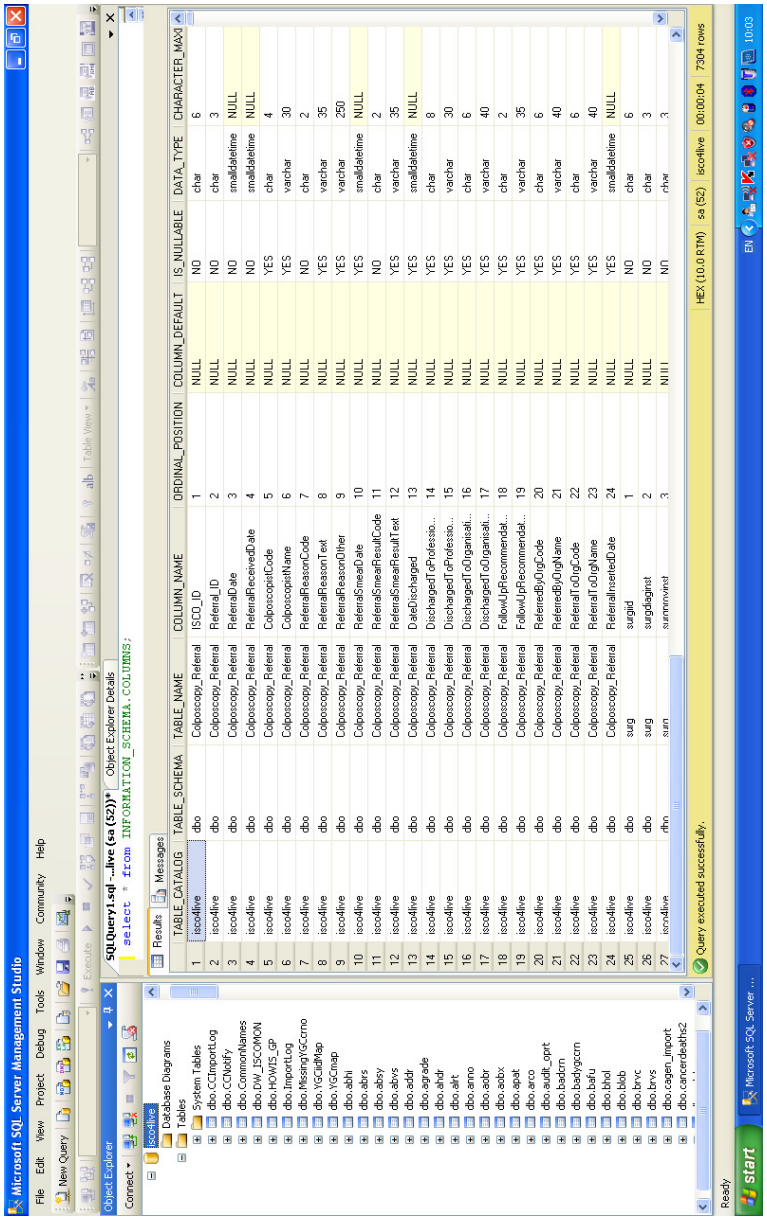

Figure 10.20: List of Tables in Canisc Database.

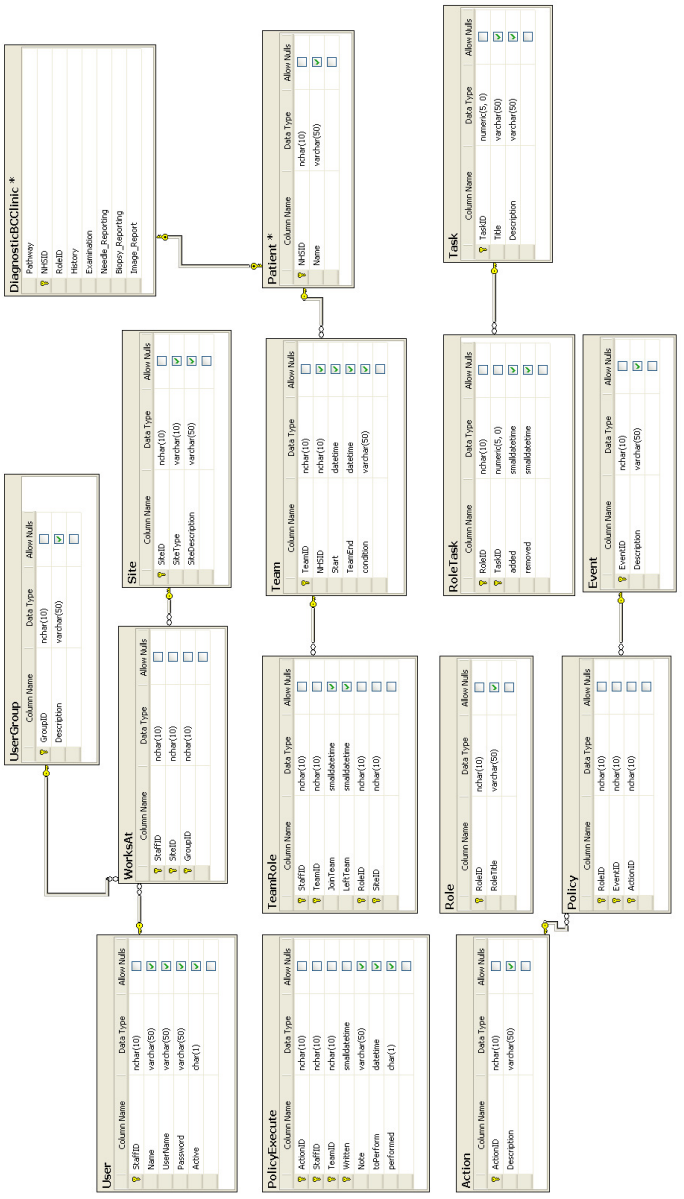

Figure 10.21: Subset of Cansic Database - View used.

10.4 Putting It All Together

In this section, the breast cancer ICP scenario (section 10.2) will be linked to the different process mapping elements (section 10.3). This is to clarify the interpretation process of the guideline stages into process definitions. The process definitions are mapped into process objects and activities. Each of these activities and objects define what information needs to be processed, how it is going to be processed, and by which actor or role these actions will be processed. This leads to the granularity and the interactions with legacy databases being defined. This representation of the coordination process is a challenge since the clinical guidelines do not provide enough information about the details of the treatment stages and all the related elements.

In section 10.2.2 critical stages within the treatment flow needing support were identified (see figure 10.11). One of the critical stages, identified in 10.2, is the notification to MDT reviewers about the outcome of the triple assessment results and clinical examination notes. This notification stage is shown in figure 10.11, and requires the gathering of results of the triple assessment before the inclusion of the case for discussion at the next MDT meeting. Figure 10.22 is part of figure 10.17 showing how this single step in the clinical guidelines is interpreted in the process map. The interpretation consists of the following:

1. On completion of the triple assessment the patient gets referred to the MDT. On the map this requires the triple assessment's process object to reach the state of being "completed".

2. At the point when the triple assessment is completed, the system suggests to the user a referral of the patient's case to the MDT review meeting. This is done through a referral activity in which the role and the user will be specified. This is to ensure that the referral is delivered to the right user's inbox (see figure 10.23).

3. When the referral is completed, the process object of the referral will change its state to being "done". This is when the case summary of the patient will be gathered. As a result a case summary process object will be created, which then calls an ASP activity which gathers all the required assessment results for the MDT.

4. The ASP activity will be linked to the module including its logic, as shown in figure 10.17. The logic here will connect to the multiple databases containing the assessment results within a C# code (see figure 10.24), examples include accessing the oncology database for medical history, the radiology for images, and the pathology for fine needle aspiration results. Using the patient's information extracted from these database, the treatment flow is suggested, using the data-flow feature of the WFMS. The data collected will then be

gathered on a single screen designed and structured in the module's code, within the VB.NET code (see figure 10.25).

5. When the summary is ready, the case summary state changes to "done". The MDT meeting is scheduled for the inclusion of the patient's case only after this stage is reached.

In order to map the above stages a considerable amount of preparatory work was undertaken and decisions made. An example of preparatory work, is identifying the different roles involved in the treatment process and the different shared inboxes/intrays for the different departments within an organisation. An example of a decision being taken is sending the MDT summary to the MDT secretary rather than the MDT members attending the meeting. This gives a taste of the challenges involved in mapping the coordination stages in the clinical guidelines into a WFMS. The implementer at the mapping stage will have to localise the map to the local procedures of the organisation which will run the system.

Our experience, showed that the process of translating the ICP into a WFMS requires a full understanding of the actual treatment process. It is essential to understand each of the treatment stages within the ICP and the related communication and coordination requirements that are necessary in these stages and between stages to ensure the care team members are fully informed about the patient's progress and the team member's role in the treatment. Therefore, the involvement of the stakeholders so that their requirements are understood and mapped into the flow stages is a key part of the mapping process. The actual detail of each of the treatment stages is what gets implemented in the map; actions are represented as activities, requirements of each of these stages and their outcomes are represented as objects and their states, users are represented as roles, and the sequence of the processes is represented in transition objects. These elements will then be used to construct the VO surrounding the patient.

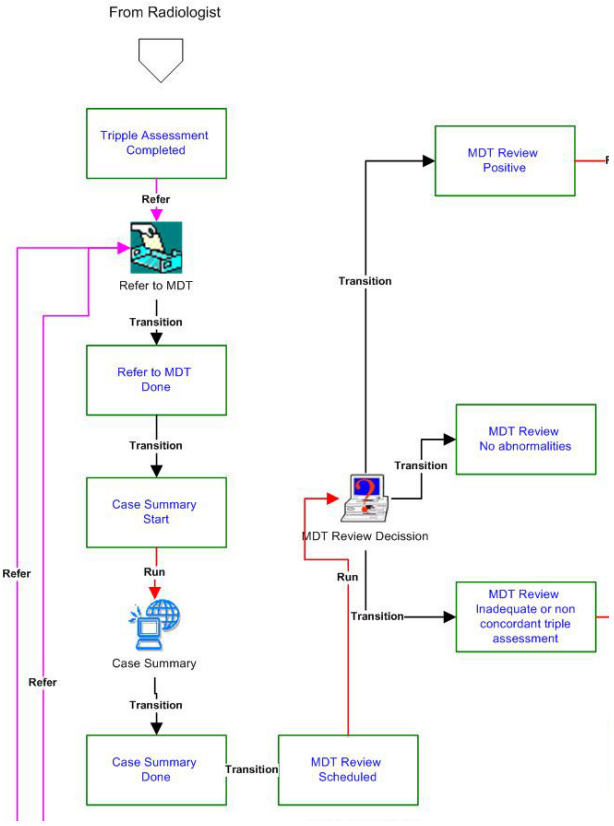

Figure 10.22: Notification to MDT Process Map.

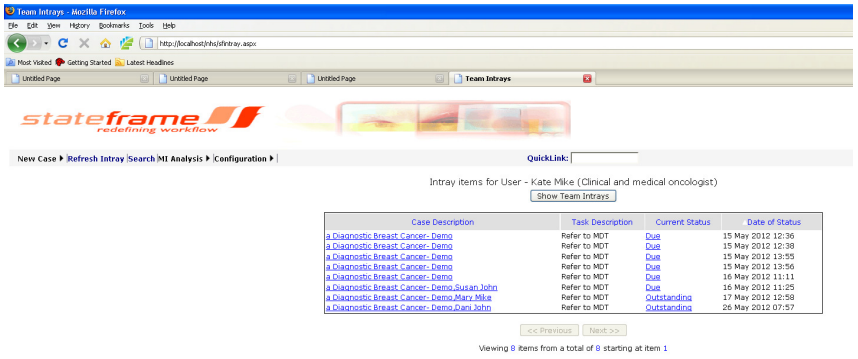

Figure 10.23: Referral to MDT's secretarial.

```
protected void Button8_Click(object sender, EventArgs e)
{ //all
    //Variables
    string CID = (string)Session["PID"];
    Label1.Text = CID;

    string sConnString = "data source=(local); initial catalog=Policies;" +
            "user id=sa; password=alysia;";

    SqlConnection conn = new SqlConnection(sConnString);
    conn.Open();

    try
    {
        SqlDataReader myReader = null;
        string abc = ("Select * from [Policies].[dbo].[DiagnosticBCClinic] WHERE [NHSID]='" + CID + "'");

        SqlCommand myCommand = new SqlCommand(abc, conn);
        myReader = myCommand.ExecuteReader();

        while (myReader.Read())
        {
            his = myReader["History"].ToString();
            exa = myReader["Examination"].ToString();
            nee = myReader["Needle_Reporting"].ToString();
            bio = myReader["Biopsy_Reporting"].ToString();
            ima = myReader["Image_Report"].ToString();

        }

    }
    catch (Exception ex)
    {
        Console.WriteLine(ex.ToString());
        TextBox1.Text = ex.ToString();
    }
```

Figure 10.24: C# code for database access.

```
<th style="text-align:center; width: 486px;" colspan="2">
    Tripple Assessment Summary</th>
</tr>
  <tr></tr>
    <tr>
    <td style="width: 522px">
        <asp:Button ID="HistoryBTN" runat="server" Text="History" OnClick="Button3_Click" />
        <asp:Button ID="ExaminationBTN" runat="server" Text="Examination" OnClick="Button4_Click" Width="84px" />
        <asp:Button ID="FineNeedleBTN" runat="server" Text="Fine Needle" OnClick="Button5_Click" Width="88px" />
        <asp:Button ID="CoreBiopsyBTN" runat="server" Text="Core Biopsy" OnClick="Button6_Click" Width="88px" />
        <asp:Button ID="ImagingBTN" runat="server" Text="Imaging" OnClick="Button7_Click" />
        <asp:Button ID="ViewAllBTN" runat="server" Text="View All" Width="110px" OnClick="Button8_Click" /><br />
        <br />
        <br />
        <asp:Button ID="RetrieveNameBTN" runat="server" Text="who" OnClick="Button1_Click" />
        <asp:Label ID="Label1" runat="server" Text=""></asp:Label></td>
    </tr>
    <tr></tr><tr></tr>
    <tr>
    <td style="width: 522px; text-align: center">
        <strong>Results</strong></td>
    </tr>
    <tr>
    <td style="width: 522px; height: 18px;">
        <asp:TextBox ID="TextBox1" runat="server" Height="42px" Width="540px"></asp:TextBox>
```

Figure 10.25: VB.NET code for triple assessment result's summary.

Chapter 11

Implications of the Proposed Approach

Overview

This chapter lists the implications of WffICP. The functionalities will then be discussed to see how they can support the care pathway. The operation of the implications will be explained. This will be supported by some examples and screenshots.

11.1 Introduction

The prototype was implemented to test and demonstrate the functionalities that can be provided by the proposed system. This chapter lists these functionalities and discusses how each supports the implementation of the clinical guidelines. The focus will be on how practically the functionalities will operate to support the implementation of the ICP and therefore the team communication and care coordination along the patients treatment journey(s).

11.2 System Functionalities

In section 3.3 we gave the research hypothesis as:

"By mapping the Integrated Care Pathway (ICP) representing the national clinical guidelines that reflect a patient centric treatment pathway into a Workflow Management System (WfMS) or a Business Process Management (BPM) System in an independent layer, and incorporating its interface in an evolutionary development approach into existing Clinical Information Systems (CISs), we can augment the functionalities of these systems to support team communication and care coordination among the multi-professional care team members working on a shared patient treatment journey(s) by formalising the treatment process, ensuring care continuity, filtering and gathering the information and pro-acting to changes."

The proof of concept prototype showed that the application of Workflow Technology in this healthcare domain is very promising. The aim of implementing a proof of concept prototype was to test and demonstrate the functionalities that can be achieved by mapping an integrated care pathway into a business process management system. The test aimed at demonstrating that those functionalities are achievable using the technology, and to show how each of these functionalities will be implemented and presented.

When appropriate, an example of each of these functionalities will be included in this chapter to clarify the concepts's use. This will be followed by a screenshot to demonstrate the implementation interface for the example's usage. Further research is required to identify how healthcare professionals would like to have these functionalities presented to them. This is identified as future work in chapter 14. The functionalities we claim to be achievable using the proposed system are: formalising the treatment process, ensuring care continuity, filtering and gathering the information and pro-acting to changes in treatment or a patient's condition. In the following sections each of these four functionalities will be explained in detail.

11.2.1 Formalising the Process

Mapping the ICP into a WFMS automates the treatment process in the clinical guidelines. The system will access the sequence of processes and the consequences of each decision made and therefore undertake context-based actions. The routing takes three forms. First, by suggesting what the next treatment stage might be according to the logic of the clinical guidelines, the patient's condition and any additional factors. Second, providing users with a tool to accept the system's suggestion, reject it, or suggest their own. Third, by automating a set of pre-defined processes to perform tasks selected by the users. The following sections will clarify each of these routing types.

Suggest Next Step

Mapping the ICPs into a WFMS and linking it with CISs, aims to provide a tool which enhances the CISs support for healthcare providers. This tool is not provided to drive the clinical decisions but to guide and support the decision making processes of the care team and its members. Therefore, the system will suggest the next treatment stage according to the logic of the clinical guidelines and the relevant factors affecting the flow. The driver of the routing suggestion is the patient's medical condition. An example of this would be suggesting an MDT referral after a patient undergoes the triple assessment. Another example would be suggesting a mammogram for a breast cancer patient older than a certain age, or imaging otherwise (see figure 11.1). The manual step represented in figure 11.1 can also be done automatically by checking the patients age as recorded in the database.

Drive the Next Step

The multi-professionals will drive their patient's treatment flow according to their own choice. This will begin by receiving the system's suggestion of the next step and the care team act on it by accepting, rejecting, or suggesting a new route. The driver to the next treatment step is the user of the system. So the only driver of the system will be the multi-care professionals choice. An example of this would be accepting an MDT referral suggestion after a patient undergoes the triple assessment.

Task Automation

Task automation is performed when a number of tasks need to be processed as a set. In this context it includes tasks that do not require user interaction/input. This would be a set of steps

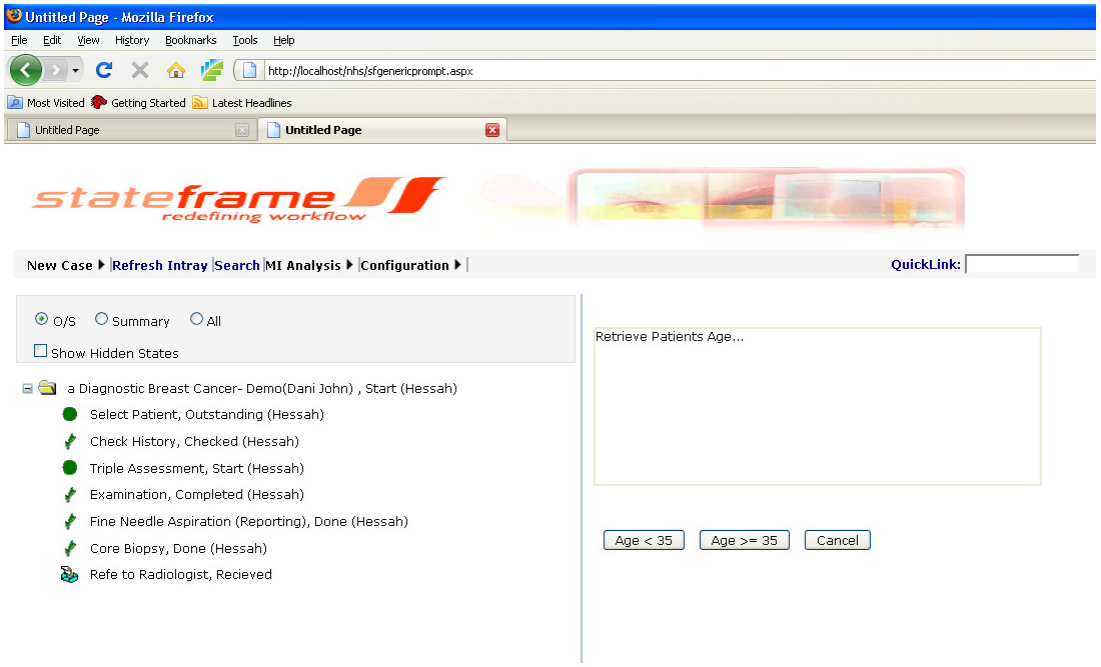

Figure 11.1: Suggest Next Step.

and their sequence defining the treatment to be given. An example of this would be informing the GP about a diagnosis of a patient's lump as benign or malignant.

11.2.2 Ensuring Care Continuity

Ensuring care continuity of patients especially when their treatment is undertaken by multiple organisations. This is done to ensure that patients do not drop out of the system and that they continuously receive the required treatment. The proposal offers support for care continuity in two ways; first, by automating the referral process; second, by setting timers on certain processes, such as overdue requests and processes that need to be activated after a certain time. An example is an urgent referral which needs to be scheduled within a week. Here the timer will cause the system to send a reminder if a receipt of delivery of the referral is not received by half way through the week. Another example of this would be a patient needing two weeks to recover after surgery before they are referred for a clinical visit. In this case the reminder will be processed after the two weeks has passed if no referral has occurred.

11.2.3 Filtering and gathering the Information

The linkage of Workflow Technology into CISs, can support information extraction and filtering from the medical records of patients as the treatment follows the care pathway. Having the logic

of the clinical guidelines mapped into the system, means the system can identify the logic that leads to the currently active process and therefore its information needs. An example of this would be a notification of the latest triple assessments done on a patient and gathering the results ready for an MDT meeting.

Another approach to improve the presentation of the medical information using WFMSs, is the summary history of the treatment and its milestones. The visibility level of each process and the milestones can be identified during the mapping processes of the ICP into the WFMS. This is used to ensure treatment history, important stages, order, time and care team providers are summarised to healthcare professionals when viewing the records of their patients (see figure 10.11).

Using these functionalities healthcare professionals will be aware of the development of the care process and they will access the medical information more readily and faster. These are supported through the different functionalities provided by the system as follows:

View Treatment History Hierarchy

The system provides a view of the treatment history of patients in a hierarchy, showing the different treatment stages. This hierarchy can be viewed at different levels of detail, by expanding the hierarchy to view further details about the stages and also by scaling down to reduce the details. The hierarchy gives the healthcare providers a quick highlight overview of the treatment of the patient and the progress of the treatment (see figure 10.11).

View Milestones

Another way to support a better view of the treatment history of patients is by identifying the milestones. Once identified during the mapping process, these can be the main stages in the history hierarchy. This is used to highlight treatments, tests, and medications that need to be known by the healthcare team when dealing with their patients at these milestones (see figure 10.11).

View Order and Time

A strength of the hierarchy used by the WFMS is its ability to show the sequence of the treatment stages. This functionality provides the healthcare team with accurate information about the order and timing of the treatment stages, which puts the history and milestones in a better

context and includes further details. This helps the healthcare teams come to a better understanding of the causes of and consequences of some of these treatment stages (see figure 10.11).

View Healthcare Professionals

In the hierarchy the healthcare team members involved in the treatment of patients will be included. Knowing the role and the specified healthcare professional for a role can help the healthcare professionals, when further clarification of a patient's state or referral is required (see figure 10.11).

User Specific Messaging (targeted)

This is the feature which customises the patient's information to the format required by a user. The information in the view is decided by the different users according to their roles. This functionality was suggested by the clinicians who were interviewed [248, 249, 250, 251, 252]. It can be added to the proposed system once the information requirements of each of the different roles are identified. Therefore, it is included as future work, see section 13.3.3.

11.2.4 Pro-acting to Changes

This is an important functionality coming from the use of Workflow Technology in the healthcare domain [253, 252, 251, 250, 249, 248]. It is the distinction between having an active and a proactive system. In the case of an active system, which most traditional CIS are; reactions are a response to requests made by the users, while proactive systems are capable of identifying the need to take an action and doing it if it is possible without intervention. The workflow engine within the workflow management system can be coded to fetch triggers, understand which of the users or roles are affected by this trigger, how they are affected and finally, take the appropriate action. These pro-active functionalities can be used to execute many different actions such as: alert, notify, refer, schedule and set timers. A clarification of how these different actions are executed will be given in the following sections.

Alert

Alerts in this context include cases when urgent or immediate reaction is required and also when specific information needs to be highlighted and considered by the team dealing with the patient. When an immediate action is required, the system sends an alert message to the inbox

of the identified user or role. In the case of important information within the patient record that needs attention, the system appends an alert sign to the information to make it clearly visible. An example of this is a patient undertaking chemotherapy or radiotherapy which the clinicians or nurses dealing with the patient need to be aware of, as it can affect their clinical decisions related to this particular patient (see figure 11.2).

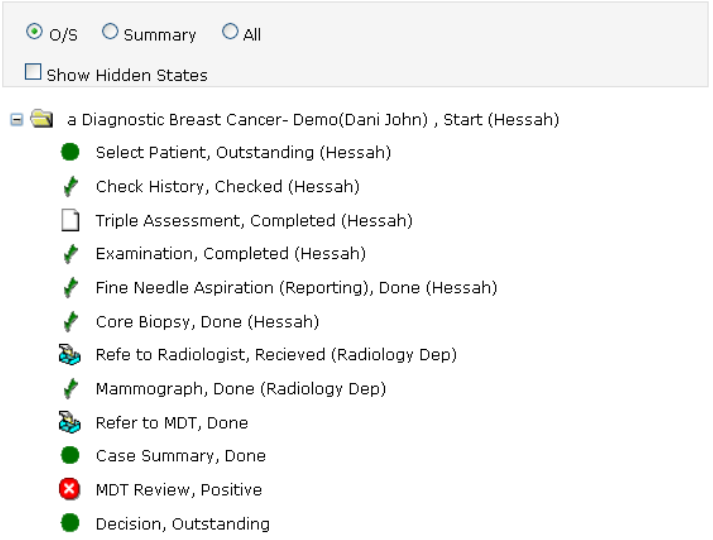

Figure 11.2: Alert.

Notify

The notification in this context is executed by gathering the information required at a certain stage of the process flow from single or multiple locations and making it available to the user. An example of this would be at a clinical visit when a clinical decision has to be taken based on the patient's current state. All requested test results and previous examination reports need to be available (e.g. for a MDT review) (see figure 11.3).

Refer

Automatic referral is a functionality that is currently being considered by the NHS for inclusion [253]. The NHS referral process proposes that a referral is targeted to organisations however we propose that it is delivered to an exact administrator or even to the specific person whose role means he/she will be taking the action needed to make this happen. This is done by delivering the referral letter to the targeted user and making it available in their inbox. An example would

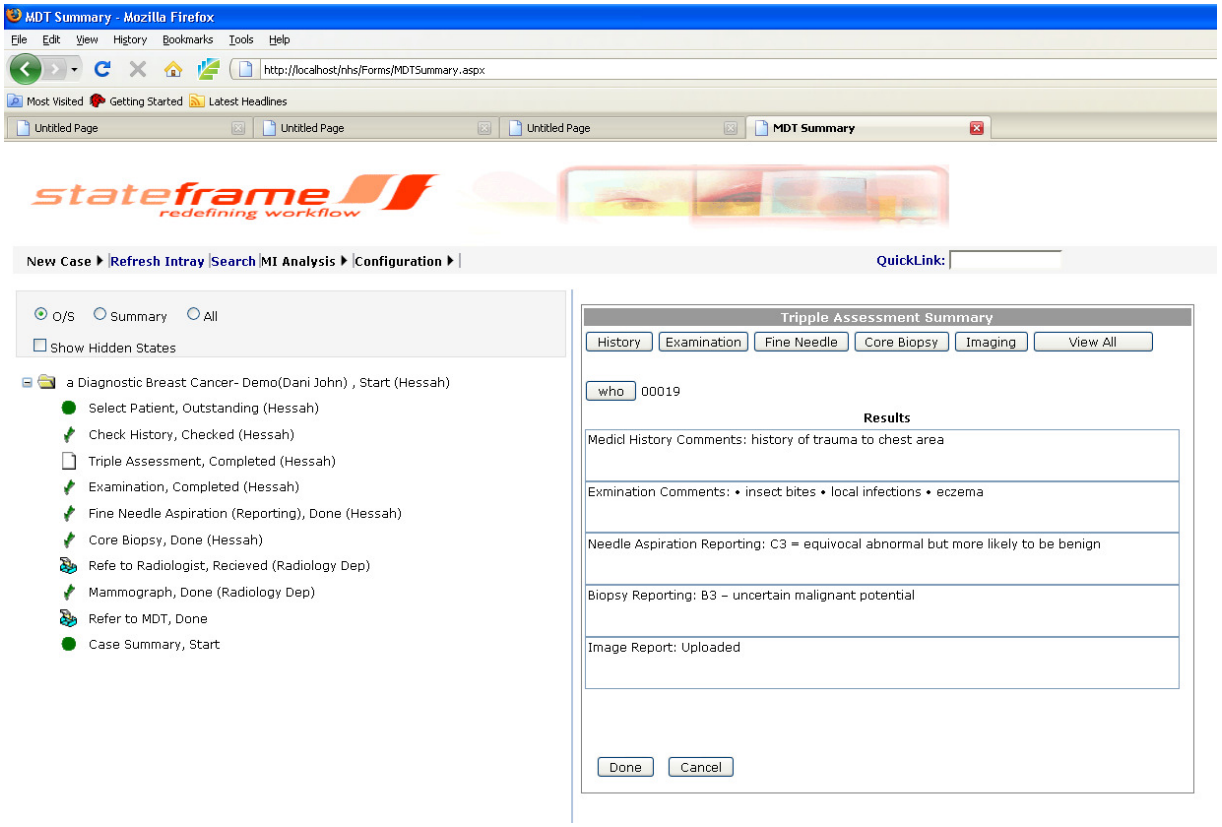

Figure 11.3: Notification for MDT.

be a GP referring a patient to the Oncologist who previously treated the patient when new symptoms needing further investigation occur. This overlaps with the care continuity functionality explained in section 11.2.2.

Schedule

The scheduling functionality presented here is that which is needed to formalise a process. This involves ensuring prerequisites or a sequence of steps are performed after or at a certain stage in the treatment. This is essential and is regarded as a highly important provision in the care process. An example of this would be a patient who needs to stop taking aspirin two weeks before scheduled surgery. Another example would be to enforce a two week delay between chemotherapy and radiotherapy sessions undertaken by a cancer patient.

Set Timers

Setting timers is needed when a certain action needs to be taken at a specific time. This is extremely important in ensuring continuity of care and that patients do not get lost in the execution

of the process (section 11.2.2). This functionality is carried out by making sure that information is delivered to the targeted user at the exact time it is needed. This can involve: sending letters to a user's inbox, executing alerts, sending notification, and/or doing referrals at a specific time. This overlaps with the care continuity function explained in section 11.2.2.

Chapter 12

Evaluation of the Proposed Approach

Overview

This chapter discusses the evaluation of the proposal. This includes: the usefulness evaluation by the healthcare providers, the technical evaluation by the community of the technology and the setup evaluation by CISs developers. This chapter concludes with an analysis of the results.

12.1 Introduction

This chapter evaluates the proposed techniques and technology to manage the treatment journey of patients in a modern NHS setting. It is evaluated by the three communities; the users, the technology experts, and the developers of CISs.

The actual users of the CISs are the healthcare professionals. They evaluated the usefulness of the implementation and the potential implications. The technology experts are the experts in the use of the technology. They evaluated the technicality of our vision and usage of the technology. The developers of CISs are IT developers involved in developing CISs. They did the setup evaluation of the technical possibility of implementing the proposal and adapting it to the existing CISs.

In section 3.2 we gave the research hypothesis as:

"By mapping the Integrated Care Pathway (ICP) representing the national clinical guidelines that reflect a patient centric treatment pathway into a Workflow Management System (WfMS) or a Business Process Management (BPM) System in an independent layer, and incorporating its interface in an evolutionary development approach into existing Clinical Information Systems (CISs), we can augment the functionalities of these systems to support team communication and care coordination among the multi-professional care team members working on a shared patient treatment journey(s) by formalising the treatment process, ensuring care continuity, filtering and gathering the information and pro-acting to changes."

In section 11.2, we described and showed the different functionalities the proposed system can provide to the user of the system. However, to validate the hypothesis we need to evaluate these functionalities to show: First, the added value; that is what it can offer is more than what is provided by the existing system. Second, the support; for team communication and care coordination among the multi-professional care team members. Finally, the feasibility; by showing it is technically possible to incorporate the interface of the proposed system with currently used systems.

12.2 Usefulness Evaluation

The user's evaluation aims to evaluate the usefulness of the proposed approach. It aims to get user feedback on the problems they have with the current systems, their perspective on the proposed approach, any advantages or disadvantages they can see of the new approach, and how the proposed approach can help address such issues.

12.2.1 Interview Structure

One-to-one interviews with five care providers at Velindre NHS Trust were conducted [252, 251, 250, 249, 248]. These were a physiotherapist [248], a palliative care consultant [249], and three consultant oncologists [252, 251, 250]. It is believed that this is a representative sample of the healthcare providers in a cancer centre. This is because the different specialities interviewed represented an approximate proportion of their actual percentage in a cancer centre setting. The number of Oncologist is usually more than double the palliative care consultants or the physiotherapists in a cancer unit.

Each of the interviews lasted for about an hour (for the interview transcripts see Appendix A). In each interview, the PhD researcher spent about ten to fifteen minutes presenting the proposed system and showing how it could support the treatment process along a patient's treatment journey. The aim of these clinician interviews was to evaluate the usefulness of the proposal from their perspective. The interview also aimed to elicit the interviewees thoughts on the proposal, how beneficial they think it would be and any concerns they have. The interview covered the multi-professional care team members' difficulties in currently getting a patient's information, its effect on the decision making process, and any information they would like to have available which was not currently available. A set of open questions were discussed with the interviewees, these questions covered:

1. Using the current system, do you have any problems in:
   (a) Not getting the information?
   (b) Getting information late?
   (c) Getting inappropriate information? If answer is YES, Please provide examples?
2. During clinical visits when making medical decisions depending on the patient information provided by the current information systems, how often do you:
   (a) Become unable to make a decision?
   (b) Need to make assumptions?
   (c) Rely on patients as a source of information?
3. Specify other information you would like to have in the system?
4. How much could this proposal:
   (a) Reduce your workload?
   (b) Save your time?

(c) Support medical decisions?

5. What are the disadvantages of using this proposal?

The first group (question 1 above) of the interview questions addressed the healthcare professionals' difficulties in getting a patient's stored information covering the three issues: information not being received, received late, or inappropriate information received. The second group (question 2) addressed its effect on the decision making process, covering the three situations: unable to make decisions, need to make assumptions or rely on patients as the source of information. The third open-ended question (question 3) aimed to address extra information they would like to have access to in the information systems they used. Finally, the fourth and fifth group (questions 4 and 5) examined the interviewees thoughts on the advantages and disadvantages of the proposed system.

12.2.2 Analysis and Results

The interview transcripts (in Appendix A), were primarily analysed by extracting information into three different tables. The first table presents the interviewee's information issues with the currently used systems (see table 12.1). The second table, table 12.2, is a summary of the behaviour of the existing systems in use and the functionalities the users would like to have in the information systems they use. The last table presents the interviewees thoughts on the potential benefits of the proposal and their concerns (see table 12.3). The results of the analysis in the three different categories are:

Information Issues

In table 12.1, the information issues discussed in the interviews are categorised into eight different areas. These information issues' areas are:

1. **Delivery**; this is the delivery information.
2. **Timing**; this is the delivery time.
3. **Content**; this is the content of information.
4. **Access**; this is how information is accessed.
5. **Effect of missing information on decision making**.
6. **Extra information needed**; what are the extra information items needed.

7. **Delivering mechanism**; ways of getting information.

8. **Passing mechanism**; ways of passing the information.

Some of these eight categories in table 12.1 have been mentioned/commented on in different ways, as listed in the table. The table presents each interviewees response to each of the categories, it shows whether they agree (✓), disagree (X), or did not mention it at all (␣). Some expressions used to describe the situation are included in the table.

Table 12.1 shows the specialists information issues with the current system numbered from 1 to 7. The table also shows the different comments discussed within each of these information issues and each of the five specialists responses (S1 to S5). Specialist one (S1) is a physiotherapist, specialist two (S2) a palliative care consultant, and specialists three (S3), four (S4) and five (S5) are consultant oncologists. We can see that the physiotherapist (S1) responded differently in most of the areas discussed. The consultant oncologists, specialist three (S3) and specialist five (S5), had almost similar views which the palliative care consultant (S2) also agreed on. Table 12.1 also shows that, the consultant oncologist (S4) had some differences in his responses from the other oncologists.

These differences are mainly due to the specialist's different roles in the patients' treatment and the way they actually work. The physiotherapist (S1) explained that she does not require a lot of information to handle the patient treatment and she is not involved in the decision making process. Urgent or critical cases are usually inpatient so they are treated in the ward where team communication and care coordination are done verbally or written in the case notes before information is electronically stored. The palliative care consultant (S2) is involved in research groups for CIS development which makes her more aware of not only palliative care specialist problems but also the need of other specialists. The two consultant oncologists in Lung and Urology (S3 and S5), had similar responses as they both have similar practice. The consultant oncologist in Bladder and Prostate (S4), responded slightly different to the other specialist oncologists. He explained that he treats a special group of cancer patients who get referred to him by a surgeon oncologist. This means he relies on a single source for his information who deals with the information collection. Moreover, as the treated group is limited the required communication and coordination is limited and therefore manageable. In the following sections the responses to each of the information issues (1 to 8) are discussed:

Comments	S1	S2	S3	S4	S5
1. Delivery					
Problems getting information	X	✓	✓	X	✓
Rely on different Sources of information	X	✓	✓	X	✓
Reports delivered but information needed missing			✓		✓
Reports not delivered		✓	✓		✓
Depend on amount of info you need	✓				
2. Timing					
Get information late	X	✓	✓	✓	✓
3. Content					
Inappropriate information	X	✓	✓	-	✓
4. Access					
Problems in the way information accessed	-	✓	✓	✓	
Use multiple screens		✓	✓	✓	
Use multiple tabs	✓				
Current way to access information is time consuming	X	✓			
5. Effect of missing information on decision Making					
How often do you become unable to make decision	N/A	-	+	-	-
Need to make assumptions	N/A		✓		X
Rely on patients as source of information	✓	✓	✓	✓	✓
6. Delivering mechanism					
Electronic	✓	✓	✓	✓	
Letter/Fax	✓		✓	✓	✓
Verbal/Phone	✓	✓			
E-mail					
7. Passing mechanism					
Electronic					
Letter/Fax				✓	✓
Verbal/Phone	✓	✓			
E-mail	✓				
Write in patient notes	✓				
8. Extra information needed					
Require more info than that provided	X	✓	✓		✓
Name of relevant care team			✓		✓
Coordination related info		✓	✓		✓
Relevant guidelines			✓		
Referral related information			✓		✓

Table 12.1: Information issues with currently used system.
Key: S{1-5}-Specialist interviewed, (✓) Agree, (X) Disagree, (␣) Not Mentioned, (+) Often, (-) Occasionally

Delivery

Table 12.1 (section 1) shows that, all interviewees rely on multiple resources to gather a patient's medical information, have problems getting the medical information they need about their pa-

tients (section 1). They clarified that sometimes reports do not get delivered (e.g. not typed yet, fax did not arrive or report not handed in yet) and occasionally they receive the required reports without a particular piece of information or detail they need (such as: size of tumour or the X-ray image). A care team provider explained that it really depends on the amount of information required to make an informed decision. However, they mainly felt that the more information they have the better informed the decisions are that they can make.

Timing

The specialists clarified that sometimes they receive the medication information late (section 2) (e.g. information in e-records is usually 2 weeks behind and when an image is requested, it usually takes 24 to 48 hours to be uploaded).

Content

The majority of the clinician's had problems with getting inappropriate information (section 3). One of the clinicians explained that it is a training problem rather than a problem with the current information systems, in that the change of the system will not improve the situation, if the staff do not receive training to improve their interaction with the system.

Access

Information access (section 4) was highlighted as one of the problems with the current system. Some of the users stated that finding the required information on the system is time consuming and difficult. This is because they need to use multiple systems and browse through multiple tabs within each screen to gather the information they require.

Effect of missing information on decision making

The majority of the clinicians clarified that they occasionally are unable to make decisions and rarely have to make assumptions due to the lack of information (section 5). When this happens they sometimes need to reschedule appointments, or waste a considerable amount of time searching for information. However, they always rely on patients as a key source of information and this is what some of them believe is an important part of the professionalism of what they do, as it is this interaction between healthcare providers and patients which convinces the patient they are being cared for by a person interested in their welfare.

Delivering and passing mechanism

Means of communication currently in use are a mixture of manual and electronic tools (section 6 and 7). It is mainly manual for across organisation information, unless a specific item is looked up in Canisc or the WCP. Information exchange can also be achieved by handwritten notes among care team providers within a ward. However, a clinician highlighted that information in the information systems are two weeks behind the collection time and two of the clinicians stated that you cannot get any updates about a patient's treatment occurring in the last week through the system. An Oncologist also clarified that if a specific piece of information/image is requested urgently over the phone it takes 24 to 48 hours to get it uploaded on the system.

Extra information needed

The majority (three out of five) clarified that they require more information than is provided (section 8). Some of the information clinicians would like to have in the information system are: names of relevant care team members, coordination related information, referral related information and relevant guidelines. The clinicians identified the medical information they require to include (see Appendix 1):

- medical history and medications,
- recent treatments and medications,
- standard checks and the outcome related directly to the current treatment stage,
- outcome of previously requested tests,
- follow-up information, and
- coordination related information.

Current System Behaviour and Required Functionalities

Table 12.2, summarises the system behaviour as seen by these users in this area. It starts with the existing systems' behaviour and then lists what the users would like to have in or from the system. The first part of the table shows, which of the interviewees mentioned any type of actions supported by the system, and if so how many different types of actions they mentioned. The second part shows the actions they mentioned as being needed and if it has been mentioned by more than one user.

Behaviours Analysis	**S1**	**S2**	**S3**	**S4**	**S5**
1. Existing Alerts					
Is the system in use pro-active?		✓			✓
Number of actions supported		1			1
2. Actions needed					
Would like to have any more alerts?	✓	✓	✓	✓	✓
Alerts for requested info available/ followup	✓	✓	✓	✓	✓
Alerts for dependencies		✓		✓	✓
Update about patient			✓	✓	✓
Need summary of case note/record		✓	✓	✓	
Recent changes				✓	
Need to know care team members			✓		✓
Need to ensure continuity of care		✓			✓

Table 12.2: Current systems' behaviour and required functionalities.
Key: S{1-5}-Specialist interviewed, (✓) Agree, (X) Disagree, (␣) Not Mentioned

When discussing the current system behaviour and functionalities (section 1 in table 12.2), two alerts within Canisc were mentioned. One of the alerts within the Canisc system is a drug adverse alert which is on a pilot phase for palliative care members and currently oncologists are frustrated in being unable to add alerts to the system and use this approach. The second is an alert when a patient dies.

All interviewees explained that they would like to have more alerts embedded in the system (section 2 in table 12.2) especially about the availability of their requested information and follow ups. Moreover, the majority wanted to receive updates on their patients and alerts related to their patient's treatment, which interact with or affect their decisions (dependencies alerts). Three out of the five clinicians interviewed would like to have a summary page of their patient's record, this is about basic *need to know* information. One clinician highlighted that he would like to have access to recent changes in the patient's treatment. Two of the clinicians highlighted that patients could easily drop out of the system and they would like to have support within the system to ensure the continuity of a patient's care. Others highlighted their need to know who are the care team members dealing with the patient, in order to achieve better communication and coordination in the team.

Potential Benefits and Concerns

Table 12.3 is a summary of the users' perception of the potential benefits and their concerns related to the proposal. Direct questions on the potential benefits of the proposed approach, on

workload, time, and medical decisions were asked. Other benefits listed are additional benefits mentioned during the discussion (section 1 in table 12.3). User concerns were asked for in an open question, where users listed what they could see as disadvantages of the proposal (section 2 in table 12.3).

Usability Issue	**S1**	**S2**	**S3**	**S4**	**S5**
1. Benefits/Advantages					
Reduce your workload	X	X	X	-	X
Reduce secretarial workload		✓	✓		✓
Reduce NHS workload (e.g. nurses, clinics)			✓		✓
Reduce stress				✓	
Save time	-	✓	✓	-	✓
Support medical decisions	N/A	✓	✓	-	✓
Improve communication	✓	✓	✓		✓
Improve coordination		✓	✓		
2. Concerns					
Access		✓			
Reliability			✓	✓	
Security		✓			
Training		✓			
Flexibility to fit multiple scenario					✓
Adaptability to different needs and working technique				✓	✓
Overload/ Noise				✓	✓
Definition of alerts/ triggers/ people				✓	✓
Time required to send				✓	
Time needed to receive				✓	
Price VS Benefit (use of resources)				✓	
Change Professionalism	✓			✓	

Table 12.3: Potential benefits and worries of proposal.
Key: S{1-5}-Specialist interviewed, (✓) Agree, (X) Disagree, (␣) Not Mentioned, (+) Often, (-) Occasionally

In section 1 in table 12.3, when discussing the benefits the interviewees could see from the proposed approach on their workload, the majority believed that it will not necessarily reduce their workload but will definitely reduce the secretarial workload. Others suggested that it would also reduce the NHS workload in NHS clinics, as the rescheduling of many appointments will be avoided and reduce the workload on nurses who spend a considerable time capturing information. The clinicians agreed that this proposal will support the decision making process and save them time (section 1 in table 12.3).

Concerns highlighted by the interviewees included (section 2 in table 12.3): access, reliability, security, and training. Access and reliability are important issues arising in the current system and will still remain if the proposed system was adopted. These are technical issues that do not effect the concept of the proposal. These issues require separate research and this is out of the scope of this project.

Security and information confidentiality is a very important aspect of any information system, especially in the health and medical care domain. This is being researched at the School in a separate PhD project (section 2.5.2) [51]. We will be looking at incorporating the two projects together in future work (section 13.2.2).

Training is also a concern when adopting new systems. However, in this project as we are extending functionalities of a currently running legacy system, the amount of training required if the changes were adopted should be minimal. As the changes proposed will not change the CISs that are currently in-use but will improve the interface provided to the users of these systems.

Other concerns (outlined by a couple of the interviewees) were: overload and noise and definition of alerts, triggers and people. These will require the users' involvement at the implementation stage. This will allow the user to specify their information requirement at the care point, as the interviewees say that it is standard and could be listed upfront. The documentation of the ICPs does help build up the system framework, however the healthcare providers will need to get involved in the identification and confirmation of their needs according to their specialities and roles. One of the suggestions was to give the users the option to customise their screens to meet their needs. This responder also suggested that users should have the option to switch the alerts off and have it on, only when requested by a user. These will be considered in the future work (section 13.3.3) which will look at how the care team providers would like to have the information and alerts presented to them.

Flexibility of the system to fit multiple scenarios and its adaptability to the different needs and working techniques was also a concern of two of the interviewees. We believe that this is the power of the BPM/WfM technology. It shows that each patient journey is unique and therefore has different case specific requirements. We also believe that the system has to be user-drive. This means the system is in place to support the decision process at the point of care, however, it was never intended that the system should drive the flow or make these decisions.

One of the consultants (see S4 in section 2 in table 12.3) was worried about the use of resources. He was worried about the balance between the cost and the benefits. He also questioned the time required to send and receive the information through the proposed system in comparison to the current time spent on these activities. This worry was completely understandable as the

consultant clarified that he is a specialist consultant oncologist in bladder and prostate, he gets referrals from a surgeon oncologist and treats a specific group of patients. This means he relies on a single source of information and treats a controlled group. The trouble and difficulty of the information collection about these patients is undertaken by the surgeon oncologist who refers the patients. Other consultant oncologists, who are not in this situation, disagree with his view as they thought the proposal would be a huge time and resource saver.

A couple of care team members interviewed, clarified that this proposal will change the whole professionalism of what they do. They believe that the doctor-patient interaction is what medicine is about and any change in this interaction will worry them. However, we believe that the proposal should document, confirm and detail the medical information. It should not replace their current working practice in the patient-doctor interaction but fill gaps in the information provided and confirm critical information.

12.2.3 Discussion

In the hypothesis, we claim that the implications of this proposal will augment the functionalities of the exiting system and it will improve the support for communication and coordination among the care team members. In the following sections we discuss the existence of the proposed functionalities in currently used systems. Then, we will discuss the interviewees views on the usefulness of the proposal.

Augment Systems' Functionalities

Table 12.4 shows how the different functionalities of the proposed system, listed in chapter 11, operate in the existing and proposed systems. It compares each of the functionalities and its subsets and how they are maintained or operate in both cases.

Table 12.4 shows that the proposed system will augment the current functionalities provided by the systems. Some functionalities are currently maintained manually and the proposal automate them while others are not provided at all within current system and the proposed system will provide them automatically.

Aspect	Current Systems	Proposed Approach
Process Formalisation	Manual	Automatic
Next Step	Manual	Automatic
Pre-defined Process	Manual	Automatic
Care continuity	Manual	Automatic
Referral	Manual	Automatic
Overdue Processes	Manual/None	Automatic
Information Filtering	None/ Standard	Automatic/Consider stage needs
Information Gathering	Manual/None	Automatic/Consider stage needs
Treatment Hierarchy	None	Automatic
Treatment Milestones	None	Automatic
Treatment Order and Time	None	Automatic
Involved Healthcare Professionals	Manual/None	Automatic
Reactive to change	Manual/None	Automatic
Referral	Manual	Automatic
Notification	Manual	Automatic
Alert	Manual/None	Automatic
Schedule	Manual	Automatic
Setting timers	Manual/None	Automatic

Table 12.4: Comparison between existing systems and proposed approach.

Communication and Coordination Support

Care team members communicate by exchanging medical information about their shared patients. Resources of the medical information can be manual or electronic. Coordination is a primary element of the teamwork activities in the patient centric approach. It ensures continuity of care, dependencies control, followups and updates. Coordination in current CISs, is manually maintained by the healthcare providers at the different organisations. In this section we will examine whether the potential implications of the proposed system supports and improves team communication and care coordination among the care team members.

Along the patient treatment journey, using the mapped Integrated Care Pathway, the system will support the different functionalities mentioned in section 11.1. These functionalities are :

1. Formalising the process,
2. Ensuring care continuity,
3. Filtering and gathering the information, and
4. Reacting to change.

Interviewees mentioned directly or hinted at these functionalities during the discussion sessions on the information issues in current systems in-use and their required functionalities. Table

12.5 presents the different information issues (table 12.1), the related comments to each of these issues and the relevant functionality that could support each of the comments. Only the information issues in table 12.1 which could be directly or indirectly related to the common functionalities (1 to 4) are listed in table 12.5.

Table 12.6 presents the interviewees required system functionalities (table 12.2), the related comments to each of these issues and the relevant functionality that can support each of the comments. The required functionalities in table 12.2 which can be directly or indirectly related to the common functionalities (1 to 4) are listed in table 12.6.

Comments	**Relevant Functionality**
1. Delivery	
Problems getting information	3
Rely on different Sources of information	3
Reports delivered but information needed missing	3
Reports not delivered	1
Depend on amount of info you need	N/A
2. Timing	
Get information late	1-2-4
3. Content	
Inappropriate information	1-3
4. Access	
Problems in the way information accessed	3
Use multiple screens	3
Use multiple tabs	3
Current way to access information is time consuming	3
5. Effect of missing information on decision Making	
How often do you become unable to make decision	3-4
Need to make assumptions	1-3-4
Rely on patients as source of information	3
6. Extra Information needed	
Require more info than what is provided	1
Name of relevant care team	3
Coordination related info	1-2-3-4
Relevant guidelines	1-2-4
Referral related information	2-4

Table 12.5: Functionalities linked to interviewees information issues.
Code: 1- Formalising the process, 2- Ensuring care continuity, 3- Filtering and gathering the information, 4- Reacting to change.

Comments	Relevant Functionality
Would like to have any more alerts?	1-2-4
Alerts for requested info available/ followup	1-2-4
Alerts for dependencies	1-2-4
Update about patient	2-3
Need summary of case note/record	3
Recent changes	3-4
Need to know care team members	3
Need to ensure continuity of care	1-2-4

Table 12.6: Functionalities linked to interviewees required functionalities.
Key: 1- Formalising the process, 2- Ensuring care continuity, 3- Filtering and gathering the information, 4- Reacting to change.

In the following sections we will discuss these different functionalities (1 to 4) and how they operate within the current systems. This will be followed by the link between these different functionalities and the interviewees' information issues (table 12.5) and required functionalities (table 12.6).

1. Formalising the process of the flow by automating pre-defined tasks and suggesting possible treatment progression. Currently the multi-professional care team members manually drive the treatment flow of their patients according to the national guidelines. However, using the proposed system, these functionalities will be automatically suggested by the system. Interviewees mentioned their need for a system that supports automation and treatment flow formalisation, directly and indirectly, as follows (see table 12.5 and 12.6):

   (a) Information delivery and content issues were raised by the interviewees. These include reports not being delivered, reports delivered late, and delivered reports include inappropriate information.

   (b) Direct affect of information issues on medical decisions was discussed. In such cases, healthcare providers become unable to make decisions, and/or need to make assumptions.

   (c) The interviewees need the system to provide extra information. The additional information they need, include: coordination related information, and relevant guidelines.

   (d) The interviewees would like the system to be more pro-active. The functionalities they require includes: support for alerts that requested information is available, followups, and dependencies, and to ensure care continuity.

2. Ensuring care continuity of the treatment flow is also not supported by the current systems. This ensures that the patient is tracked and a care plan is progressed to the end. This is particularly important when a patient's treatment is provided in separate organisations.

Two healthcare providers mentioned that a patient could easily drop out of the system. Care continuity in this context occurs during the referral process and when submitted tasks are overdue. Tables 12.5 and 12.6 list the care continuity related issues mentioned in the interviews. These are:

(a) Information timing issues were raised by the interviewees. The related comments mentioned: getting the information late, and getting inappropriate information.

(b) The interviewees also mentioned that they need extra information to be provided by the system. The information they require which affects care continuity includes: coordination related information, and referral related information.

(c) The Interviewees also would like the system to be pro-active. This is to support alerts for requested information, followups and dependencies, updates about patients, and to ensure care continuity.

3. Filtering and gathering the information along the patients' treatment journey. As patients undertake their treatment, the proposed system will store information about each of the treatment stages. This will enable the system to track a patient's treatment progress, summarise history, identify milestones, record the order of each process and record the timing. The associated healthcare providers with treatment stages will also be linked to each patient and therefore identified. Also, healthcare providers can receive tailored messaging according to their speciality and a patient's condition as well as according to the current treatment stage. The system will then be capable of extracting and filtering information according to the user request. Interviewees confirmed their need for these functionalities (see tables 12.5 and 12.6) as follows:

(a) The interviewees raised information issues, related to information filtering and gathering, such as: delivery, and access.

(b) Interviewees also stated that information issues affect the decision making process. Consequently, at decision points the healthcare providers become unable to make a decision, need to make assumptions, or rely on patients for information.

(c) The interviewees highlighted their need for extra information support by the system. These include: information about relevant team members, and coordination related information. This information is required to help the healthcare providers communicate with the rest of the team and obtain missing information.

(d) The functionalities required by the healthcare providers on the currently used information system which are not available include: updates about patients, summary of case notes and records, recent changes, and the involved care team members.

4. Pro-action to changes is also proposed to support communication and coordination among the healthcare providers. This is achieved by taking appropriate actions whenever they are needed according to the mapped guidelines. These actions include: alerts, notification, referral, schedule-rescheduling, and setting timers. This is achieved by associating the different processes with relevant logic, the appropriate action, the target and the actor. This enables the system to consider treatment dependencies and control follow-ups and updates. The need for a proactive system has been directly and indirectly mentioned by the interviewees as shown in tables 12.5 and 12.6, as follows:

   (a) The healthcare providers explained information issues related to getting information late.

   (b) Difficulties in making decisions has also been discussed with the interviewees. As due to lack of information they are sometimes unable to make decisions or need to make assumptions before making a decision.

   (c) The interviewees confirmed their need for extra information to be provided by the system. This information includes: coordination related information, related guidelines, and referral related information.

   (d) The users confirmed their need to have more alerts in the system. The required alert functionalities by the users include; alerts for requested information being available, followups, dependencies, recent changes, and to ensure care continuity.

Tables 12.5 and 12.6 show that the potential implications of the proposed system are that it will provide functionalities that healthcare providers would find useful and helpful. The interviewees confirmed that it will support and therefore improve the communication and care coordination among care team members and that is an outcome they welcome.

12.2.4 Usefulness Conclusion

CISs within the NHS are currently disease-centred. They were originally designed to support the previous disease-centred healthcare delivery model. These information systems mainly focused on the needs of the speciality they were built to support. This means that CISs within the NHS are discrete to hospital areas. We proposed mapping the ICP or the clinical guidelines into a WfMS or a BPM System to support the treatment flow to create a system which gives better support to care team members. The proposed system can operate as an independent top layer above current CIS systems, and interact with current legacy systems to access their information. This will be done by creating or utilising a link to existing CISs to support accessing its data. This will provide information needed in the different treatment stages according to the treatment

pathway. Thus this project's aim to logically connect the CISs within the healthcare domain through the use of a workflow based approach has been achieved.

The NHS healthcare providers confirmed that they work as a team, when they treat a shared patient. This team includes not only healthcare providers within a single organisation or level of care but also providers from different organisations and care levels. CISs currently in use, are not suited or were not originally designed to support teamwork activities. They lack an understanding of the logic and therefore are unable to undertake any action to support the treatment flow to keep it inline with the national guidelines. At any treatment stage, care team members handling these processes should be able to communicate medical information about the patient to other team members and coordinate the care provision according to the guidelines. Thus, they require different information and actions appropriate to the current treatment stages.

According to the user's evaluation conducted in section 12.1, this proposal meets the needs of the multi-professional care team members for team communication and care coordination support. Positive comments from the interviewees about the potential benefits confirmed their need for such an approach (see table 12.7).

Specialist	**Quotes**
Specialist 1	* "I do not think there is any disadvantage. I think it is the next step really. I think it is the way forward" * "I can see a need for the electronic system to incorporate that (physiotherapy and rehabilitation) part of it so there is an assessment, a rehabilitation assessment section."
Specialist 2	* we have a drug adverse alert currently in a pilot phase and only palliative care add (more alerts), oncologist are frustrated because they would like to add to it. * "I think people can drop out of the system, somehow they are lost. So this system that would actually highlight that would be very important" * "... that would be very helpful, because I think that coordination is where things go wrong and time is wasted" * If you could actually extract the most recent summary... "OH MAGIC"
Specialist 3	* Knowing about "...decisions made that affect my treatment, to know about that as they happen would be very, very helpful" * "it is still very difficult and time consuming to put it (info about the patient from different DBs) all together"
Specialist 4	"... there is no automated system going around at the moment, there is no reliable way of being given that information"
Specialist 5	* "So I think that would speed communications and improve care quite a lot" * "I could see that would be a big time saver"

Table 12.7: Quotes from specialists' interviews.

To sum up, this proposal will help support the healthcare providers daily activities as it will improve communication among the care members and improve care coordination of the treatment according to the ICP guidelines. Other benefits include:

- improved efficiency,
- better use of resources,
- reduced workload,
- saving time,
- improved traceability,
- change management,
- context-based access,
- context- based action, and
- system adaptability.

These benefits overlap, however they all come together to give better support to the multi-professional team's activities.

12.3 Technical Evaluation

A case study of the breast cancer scenario implemented in this proposal was submitted to the WfMC [11] for entry to the "Global Award for Excellence in Adaptive Case Management (ACM)" [10] in 2011. The case submitted was awarded the Golden Award in the "Medical and Healthcare" category.

12.3.1 Submission Process

The process of submitting the case study to the award was in two stages. First, an abstract was submitted for initial review. Second, depending on the reviewers, a full case study is submitted for final judgement. The feedback of the two stages will be presented in the following sections.

12.3.2 Initial Submission's Feedback

An abstract answering the following questions was submitted to ensure it was a qualifying ACM case study [10]:

- Who (by the roles within the organisation) are the users of the system?
- What area(s) of the business does the case management system affect?
- Why should this submission be considered a successful case study?

The initial feedback on the abstract submitted, by the two reviewers was as follows :

- "Healthcare is the natural place for a case management solution. From the description this is a direct fit into the desired category. I would be very interested in how the doctors are able to augment and adapt the processes directly: what formalism is used to describe the process to them, and how do they express changes " [254].
- "A good fit for (an) ACM case study. Recommended to move ahead with submission. Looking forward to reading the full story " [254].

This very positive feedback motivated the move to the next step of submitting a full case study, for inclusion in the competition.

12.3.3 Final Submission's Feedback

The full case study submitted also went into a review process were the judgement criteria were: innovation, adaptability, and impact. In the live award ceremony winners announcement, two of the reviewers explained their thoughts on this proposal (see Appendix B for full transcript of the award winners announcement). The consideration and the inclusion of the reviewer's feedback is very important, considering their experience in the technology and its usage. The reviewers were: Keith Swenson and Nathaniel Plamer. A short biography of the reviewers is:

- "Keith Swenson is Vice President of Research and Development at Fujitsu America Inc. and is the Chief Software Architect for the Interstage family of products He is known for having been a pioneer in collaboration software and web services, and has helped the development of many workflow and BPM standards. He is currently the Chairman of the Technical Committee of the Workflow Management Coalition. In the past, he led (the) development of collaboration software (at) MS2, Netscape, Ashton Tate and Fujitsu. In

2004 he was awarded the Marvin L. Manheim Award for outstanding contributions in the field of workflow" [255].

- "Nathaniel Palmer is a Principal and Chief BPM Strategist with SRA International, Inc. [NYSE: SRX] a 1.5 Billion dollar system integrator (company) based in Washington, D.C., where he serves as a leader of the BPM and SOA Practice. Also Editor-in-Chief of BPM.com, as well as the Executive Director of the Workflow Management Coalition" [256].

The judges comments on this proposal's case study we're announced in a live ceremony [10]. The judges comments are summarised in table 12.8. In table 12.8 we classify the judges comments by the three judgement criteria; innovation, adaptability, and impact.

12.3.4 Discussion

The technology experts' evaluation is considered an important evaluation stage of this research. Their acknowledgment of it is a valid approach and recognition of its innovation is an important recognition of the value of the research.

In terms of the innovation, the judges found that the approach looked in-depth into the improvement needed in the domain and that it represented a very good example in a very engaging and promising case study. The innovation involved using workflow technology as a platform for a team collaborating around the patient. This was achieved by following the lifecycle of patients and their treatment management and involving the multiple organisations and users involved in the care team. This provides context-based information in real time.

In terms of its adaptability, the judges found this to be satisfied by having the right information available at the right time. This was achieved by supporting automation with a lot of consideration to the need to adapt the pathway to the individual patient and provide options to the users to control the pathway being followed.

The impact was viewed by the judges to be supporting patient-centric care, pulling organisations and healthcare providers together and supporting collaboration among these elements. Moreover, they asserted that the proposed approach allows doctors to be knowledge workers and support the decision making process. Doctors in this case will spend more of their time looking after their patients rather than looking for the medical information they need was a conclusion of the judges. We are not sure this will be the case and future work will have to investigate this aspect.

Criteria	Judge Keith Swenson	Judge Nathaniel Palmer
Innovation	* Really good example * Very engaging and very promising case study for all of us * Make a fixed business process and lets nail exactly how we do that * I was very encouraged by this whole thing * Very mature look at the improvements that need to be done	* Use ACM as a platform for collaborating around the patient * following the lifecycle literally of the patient * Focused on care provided over the course of disease management or something that in effect is going to involve multiple hospitalisation, multiple professionals * Interesting framework on how to have that information really, in real time context, but also provide that platform for professionals to collaborate around
Adaptability	* Every patient is different and you have to adapt to it * Adapt to the needs of each patient * Flexible * Giving options * Procedures will be routine or surgeries could be routine but there is no routine patient	* Interesting framework on how to have that information really, in a real time context, but also provide that platform for professionals to collaborate around
Impact	* Patient-centric * Pull organisations together * Tool they need to then make decisions and act on them * Doctors being knowledge workers	* Collaborating around the patient * Patient centric * Following the lifecycle literally of the patient * Involve multiple hospitalisation, multiple professionals * Interesting framework on how to have that information really, in a real time context, but also provide that platform for professionals to collaborate around * Clinicians will spend their time not dealing with the paperwork but really dealing with the delivery of healthcare

Table 12.8: ACM award reviewer's feedback.

12.4 Setup Evaluation

The final approach undertaken to evaluate the proposal, was an evaluation by the actual developers of current CISs. The author had an evaluation session with four members of the CIU at

Velindre (for the session transcript see Appendix B). The members attending the session were David Howells and Rhodri Evans (Principal Software Developers), Hazel Bailey (a Principal Support and Business Analyst), and David Morrey (the head of the CIU at Velindre). The aim of this session was to evaluate the possibility of setting up and adjusting the proposal to work with the current legacy systems.

12.4.1 Session Structure

The evaluation session lasted for an hour and fifteen minutes where the author explained the approach, the scenario selection process, and the mapping process. Screenshots showing some of the prototype results were also presented and discussed. This was followed by a discussion about the usages, the approach, and the challenges of the proposal. The discussion was led by open-ended questions, which are grouped to discuss teams feedback on these aspects.

Usage

The usage questions mainly aimed to discuss the use of the approach in relation to Canisc. This included what they had already implemented for Canisc and what they plan to implement in the future.

- Would the requirements you already implemented for Canisc benefit from having a process engine?
- Can an event driven process engine, implement any of your future plans to improve the user functionalities?
- Would you consider moving to a more active system?

Challenge

The challenges set of questions aimed to discuss the possibility of applying the proposed approach, and the barriers to its implementation.

- Do you find the implementation of this approach possible?
- What would the barriers be to its implementation?
- Does it require re-engineering?

Approach

The approach questions aimed to discuss the advantages and disadvantages of using the proposed approach.

- Did you consider using similar ideas in the past?
- Would you consider using this approach in the future?
- What are the advantages of this approach?
- What are the disadvantages of this approach?

12.4.2 Analysis and Results

The CIU team at Velindre agreed that having a process engine that recognises the pathway is very useful. They see the need for it in healthcare systems and in cancer care in particular. They confirmed that the adoption of the approach can make the treatment process more efficient. Moreover, it will merely transform the pathway to be electronic.

In terms of the usage of the proposal, the team confirmed that it is extremely relevant and lined up with the future plans for Canisc. In particular, it is ideally suited for the management of the MDTs within Canisc.

The team at Velindre also pointed out that Canisc already implements some of the workflow elements. One of these applications is the Ionising Radiation (Medical Exposure) Regulations (e-IRMER) [257], which is a radiotherapy planning and treatment scheduling and prescribing module. E-IRMER is both process and role based. The MDT summary in Canisc is also similar to this concept, where the system view everything the clinicians need to know, for an MDT, in one screen. Within the system, they list three of the most recent summaries and give the access to information available elsewhere.

Although similar elements of process engine have been implemented within Canisc, the team believe that the implemented functionalities can be done better using the proposed approach. These additional advantages include, the automation of the process which facilitates the team updates. They also clearly recognise that any planning process for any treatment can benefit from this approach.

The team at the CIU identified the clinicians ability to describe their needs as one of the barriers of implementation. Dr. Morrey said: "It is like chicken and egg, the clinicians are not used to thinking or expressing their business requirements in terms of an event driven system". The team

agreed that clinicians are used to a more passive system. Therefore, they are used to expressing their requirements as access to the dataset within these systems. However, if clinicians express their needs as events, this will help information system developers understand what they want.

Mr. Howells drew attention to the worry that this approach could be rigid and never change to meet different cases. However, Mr. Evans stated that this depends on how high level you view it as if you pitch it at a higher level you should cover 80% of the cases. Additionally, if the process map is done at a high level, probably 97% of cases will be covered. The higher this percentage covered is, the higher the risk becomes. This is because the clinicians will find it harder to remember the rest of the cases which do not fall into the mapped path.

This led to a discussion on finding the balance between presenting the right information at the right time and the risk of information not being available. This is because not all the information can be shown to the users which introduces a risk. However, Ms. Bailey stated that clinicians constantly make decisions where they do not have all the information available that there is a bigger risk, in stopping them from looking at the information. Therefore, they suggested providing access to other information or just giving the user the ability to flip between the workflow view and the traditional system.

In the discussion regarding the approach, the question about who is the decision makers was raised - namely is it the system or the clinicians?. This is when the author confirmed that decisions within the system are user driven and the system should not act on behalf of them. At the clinical decision points, the system indicates that relevant information is available and the final decision is taken by the clinician. This is when it was clarified that the system should be role based driven with respect to clinical decisions as well as patient driven according to the medical condition.

Another aspect discussed, regarding the approach, is where the data will be stored. At this stage it was clarified that the clinical data are stored in their own database. However, the process and coordination databases will be stored at the interface layer attached immediately to the workflow engine. Here the problem of information overload within the engine was raised.

The CIU team at Velindre described their move to this approach as an incremental step. The barrier to its implementation within Canisc will be the cost and specifying the requirements to justify the cost and the learning process. Add to this, the time needed for setup.

Mr. Howells believed that the interface with legacy systems is possible but not easy. This is as different versions of Health Level Seven (HL7) [258] are used in the implementations and each is engineered differently within the legacy systems.

In terms of whether the approach requires re-engineering, Mr. Howells thought it does, while Mr, Evans clarified that if it gets implemented on top of the current system only a web layer is

required, which should not be a worry. Although it is not a straightforward process, it will not require re-writing the system but adding databases and engines. Moreover, the data exchange mechanism among legacy systems needs to be identified as to whether it is setting triggers to fetch new information or just waiting for the information to be sent (i.e. pull or push).

The disadvantage of this approach is the maintenance overhead, which could be costly depending upon how often it needs to be changed and how easy it is to change. This is the biggest disadvantage of the workflow items already used within Canisc according to Ms. Bailey [259]. However, having the workflow managed in a separate workflow system should make changes to the workflow easier to implement [259].

12.4.3 Recommendations

The team at the CIU suggested a number of recommendations as follows:

- The inclusion of the role based access to identify the people who need to know the information. This is to ensure the treatment process is user driven as well as patient driven.

- The use of the MoM guidelines to give the level of abstraction required for the map is valid. However, this should be followed by getting the users perception on this represented in a conceptual model or demonstrated in a prototype. Accordingly, users should alter the requirements to satisfy their clinical needs. Moreover, the developers need to discuss with the user and explain how things could be done more efficiently using an event driven approach.

- The team also suggested giving the users the option to switch from the workflow layer to Canisc to provide access to the full clinical record. This is to ensure that the system is not preventing access to any of the medical information that could possibly be required for a decision.

- The team agreed that this proposal is better implemented with something like the WCP. This is because it has interface access to many of the required legacy systems at the moment. This means that the WCP can be used as the connection to the other systems. This is probably the right place for this approach, to avoid doing the interfacing with the legacy systems again. Although it could be used as a type of functionality within Canisc, it may be more generic in the WCP.

12.4.4 Discussion

The developers evaluation confirmed the possibility of adopting the proposal. They confirmed that the existing system can benefit from having a process engine and confirmed that they are moving towards implementing workflow concepts. Within the currently used system (Canisc) some workflow elements are already implemented but not by having a WFMS. However, the CIU team at Velindre confirmed that these would be implemented in a better way using the proposed approach.

Worries including the flexibility of the approach and the balance between the information being presented and withheld were raised. This was discussed fully and it should be addressed by not limiting the access information and showing the most-likely needed information. Add to this the fact that clinicians have confirmed that they can identify upfront the information they require to make the medical decision (see section 12.2). This links back to the team's recommendation to involve users before the final implementation to ensure their needs are met. The presentation of the information was another issue that has been highlighted as part of the planned future work (see section 13.3.2). Other worries such as the cost, resources and setup, are general worries and are not directly related to the approach proposed.

In terms of the connection to the WCP, this can be used to reduce the technical effort needed to setup the interfaces to the legacy systems. However, this is only if the WCP is to be used as middleware system to facilitate the connection and provide access to medical data. This is because a major part of this project is following up the treatment stages as the patient care progresses along the treatment pathway.

12.5 Generality of the Approach

As mentioned in section 10.2, there are many similarities between the stages of the different cancer treatment ICPs. For this research, we mapped the breast cancer ICP into a workflow system. In this case, the proof-of-concept prototype can only be used for the breast cancer scenario as we never intended to make it usable/adaptable to support other cancer treatments. However, if it was to be extended to support other cancer treatments, we would undertake the mapping into a workflow system in a different way. This would involve mapping the common stages in the different cancer ICPs into separate workflows. This would be called as needed in the progress along the stages of the different cancer ICPs. Examples of these workflows include: an assessment workflow, an MDT referral workflow, and a treatment options workflow.

This would mean that the process of constructing a full workflow process would be similar

to using building blocks to construct a complete structure. The different combinations of the building blocks could be changed to improve or change the resulting structure so that it targeted particular goals. Similarly, the sequence of the sub-processes representing parts of the ICP could be changed to easily adapt for changes in the treatment practice and the ordering of the stages could be easily changed so that the system supported other similar cancer treatments. However, a skeleton workflow process is needed for each of the cancer ICPs, which identifies its progress logic. This skeleton workflow would include the unique treatments stages of the target cancer ICPs and call the common sub-processes and specialised in the right time and order for this ICP.

12.6 Conclusion

The three different evaluations conducted on the approach, confirm that the proposed approach is useful, innovative and possible to implement. The healthcare providers confirmed their need for the functionalities provided by this approach to support team communication and care co-ordination. The workflow technology and BPM community acknowledged the novelty of the approach, and its impact. Finally, the team at the CIU at Velindre NHS Trust confirmed that it is possible to adopt the approach and adjust it to link with the legacy systems.

Chapter 13

Future Work

Overview

This chapter suggests future work which could be carried out based on this research or in areas that this research has identified which could be worth further investigation.

13.1 Introduction

The use of workflow technology in the healthcare domain is very promising. The approach proposed in this research proved to be useful, as a way to implement support for patient-centric care in a novel way (see chapter 12). However, we still believe that more advantages can be achieved using this approach. In addition, some ideas were identified while developing this research that are worth further consideration as future work.

These will be discussed under four areas - Firstly, integration with health informatics projects at Cardiff School of Computer & Informatics; Secondly, extension of the research for inclusion of other aspects; Thirdly, generalisation of the approach; and Finally, inclusion of other areas of interest which are not directly related to the approach.

13.2 Integration with Work at Cardiff School of Computer Science & Informatics

As explained in chapter 2 (see section 2.5), a number of related projects have been undertaken at Cardiff School of Computer Science & Informatics in Cardiff University. Some of these projects are directly related to this project and are based on the same background. For future work it is hoped that this work gets integrated with this related, relevant work to advance support for patient-centred care by creating systems with greater functionality. In particular the following should be considered.

13.2.1 Integration with Coordination Database

The inclusion of a relational database to link patients to care teams and care teams to roles and policies will add a lot to the offered functionalities by the workflow engine. This has been discussed and introduced in [7, 6] (see section 2.5.2). Skilton's project VOICE [48], supports role-based access and allows practitioners to identify other team members. The inclusion of policies within VOICE allows the system to provide active notification and basic communication tools for care teams. Linking WffICP and VOICE would allow dynamic support and automation as the patient progresses along the care pathway by ensuring that patient related data is up-to-date, can be accessed when necessary in an efficient way, and that appropriate actions are taken with respect to changes in the patient's care flow. It would allow advanced support for the different teams and roles. This can be achieved by retrieving the involved healthcare providers within the coordination database and their roles, identifying who are affected by the change happening in

the treatment, and executing the appropriate policy for each role. Although part of this integration has been researched to show it is achievable, we still need to do the practical integration of VOICE and WffICP, in order to investigate the advanced support for team communication and care co-ordination that can be achieved through this integration. Moreover, how this can be implemented is also worth investigation.

13.2.2 Integration with the Security Project

Inclusion of security aspects within the flow is a very natural extension of this work (see section 2.5.3). Alsalamah's project [51] is looking at setting different security constraints for information sharing in a distributed care environment. These rules are identified according to the role of the healthcare professional in the treatment and the organisation's role in the communication process (i.e. sender or receiver). The project also looks at setting different constraints at different parts of a single medical report or document. In this research we showed that the WFMS layer accesses different sources of medical information attached through links to distributed legacy systems. These medical information sources are viewed by healthcare providers at the point of care, as required. If this project's outcome is to be applied in this domain, rules according to permissions associated with roles will require further study. Moreover, a further investigation on how this might affect the project needs to be undertaken as the initial stage.

13.2.3 Collection of Experiences

In section 2.5 related projects within the school were introduced. Most of these projects are looking at the collaboration and the team work aspects of patient-centric care. Also, the majority of these projects focus on the cancer care needs as a model for collaborative patient-centred care. An earlier project also looked at the communication between the GP and a cancer unit and specified a common EPR which could be used to fulfil the information needs [54]. Most of the research in this area build on and/or complement each other. It is hoped that the experience of these researchers and the outcomes of the work is brought together in a single publication/-book. The size of work conducted is large as it has been accumulated work of about 10 years. These different projects addressed the same problem domain but from different angles, such as: database structure, treatment flow, and security. Therefore, it would be a useful initiative to document this experience in a single publication and link all of the aspects together. This will also open-up other areas that could be researched in the future.

13.3 Extension of the Research

There are a lot of interesting areas in this research which could be extended by future investigation. These were not included in this project due to the time limit on this project. These are overviewed in the following sections.

13.3.1 Extension of Actions

This research showed that a lot of advantages are achieved by using workflow technology in this domain. However, we believe that there is a lot more that can be achieved using this approach. We focused on just part of the breast cancer care domain, in that we looked for stages where healthcare providers need support. We are certain that the inclusion of the whole breast cancer ICP or other Cancer ICPs will show other cases and open-up new opportunities for different actions to be investigated in future projects.

13.3.2 Presentation of Actions

A very interesting yet important aspect of this research is the Human Computer Interaction (HCI). This requires a full study on the best way to present information, execute actions, and support process execution. This includes the science and the preference of the healthcare providers as to what is presented and how it is presented. Moreover, the integration of the WFMS's interface with the legacy systems needs investigation. It could be achieved in a separate tab, link or within the medical summary page. These different options need to be investigated further to determine which would be best suited to the approach.

13.3.3 Advance Features

Some examples of advanced features that are worthy of investigation include:

Advance Scheduling and Optimisation

One of the implications of this approach, mentioned in section 11.2.4, is that the scheduling functionality needs further study. In this research we used scheduling to check for incompatible actions and to avoid any possible complications. The example used was the gap required between chemotherapy and radiotherapy treatment and how it could be enforced using workflow technology. This scheduling functionality could be extended to support optimisation. This

could be done by considering the undertaken and upcoming events. An example of an undertaken events, which could be used for optimisation, are laboratory tests. These could be used by the multiple healthcare providers involved in the treatment of a single patient. Scheduling can also cover upcoming events. The system would check the anticipated care pathway and determine whether when it is likely that a patient will need to have other laboratory tests while one is currently being ordered, to determine whether a combination of the required checks could be requested. This avoids duplication and also ensures better use of staff time. Moreover, if implemented properly, benefits will include cutting down cost, and waiting times as well as improving a patient's satisfaction with the treatment and well-being if the extra tests provide more relevant input to the treatment.

Customisation

The clinicians interviewed confirmed that they can specify in advance the medical information they require to make an informed decision (see section 12.2). Others also expressed their preference to have control over how to get the alerts within the system (see section 12.2). These are very interesting areas to investigate further as they will lead to different ways to give the users the ability to customise the system to suit their personal preference and their roles.

13.4 Generalisation of Approach

The proposed approach in this research has been carefully studied for the breast cancer care scenario. The ideas proposed can be applied to other cancer or non-cancer treatments of patients following an ICP. However, this needs to be confirmed by further investigation. This requires further understanding and investigation of the requirement within different ICPs and identifying how they relate to the requirements in the breast cancer scenario. Other generalisation ideas include:

13.4.1 Generic Pathway

One of the areas that the author is personally interested in investigating is the possibility to identify a generic pathway which could be applied to the different ICPs. It is believed that there is commonality and that there should be an abstract guideline which defines the treatment journey patients go through. This could be from testing, through to clinical decisions, to treatment options. This requires further study and if achieved could be used to generalise the concept proposed into a number of treatment areas.

13.4.2 Requirement of Different Domains

It would be very interesting to identify the requirements of different ICP pathways, other than cancer, and the breast cancer ICP. This will help first identify more actions (see section 13.3.2) and help in generalising the approach to identify, what can and/or can not be done using this approach.

13.4.3 Requirements of Concurrent ICPs

To take this proposed approach to a more advance level, we need to investigate scenarios where patients follow multiple ICPs. This will occur when a patient is being treated for more than one medical condition. This will introduce more complex requirements. Discussing these fuller requirements will help address these more complex scenarios and thus generalise the concept to apply to more complex scenarios.

13.5 Investigation of other Areas of Interest

There are interesting areas emerging within eHealth which the author also finds interesting. These are not necessarily directly related to this research but are important. They include:

13.5.1 Empowering Patients

This is a very interesting area and is one of the topics discussed very often recently especially with the new approaches being followed in the NHS [260]. We believe that the patient should be involved in the process and the workflow technology might have a role in allowing this. This is an area that should be investigated further. In the context of empowering patients, MoM Healthguides provides versions of ICPs provided to patients through NHS Choices [261].

Chapter 14

Conclusions

Overview

This chapter highlights the key aspects of the work, assesses the achievements against the aims and concludes the overall research experience and outcomes.

14.1 Conclusions

This research focused on the requirements of the emerging patient-centric delivery model. This is where the healthcare providers need to collaborate together as a team to support the needs of each patient and take account of the patient's treatment in a holistic way. Team communication and care coordination were tools needed to facilitate this team collaboration. The ICP is a national guideline that reflects a patient-centric treatment pathway. It outlines the suggested guideline for treatment of a patient, including the different treatment stages and their logical sequence, the involved CISs and healthcare providers within each stage, and the information requirement of each stage as well as its deliverable(s).

The IT development team at the Velindre Hospital identified their need to support the healthcare providers to implement patient-centric care. They identified that difficulty in accessing the medical information is what is hindering the implementation of patient-centric care. The team also clarified that they plan to add alerts within Canisc. This is needed to support healthcare providers in making informed medical decisions by having all relevant information available at the point of decision.

Legacy systems currently used at healthcare organisations are usually clinically-centred. These were designed to support the early disease-centred delivery model. Each of these systems is connected to their own data which stores their disease-focused medical information. These are mainly administrative systems which recall the required data within their own repository about the disease, when needed. The main constraint within the healthcare environment is the fact that these legacy systems cannot be changed across all healthcare organisations at the same time. Therefore, as access is needed to several of these systems, they need to be evolved to support the emerging requirements.

This research proposes an approach that uses workflow technology to support the implementation of patient-centric care. This research shows how ICPs can be mapped into a workflow engine and where it can be placed within the software architecture. This is to implement a WFMS which constructs an independent layer and places it as an interface between the users of the CISs and the legacy system. The interface of the WFMS will be linked to the interface of the legacy systems to provide more functionalities. This will keep legacy systems in place but enhance their operation by enabling them to provide information to other organisations and diverse care teams.

This research proposes an approach which constructs a VO around a patient. It allows the different CISs and healthcare providers within the different healthcare organisations to operate around the requirements of patient care in a patient-centric approach. This VO supports the information exchange and data access from the discrete CISs allowing its operation as if it

is integrated in a single place. This is achieved by virtually integrating the data within these systems as needed.

A proof-of-concept prototype, WffICP, has been implemented. For the implementation, an anonymised subset of Canisc database was used as Canisc is a CIS and this shows that the WffICP prototype can use real clinical data. We mapped the ICP of a breast cancer treatment into a Stateframe WFMS. The mapped ICP represented the guidelines for the treatment process, as an ideal or anticipated flow. However, at run time, for each patient, an instance/object of the process is created. This constructs an instance with a unique combination of stages that represents only the patient being treated by the care team. The flow and stages within the treatment is dependent on elements such as: the patient's medical condition, available resources, and the choices of the patient and/or the healthcare provider. The treatment flow within the WFMS represents the patient's own version of the ICP. This is at the heart of patient-centric care.

The implementation of WffICP helped investigate and demonstrate the implications of the approach. It supports team communication and care coordination by: formalising the treatment process, filtering and gathering the patient's information, ensuring care continuity, and proacting to change. The prototype demonstrated the following actions: refer, alert, notify, schedule, and set timer. These functionalities are executed according to the medical condition and the treatment stage.

This proposal speeds up the administrative process, within the treatment flow, by automating some tasks and driving the task submission process. It also supports the clinical decisions, and helps the treatment to follow the clinical guidelines, by suggesting the next step according to the guidelines. However, the final decision is made by the healthcare providers. Thus the care team is the control of the treatment pathway. Additionally, it ensures patients do not get lost within the system by embedding flow checks within the care pathway.

The proposal also provides a tool to track the patient's progress along the treatment journey. This is achieved by keeping a record of the treatment stages of each patient. This presents the treatment history, the milestones within this history, the order and the time of each treatment stage and the organisation and the healthcare care provider involved in each stage. This ensures better informed decisions are made and eases communication among the healthcare providers whenever they are needed.

Safety, error reduction, and correction functionalities are also supported through this proposal. This is achieved by setting safety constraints within the systems engine and ensuring that these are met along the treatment flow. In case these constraints are not met, the system takes appropriate action.

A major benefit of using this approach is the fact that it improves the information system in use but retains complete autonomy. This is by keeping legacy systems in operation and evolving their functionalities. This makes the proposal more realistic, possible to implement and economical.

The biggest achievement of this research is the ability of the proposal to take account of team communication and care coordination required within the treatment stages. It is the support for team communication and care coordination as It identifies the requirements of the current treatment stage, retrieves the required information within the silos of heterogeneous distributed databases, and presents this information as needed. Moreover, this is done within the one system that is in operation. It is also driven according to the national guidelines and is customised to fit each individual patient.

This proposed approach has been evaluated at three stages; First, a usefulness evaluation by the healthcare providers representing the users; Second, a setup evaluation by developers of CISs, Finally, a technical evaluation by the community of workflow technology. The healthcare providers' confirmed their need for better support and the benefits that could be gained if an adaptive and a proactive system like this was used. The IT team at Velindre believe that it is possible to adopt and adapt the proposed system and have it operate with the systems currently in use. Moreover, they confirmed that the offered functionalities by the proposal cover some of their planned improvements for the currently used information system. The community of workflow technology confirmed the novelty and innovation of the proposed approach.

The current projects that use workflow technology in the healthcare domain mainly use it for administrative purposes. None of these current projects propose the mapping of the ICP for team communication and care coordination support in patient centric care into a workflow. Moreover, none of these projects looked at constructing an independent layer of a WFMS which accesses the different CISs holding appropriate information through a wrapper to do the required support for team communication and care coordination and access to distributed information.

This research proved that the use of the workflow technology in the healthcare domain is very promising. It is a powerful tool that can be used to support more functionalities than those presented in this research. This research suggested areas to investigate as future work. These include: extending the approach to present more actions and investigate how these actions should be presented, and generalising the approach (if possible) by investigating the user requirements in other domains and if appropriate to model a generic pathway.

This work proved that such a system can support the healthcare providers by allowing them to operate in a patient-centric care approach. It supports this process without taking control, which makes the approach completely controllable by the healthcare providers as the decision

makers. The proposal provides support with a lot of focus on the needs at the treatment stages. Therefore, we argue that, it extends this support as it can also be used in treatment-centred care. This proposal changes the way information within the silo databases are used, in that it utilises this information in an active rather than passive situation.

Appendix A

Clinician's interviews

Overview

Five one-to-one interviews with clinicians has been conducted to evaluate the usefulness of the proposal. Each interview lasted about an hour. Full Transcripts of the interviews with the clinicians is in this section. The **bold** text represent interviewee's part of the interview.The clinician's were interviewed by the author and the transcripts was done by Isabel's Typing Services (http://www.isabels-typing-services.co.uk/).

A.1 Usefulness Evaluatin

A.1.1 Interview with Helen Taylor

Helen Taylor - Therapies Service Manager

The bigger picture, so what we're looking at mainly is supporting the team work along the integrated care pathway or multidisciplinary care. How we see it is it's a set of processes that the patient goes through and to support the flow of the treatment we believe that we need to manage the changes within the flow. So if there's some points where the flow could go into different paths, and whenever a decision is made how we can manage the whole set of actions that are coming along the way.
It's by managing the changes happening and taking the appropriate action according to the decision that is made, and along the pathway the patient passes through different care team members or care team members do take care of the patient and you need to make sure that you keep a record of who was involved in the treatment incase you need to do an alteration. For example, you know exactly how to notify, just to make sure that there's no information overload to anybody and the exact information you need to send is sent to the right person.
So this is an example of an integrated care pathway. I took this one from the Map of Medicine.
Right. Yes.
So this is a diagnostic of breast cancer clinic. Here's the oncologist that will be involved. There's a history considering the following investigations, examinations, imaging and fine needle aspiration for example. Then there are more tests and then there's the multidisciplinary care team review. The multidisciplinary take the decision, they look at the history and all the tests and then they decide whether there's positive finding if the patient has cancer or they need, I think, inadequate or non-concordant, triple assessment so more assessment is needed or there is no abnormalities. This is a decision point, for example, we're looking at and if there is positive finding and there is, for example, cancer, then you need to notify people treating the patient, the people involved that the patient has cancer. For example, here inform the GP, you have to have a record of who is the GP and send the information.
So what's motivating this project is a move towards patient centric, the idea that clinicians shouldn't work in isolation and they all need to work in a team to look after the patient. So we believe that each of them need to be aware of the patient's different treatments and to be notified about the patient's progress, if the patient is under chemotherapy, for example, and alerted about changes happening to the patient, if a diabetes doctor is looking at the patient and the patient has cancer, maybe they need to know about this new condition, and maybe they need to change, I don't know, medication.
Okay. For the clinicians, we believe that if this project could be implemented into the care system it will reduce their work load because information will be available in their notification. You don't need to go and look for the information, it should be alerted or shown in your mail or something, it will save your time by having the information available and not having to look for it, and supporting the decision making process, so you make sure

that you have all the information available before you make a decision. The driver is also the expansion in the health and in what context the project [00:06:13] and better access to medical records, better information exchange, and we're involving here the GP, the general hospital, a specialist like Velindre and there's new approaches being introduced.
So the next step is we're looking the care and we believe that at some stage communication is provided, so we believe that at some stage maybe in the future, I'm not sure exactly how it is here but clinicians may be able to access the information through Canisc, but you need to log into the Welsh Clinical Portal and get the information. But we believe that coordination is also important and it's missing in the care system, how to coordinate the care among different teams and the different locations.
So what we're looking at is making the system more proactive and that it does take actions whenever needed, because we're looking at the integrated care pathway, the system can understand the history and the anticipated care pathway and the current stage, who is involved in the different healthcare issues. So it's not a one integrated care pathway, it's the idea of understanding the multiple integrated pathways, so that a single patient might be following, like diabetes in cancer. The changes in any treatment followed take the actions across all of the care pathways.
So what we're proposing is there's a work flow management system technology, or work flow technology which we believe can be adapted to the existing systems to support the flow, so you keep track of the movement of the patient and take actions according to that. So the integrated care pathway can be implemented or mapped to the work flow management system, all of this incorporated within the health informatics system, like Canisc, for example, and then to improve care coordination, and the system can automatically detect changes, identify the teams and manage the changes.
Another example is alerting if there is something that needs to be alerted, notifying, scheduling, timing, for example, after the surgery when the patient waits for two weeks I think, before they see the doctor again and they want to make sure that patient doesn't get lost in the process and the referral has been within a certain length of time.
So to Canisc, we're not proposing a new system at all, it's amending the functionalities to support the proactive system. I am aware that Canisc is not as we've explained, it's not proactive, it doesn't take action, it does the communication bit, but it doesn't alert whenever it's needed or send specific notifications to refer, I think a referral is included now?
'm not sure.
[00:10:01]. I want to show you an example here that just presents the idea. So this is the work flow we were looking at just now and it shows you the different people involved, and this is the same pathway we were looking at, this is the multidisciplinary team, and this is the different.
And this is from the Map of Medicine, is it?
This is from the Map of Medicine, this is one piece, and this is one I extracted from another flow, but it does show here there is something in the middle, some steps. But at some stage when the patient is diagnosed with cancer, there are options of treatment, radiotherapy, chemotherapy, surgery somewhere here. So the patient moves through the stages, the patient is here, the General Practitioner refers the patient now to this cancer unit and then a number of examinations, so this is an examination document, and this is the image document, for example, and then when the case is discussed in the MDT review we need

to make sure that.
All the information goes with the patient.
All the information goes with the patient. So this is one example and this is a good example, the notification. Then here if the patient has cancer and primary breast cancer is confirmed then you need to put an alert in to everyone who is involved with the patient that they have cancer. If he's following non-surgical options and the patient is doing grade D therapy then you have to be careful, chemotherapy, then you have to be careful with scheduling and rescheduling because it has to be.
Yes, at a certain time, yes.
Yes, at a certain time. This is when the patient is doing both and the patient goes to the surgical options, after the surgery there is a timer to check when the patient should be referred. So this is just an example to show in one pathway how much the work flow management system can operate and process, and having patients with multiple conditions, that's another story.
Yes, it's never that simple, is it?
It's never that simple. So this is what I am mainly looking at and I would like to know from you how much you see this as being beneficial to the system. So I have a couple of questions at the end of.
Okay.
Not really a couple, but [laughs].
That's fine.
A number of questions. But to start with, using the current system do you have any problems? I mean the current system, do you mind if I write it down?
That's fine, no. The current system we don't use, we only use a very small part of it in therapies, so we don't have any problems gaining the information we require.
Yes, so the information you need is limited, let's say?
Yes. I mean physiotherapists may like to look at radiology reports and perhaps haematology reports. The dieticians may like to look at the biochemistry reports. So that's the sort of level that they would need.
So you don't rely on information coming from another resource?
No.
You provide that information?
Yes.
It's the other way around.
Yes.
But how is the referral done? I mean if the patient needs to have therapy, how do you get the?
By a written referral.
A written referral?
Yes.
There's sometimes urgent cases, do referrals get lost or?
I mean most of the urgent ones would be in the in-patient setting, so it's all word-of-mouth. We have a multidisciplinary team meeting every morning so that the patient will be discussed, so we will then go and see the patient on wards. If it's on the out-patient setting then we have a fourteen week waiting time target, so there's always plenty of time to get the information that we require.

So you've never needed extra information, so it's just the referral and then the patient comes?
Yes, and then we do our own assessment on the patient.
Oh yes, I see. So I think that, doesn't that also apply to the therapy?
I suppose that's medical decisions, isn't it?
Medical decisions, yes.
Yes. So no, that wouldn't apply to therapies.
How much do you think could this proposal reduce your work load? I mean if you get it electronically to your in-tray or to your inbox?
Yes. I mean it would save a little bit of time from an in-patient point of view because we do have to go to the medical notes at the moment and read them through so that they're, at the current status of the patient as they come into the hospital is recorded in the medical notes. I wouldn't see a patient and a therapist wouldn't see a patient without reading that. If it was on the Canisc case record notes it would save a small amount of time just because we wouldn't have to go to the notes, we'd just read it on the screen. But you're on the ward anyway, do you know what I mean? So you're reading the notes. You've got to read the current day's update because you need to know what happened to the patient last night, let's say, and speak to the nurses. So I wouldn't say that this proposal would save the therapists any time.
Yes. So with the in-patients, you read the written medical notes. But with the outpatients you access the Canisc and read the record notes?
Yes, yes.
So it's not a file, it's an electronic system?
Yes, yes.
But do you need the system to highlight some bits for you? I mean what would you be interested in, what kind of information would the therapist be interested in?
I mean the physiotherapists at the moment in the out-patients we see are the post-breast surgery patients and the post-head and neck surgery patients, and for those patients it would be useful to have radiology reports, if there was any possible cord compression or something like that. But to be honest that would be flagged up anyway I would have thought. Bone scans, I think they're all held though aren't they, they're all there in Canisc.
Yes, but it easy to search or does it need more highlights in the system just to make sure you see it when you?
I mean at the moment if they're looking for radiology they just go on the drop-down list to radiology and look for what they need. I suppose if there was a drop-down list that said, chest x-rays, spinal x-ray, you could just click on that rather than having to go through every report.
Yes, I understand. So it's easy to access anyway? Yes, there are certain things, but it's easy to access?
Yes.
Did you say an alert would help?
I suppose if there had been a recent bone scan, and perhaps if it was a positive bone scan if there was an alert that automatically came up to say, rather than somebody having to go and look for it. But then we would look for it anyway because it would be something that we would have to know in the interest of the patient.
Yes, I see. Okay, this is about the work load and saving your time.
It wouldn't reduce the work load because the work load is in the treating of the patients really, so we would have to get that information. Saving the time, it might be a small amount, it's

easier to read on a screen than it is on notes, sometimes you can't find the notes, they may be with the doctors, so a small amount of time there would be saved on making difficult decisions. So that wouldn't affect us because we're not making the medical decisions. But then I suppose if we were inputting information that the medics might look at, if it was about say, rehabilitation potential, that might support their decision on where that patient might be discharged to.

So the information you're feeding to the, how do you write the report, do you store it in the system?

Yes, we store it on the therapy tab and there's a drop-down list then for physiotherapy, occupational therapy, dietetics, speech and language therapy, complimentary therapies. So they just annotate their daily input, whatever treatment they've given it's annotated.

And there's no urgent things that you need to, I mean if there's something urgent, are there some cases where the permission or the oncologist to know about now?

Yes, perhaps there are a few things, although I don't think they tend to read it at the moment. We would like the nurses to read it more but they don't seem to have an interest or the time, they always say that they're too busy to go onto the system to look.

So how do you inform the nurses about urgent?

Verbally.

Verbally. Does it work very well?

They write it down but it doesn't always get handed over. We always tell them that it's on Canisc if they need to know, because we will tell them, write up our notes. We have to write our notes within twenty-four hours of seeing the patient. So we always say to them, you know we might say to this nurse today, this patient is now sat up to 60, if it's a cord compression patient. She might write it down, she should hand it over to the next shift but if she forgets the next shift can look and say, oh yes, he's at 60 degrees, because it can be written.

So by telling this information there's no action that needs to be taken straight away. I mean if you have an alert which will show straight away when they open, it might help with taking actions quickly. I'm not sure but.

It's not necessarily anything that the nurse has to do though, it's just that the nurse has to be aware of it so if they then go and wash the patient they know how to sit him back in the position he's supposed to be in. So it's nothing that they have to act on necessarily.

Yes, I understand.

Sometimes it is. Sometimes you'll say, can you in ten minutes go and look at that patient and make sure that he's not in pain or he hasn't lost any power in his legs. But they wouldn't go to Canisc to find that out, on the wards that would be done verbally.

Yes, and is there certain information that you might need to pass to the oncologist before he sees the patient?

Occasionally, very rarely though. It would be perhaps if the patient has a lot of pain. Perhaps in the out-patients setting I can think perhaps of some situations, but if the physiotherapist has seen a patient for say, shoulder dysfunction and she's worried, maybe she's picked up a lump or something abnormal, what she would normally do at the moment would be to write a letter to the doctor, whereas if she was able to put it into Canisc with an alert that the doctor saw it. But then there would have to be an alert mechanism because the doctor wouldn't necessarily be looking at that patient that day, so there would have to be some alert that popped out.

Which is not in the system right now?

No. Well, if there is we don't use it. The physiotherapist would write the letter.

How long does the process take from putting the information in to the oncologist seeing it,

does it take time or is it immediate when you put it in the system until the oncologist can see it?
Oh, they can see it straight away, but they wouldn't necessarily be looking for it so the physiotherapist would have to contact the doctor to say, look at Mrs. So and So. But generally what she would do is ring him and say, I'm worried about Mrs. So and So, I found a lump today can you see her more urgently? Or contact the secretary and say, could you book this patient in with the doctor because I'm not happy with the symptoms today. She would have to document that, so she's put that in the physiotherapy annotation. But if that popped up as an alert, but then if the doctor didn't go onto the computer that day he wouldn't see it. So it's better to be done by a phone call or an email to say, I'm concerned about so and so, can you see them?
Don't you think that is quite time consuming?
Yes. I mean if every doctor looked at every case note or went onto Canisc and looked at all the alerts, like a news-feed almost, to say what's happening and who's put what about my patients today, then yes they could act on it.
Also the idea of you having to ring whenever, but maybe it doesn't happening that much?
No, no it doesn't happen really.
That's why it's not.
No, it's not going to reduce work load or save time dramatically because this is small amounts.
So what do you think the disadvantages are of using the [00:25:24]?
I don't think there are any disadvantages. I think it's just the next step really, I think it's the way forward. But for me as a therapist team I don't think we have, we're not taking part in the active cancer treatment, we're there for supportive care and rehabilitation. So from my point of view I don't see any disadvantages.
Yes, this is one of the questions I maybe asked you before. I suppose as you mentioned you look at certain things before you treat the patient and you can find them easily in the current system.
Yes, at the moment I don't hear any complaints from the staff to say, I couldn't find this and I couldn't find that or I need to know this and couldn't get it. Everything is there that we need.
What if the patient has other medical problems, not only cancer, do you as a therapist need to know information?
For some things, yes. But then we always take our own history of the patient anyway.
How do you take it?
Verbally.
Verbally?
Yes.
Is it, I mean maybe not all of the patients are?
No, we always ask them. For example, when you take a history, when you have a new patient then you ask them why they've come today, what their problems are and what their past medical history is. So you'll just ask them, have you had any major illnesses? I mean if that was already stored and you didn't have to ask that, that would change the whole sort of professionalism of what we do. I mean I know all doctors when they see a new patient they always ask those questions, it's part of your standard clerking process. If that was already stored then you would have had to have read it anyway, do you know what I mean?
Yes, I understand.
So it's the difference between asking the patient or reading it, I suppose if it's already there.
So would you prefer to have it on the system or, milestones in the history, things that any

doctor or any therapist would need to know?
Yes, I mean if it was there already that you could have access to, that they had a heart attack last year, if that was already in there that would be useful to know when you're then confronting the patient you may want to do exercise with. But like I say, traditionally physio will ask that, just because we need to know.
Knowing your history how much time does it take for the visit?
It's a very small part.
A minute or two, something like that?
Yes. Yes, and it would probably take you that long to read it anyway wouldn't it?
Yes. So when you look at history you look at big things?
Yes. From a therapist point of view we wouldn't need to know the detail. If we were using the example of a cardiac incident this would only be if you were trying to say, get somebody to do some exercise and you'd know what their blood pressure was, you'd have to know that today, not what it was a year ago. Do you know what I mean? Because it's today we're doing the exercise.
Yes, I understand. Good. I think that's, oh I had, it's not here. Sorry. I had a thank you slide. [Laughter].
No problem. No problem.
Thank you very much for your time.
I mean I think we've sort of said the therapy side of this sits to the side of the thing, it's not necessarily in the mainstream, however I think in the future rehabilitation will be something that has to be addressed formally and there are discussions at the moment of a patient coming to the end of their treatment, so on your Map of Medicine slides where at the moment it ends with radiotherapy, chemotherapy, the active treatment, I think there should also now be a section on rehabilitation and that the patient will be assessed at the end of their formal first line cancer treatments for a rehabilitation appointment to be made with them for their needs to be assessed, because patients are living longer but they're not necessarily living symptom free, they've been changed by their disease, even if they've been cured, they've been changed, and there's still a problem perhaps. For me I think I can see a need for the electronic system to incorporate that part of it so there's an assessment, a rehabilitation assessment section, shall we say. But it's not there yet.
Yes, I understand.
Okay.
Thank you very, very much. I appreciate your time.
No problem. No problem.

A.1.2 Interview with Dr. Rhian Owen

Dr. Rhian Owen - Consultant in Palliative Care

This is my 2nd evaluation meeting with Dr. Rhian. For me someone who looked at the system it was planned to be a clinician evaluation, but to be involved in the development at Canisc, and it's going to make a huge difference now, this research, I'm sure. What we are looking at is applying the technology and getting involved. I believe you got involved in the details of the functionality and stuff like that.
Yes, to some extent [laughs].
To some extent [laughs]. No, but having both views is really what I am looking for. So just to give you an idea of what we're trying to do. Okay. First of all I am a PhD student at Cardiff University of Computer Science and I'm in the final year. [00:01:11] last two years. The bigger picture of mainly what we are looking at is the team work. We believe that the healthcare professionals or healthcare providers each work as a team in the patient's centric approach or the collaborated delivery model*, and what weÕre looking at is how we can support the flow and the progress and the process of the patient, the healthcare delivery for patients.
We understand that there are integrated care pathways and guidelines that are available and these show how the process should flow, not necessarily exactly but around.
Kind of the best practice in what should follow in a patient's journey.
Yes, in the patient's journey.
Right.
We're not restricted to that, we're not restricting the flow to that because we understand that each patient's pathway is unique and patients can be following more than one integrated pathway at the same time. But what we're looking at is how you manage the changes along the pathway, and what we mean by changes is something happening to the patient, a new decision is made, a new medication is given, how can you make sure that you manage that and that the patient is safe throughout the process.
So what we're looking at is the different change point in the process. So for example, if the patient has cancer confirmed, the clinicians confirmed that the patient has cancer, so this is something maybe other clinicians dealing with the patient need to be aware of. Another thing we're looking at is how you associate the care team members with the patient. So you make sure that you keep track of who's the oncologist dealing with the patient, who is the GP of the patient, so whenever a change happens you make sure that you deliver the message to the right person. So there's a problem of information overload and making sure that you target the information to the right person.
This is an example I have extracted from the Map of Medicine and it shows the breast cancer clinic, a diagnostic for breast cancer. It shows the flow where the history is checked by the oncologist and then considering the following investigations, examination, imaging and finding aspiration, for example, and then at some stage a multidisciplinary team will review the test results and then a decision will be made. So this we believe, or this is what we call, the change point.
Right.
Here a decision is made and at some stage here the GP needs to be informed, for example if breast cancer is confirmed. But we believe it's not only the GP who needs to know, you

need to make sure that you understand the complications of the case and notify whoever is involved in the process. So the motivation basically is the patient centric and the collaborated model and the move towards the idea of teams rather than disease centred.
Can I just? How does this take onboard the issues surrounding information governance?
I am not sure. What do you mean by information governance?
Information governance is who has access to which part of a patient's record.
Oh yes. What we're looking at is, my research is not really looking at the security and the confidentiality.
That is to be sorted at another aspect, kind of thing?
Yes. But we are assuming currently, well, I understand that clinicians do have access to the Welsh Clinical Portal or will be having access to the Welsh Clinical Portal?
Yes.
Which has all the information, so it's just a way of reorganising this information and putting it in a visible way for the clinicians, to save them time searching for the information. But the restrictions of who accesses what is not what I'm looking at.
Okay. This is assuming that that's all worked out?
Yes.
In a way [laughs].
In a way [laughs]. We have another PhD student who is my sister. She is working on security in the healthcare domain. So she is looking at this level after we're, maybe she can be an exception to this.
Yes, keep it in the family, but not you [laughs].
[Laughs]. She's working at this university, you might see her soon evaluating her work or something. But yes, it's future work and we're planning to extend this to that level later. So what we're looking at is making sure that the clinicians or the care professionals are aware of their patient's different treatments, notified about their progress if they need to, and to be alerted about any changes happening to the patient as appropriate. So not everyone, but whoever is involved and not only everybody involved, but who is involved and needs to know the information. For the clinicians we hope it's going to reduce their workload. They might see it in a different way in that they need to do some coding or enter some data entry into the system. But looking at the Canisc system I believe it's going to see the time of logging into other work clinical portals and trying to look for the information you need. I'm hoping that will save your time as a clinician and support the decision making process. You have all the information, you are aware of the medications that you need to be aware of, medical problems, and hopefully make a better decision.
So the main driver is the e-health expanding, and in this project we're looking at better access to medical records by different healthcare members from the different locations, better information exchange, and new approaches are being introduced. So we believe that the next step will be improving coordination. We suppose, or we believe that at one stage communication will be available and information will be accessible, no matter how. But there is still the coordination among the team and passing the information between one another, and our focus is on providing a proactive system that does take an action, a meaningful action according to the treatment history, the anticipated care pathway, so what happened, what's going to happen, which stage the patient is at now, and who is involved, different healthcare issues and hopefully the changes throughout this flow.
So what we are doing is looking at the guidelines of the best process and mapping that into

an integrated care pathway to a work flow management system, and incorporating it into the existing Canisc information system. So nothing is going to change, the Canisc information system should stay as it is and you have this as a higher level, a top layer that keeps track of the movement of the patient and what are the different stages that the patient is passing through.
We believe by doing this we can improve the coordination along the journey by automatically detecting changes and identifying who is involved and what needs to be done, so a manageable change process by either alerting or notifying, etc. To Canisc we're not proposing a new system it's just to keep the existing system as it is and we're hoping to just add more functionalities to it by making it proactive. But I understand that the current system does not have an alert notification that I'm aware of, [00:10:43]?
Not really, I don't think. In the palliative care system we've added a data item which is an alert of a drug reaction or an adverse reaction and that's then available when the patient demographics come up you can tell that an alert has been added. But that's, and I can't remember what else we're looking, oh yes, we've been looking at two different levels of alerts. We've been looking at alerts related to actually within the patient themselves such as a drug reaction, but weÕre also looking at a different kind of alert such as for whatever circumstance this individual should not be visited by one person, that there's a health professional safety issue. So that's a kind of external alert as opposed to an internal alert for that individual patient.
Yes. That's an interesting alert [laughs].
But there are times when a patient shouldn't be visited by one individual, that there should always be two people going to see that individual for various reasons.
Yes, I understand.
So I don't know if those were the alerts that you kind of think.
Yes, of course, definitely. But is it limited to only the drugs and the.
So those are the only things that I've been involved in discussion and the concept of having external alerts, and internal to the patient alerts. That's as far as we got.
Yes, and is it running now?
The adverse reaction is running.
And how is admissions dealing with it, do they like it, are they finding it useful?
Well, I think people are finding it useful. We're trying to keep it that it's, at the moment because it's in a pilot phase that itÕs only palliative care professionals that can actually add, and in fact the oncologists are getting increasingly frustrated because they would like to add in. So I think it has a use, yes.
That's great. This is what we're mainly looking at, I'd like to show you a scenario that I did just to give you an idea of what we have in mind. It's a movie, not a movie but an animated flow.
Right.
If this is the patient diagnostic for breast cancer, this is the integrated care pathway we saw before, and we're taking various steps in the [00:14:13] but these are different treatment options that the patient might go through, radiotherapy, chemotherapy, surgeries, somewhere here, and at the beginning will be by a referral either be it by a professional or a general hospital. These are the different roles or people involved in the treatment process. This is the patient and a referral is happening here by the oncologist, so this is one of the changes that we are looking at. If the patient goes through a number of tests or investigations then there might be a document from the examination, a document for the

imaging and another document for the final aspiration.
Then at some stage the case will be reviewed at the MDT where a notification is needed so you collect all the information and make sure that it's [00:15:17]. There, in the meeting and if breast cancer is confirmed then there's another, they keep it in the records, in the system so whenever any clinicians or any care team member dealing with the patient can see it's visible in their entry, and if the patient is under radiotherapy then they have to be aware of that and then if the patient is taking chemotherapy and radiotherapy then there has to be a scheduling and rescheduling here.
What I understand, I don't have a very good background, but what I understand is there has to be a gap, a fixed time between radiotherapy and chemotherapy, so the system should be able to.
To sort that one out.
To sort that one out. Just like formalising the process and making sure that it's done according, if there are restrictions then it follows these. If the patient goes to surgery then there is, go to post-surgical [00:16:43] reviews, so there is a period where the patient needs to recover before the case is reviewed or something like that, and there the system can assist like a timer and at the right time it sends the message required. If you send it early it might be forgotten, but if you send it at the right time we're hoping that it ensures that the patient is advised.
It's kind of trying to prevent people going, dropping through the system because they get lost.
They get lost. This is what I was, I remember one of [00:17:32] she said her mother-in-law passed away and they kept receiving letters two or three months after she passed away, so sometimes patients get really lost in the system. I would like you to help me evaluate the ideas we're proposing and how much that would be beneficial to the clinicians and to the decision process. So I have a couple of, not really a couple but more than a couple [laughs].
Honesty is the best policy [Laughing] .
These are some questions that I have in mind and I would like to know your opinion. So using the current system and Canisc, do you have any problems getting the information or getting information late or getting inappropriate information, so how much information does the system provide?
Are you asking that from a palliative care prospective or trying to think about any clinician and what I hear about the system?
Yes, from the general clinicians view.
Right. As it stand now.
I would like to hear both views [laughs].
As it stands now the current system would not, certainly in MDT's and I've really been more involved in colon and rectal MDT's, but very similar to the breast MDT there's a set time between having radiotherapy and then actually having your surgery in rectal cancers and there's huge potential there for the oncologist not being aware of when the surgery was undertaken. So actually that would be really helpful if there was an alert to the oncologist, that it wasn't relying on a phone call.
Yes, I understand.
I think from upper GI there are people that are discussed in the MDT and they need to come back for a re-biopsy, say in Barrett's esophagus, they need to be sure that they come back in a certain time. I think people can drop out of the system, somehow they're lost. So this system that would actually highlight that would be really important. In fact okay, Barretts is one but in

any MDT when there are issues of, we need to re-biopsy this, we're not totally conclusive of what stage this is or that they need to have further x-rays. Something that makes sure that after a certain time, well, has this person had that x-ray? This person needs to be re-discussed at the MDT, have they had the x-ray to allow them to come back to the MDT? That would be really helpful, because I think that coordination is where things go wrong and time is wasted.
So the problem is not with the information, the information is available but being aware of what's, is it?
It's relying on people in way to ensure that that appointment been made, and if there's been a delay there's nothing to flag up to the MDT, that individual needs to come back for discussion by this time and they're not being discussed, why is that the case? Does that make sense?
A lot of sense, yes.
So that there needs to be something that flags up this patient was discussed on date A, it was decided they should have a repeat biopsy, a repeat MRI, whatever that decision was that should have happened by now and we should be re-discussing the case, why aren't we?
So I'm not sure if that's not getting the information. I think that's getting the information late because that test hasn'been done, for whatever reason.
Inappropriate?
Let's see, inappropriate information. I don't know.
Yes well, I mean ideas, what is not enough?
From a palliative care prospective at the moment, not getting information yet, we don't get information yet because that's a person problem in that the clinicians aren't putting the information in. You can't do anything about that [laughing].
[Laughing] and even if you implement this it still not going to.
You've got to have people feeling comfortable in using the system. Getting the information late, again I think that's, at the moment all I can think of examples is that. There's insufficient staff to input information in a timely way, so that the information contained is perhaps two weeks behind. You need to have the drug list that is up to date, that's not a system problem, and the Canisc system it's the whole NHS. Getting inappropriate information, I can't think of anything. Again, I think that's a person, that they're actually putting in inappropriate, because people aren't trained in how to put into the e-records.
Yes, I understand you. Yes.
Sorry. ItÕs not, it's a person problem rather than a system problem.
I do understand. So during medical decisions using the current system do you believe that they sometimes become unable to make decisions, and can you just mention an example?
I think it's all to do with actually how the input at the moment.
How long it takes them to in put and how do they put the information.
Yes. It's being able to be concise but relevant, and inputting in a timely way.
Okay, if we put the time issue.
To one side.
To one side. No, it's a problem. I believe it's a problem because what we're looking at is you are automating, because what we're proposing here is up to date information but if it's not up to date is it still, the important information does it stand out, is it clear to them or do they have to, so the time is one big issue but we're also looking at how we present the information and how.
I think as it stands now from my perspective it's very difficult to get the key bits of information out because you have to troll through so much information, because it's Canisc it's patient and

then diagnosis, then it's each provider organisation. So say a patient, a palliative care patient and they live in Newport, for example, their primary diagnosis will have been made by a surgical team perhaps in Newport. So they have a page, if you like, that's the way I can describe it, for their first MDT, there's not much written there but there's a page, then they're referred to Velindre, you have the medical history which really is a rich source of information.
But okay, we might be seeing it six years down the road from that medical history or two years down the road before they had actually got metastatic disease and they're referred to us. So although it's very interesting to know how the diagnosis was made, it's a wee bit out of date but it's sometimes better than nothing. Then they may have been admitted to the Heath for some special surgical treatment that's only done in the Heath and they're seen by the palliative care team in the Heath. So that will be a separate page so we have to open up something separate. They're then transferred to Home* Tower* for an inpatient hospice, that's another page.
Yes. I think I believe that each of these pages is still not showing the key information that the clinicians need.
It's really difficult to get. It can take you at least half an hour to get all the key bits that we want to see about what's happened to their palliative phase.
Yes, I understand. How much do you rely on the patients for information?
Obviously if you're with the patient that's great, you can actually ask for their assessment. But if you're providing telephone advice, and that's certainly from our project, that's where we're trying to have a robust system that gives out of hours telephone advice, some, well again, robust information, because we cover the whole of the South East Wales network and there's one consultant in palliative medicine on call offering advice, the idea is that Canisc is going to be our real source of information because we never see the patient.
Again up in North Wales, huge area, they're never going to be able, unless they've got a helicopter, to go from Wrexham or to, and so they need to have that information and easily accessible and be able to pick out the relevant bit quickly, and it doesn't do that at the moment and that frustrates. I don't mind because as Dave* said I've been using it since 97'and you know you kind of forgive it. But they've not used it at all and they go, oh why do I have to go back to the summary page, then I have to go to list view. Yes?
Yes, I understand you. I never had in my mind throughout the last three years the consideration of someone dealing with a patient through a phone, which is really another story.
Sorry [laughs].
No. But it's really, I believe, I can see now that the work flow management system or [00:30:19] proposal can definitely support this process showing milestones of the treatment process and the keys of the flow, make them available. I think that's what they need.
If there was something that could actually extract the most recent palliative care summary. You know, what palliative care provider's have they met and what's the summary of those and the most recent ones, oh magic!
[Laughs] no, it's possible. I believe it's possible. What we can do using this technology is as you're managing the changes you can say, this is an important stage please show it up whenever I click the history of something. You can tell the system which of the steps.
[00:31:24].
Yes, which are the steps that you need to have visible and clear when you open the patient record. So that's something [laughs], something to write about. Yes. But how much could this proposal be useful to save time, support medical decisions?
I'm just thinking from the point of view of having access to critical information quickly has got

to save you time. If it can link to your radiology quickly as well so, ooh, there was an MRI can I get that up?
What is the case now?
Well, if they've had radiology in Velindre then we have access to that. If they've had radiology in other centres as long as we have rung Princess of Wales Hospital or we've rung The Gwent and asked them can they upload via web [00:32:44] then we will be able to see that x-ray.
But it's not uploaded automatically?
No. Presumably the clinical portal, if we know that there's an x-ray we'll be able to see it, I presume, I don't know. But a system that would actually tell us that there's an x-ray and possibly give us a link to it, that would definitely save time.
What about the workload?
Well, it might not save my workload but it would save possibly the secretarial workload, from ringing around, that would then support medical decisions.
Disadvantages, if you can think?
I think it's training and access. Here in Velindre you can access Canisc on every ward, at least two computers on every ward.
Only?
Only. So yes, there are times when those two computers are being used so you have to wait until you go back to your room or something to get to it. But it's definitely a lot easier. Before I retired and I was working in the Princess of Wales Hospital, in our unit we all had computers that had Canisc on them, wonderful, great, no problem. You go onto the main wards and they have, for a thirty-two bedded ward they would probably have two computers, possibly three.
You have to ask the IT department to allow that computer Canisc access, it's not sort of there, it's not part of the system. Certainly as a palliative care team we were using Canisc, the surgeons didn't know how to access it. The consultants didn't know how to use it, the pathologist didnÕt, no one else in POW really, apart from the secretaries and the cancer services no one else knew how to. So there's a huge training.
Yes. So training and access are the main, yes. I understand, training. If they're willing to be trained to use it, this is another story.
Yes.
Can you think of any other disadvantages?
Well, then I go into the security I think, which is another issue. But I think there are huge security issues of people not understanding that you have to close the system down after, you know you would, well most people would put their health record back in a trolley. They leave computers open on that case record and thatÕs a huge disadvantage.
Yes. But do you believe that clinicians shouldn't be aware of everything, do you believe in filtering information even to clinicians?
General wards are so accessible to any member of the public and I think patients deserve confidentiality above all else. **But I mean the clinicians; do you believe that information should be filtered from the view of the clinicians? I mean if the clinicians log in, do you believer that all information should be available?**
No, it should be on a need-to-know.
Need-to-know.
ThatÕs the problem isn't it? It's who has the need-to-know what?
I believe that not logging off or not closing the terminals is again a person way of doing things, but how much does the system provide is very challenging.

But it's the same with the written health record. There are individuals who will always put it back in the locked trolley and there are people that don't.
Yes.
It's not the system's fault is it?
No. No, I don't believe it's the system's fault.
It's the understanding of the risks involved.
Yes. It might be not seeing how much this information can mean to other people, and they don't care [laughs].
It's just not thinking it through. I think it's not thinking it through. It was their information that they wanted but the next person can just have a look at it.
Yes. It's a challenge. Security of the information is very challenging and it involves a lot of things.
Yes, and what happens about the individual who actually does not want their record to be an electronic record. Anyway that's beyond us, but how do we deal with that?
Are there?
Oh yes, there are people who will want to opt out.
They don't want to be in the system?
No.
Wow, and are there cases?
Oh yes.
That's not possible if, I don't know, but is it possible if the out-patient is moving across different organisations?
It's extremely difficult.
And that's [00:39:33] I believe.
Exactly. They have to be aware of the limitations though don't they?
If they are aware, if they can keep everything in their mind then.
But they're also trying to develop systems where if someone has tried to access individuals, that triggers off the alert so that people are aware of who has tried to look at certain records.
Yes, I understand. There is the idea of these marked cards and having the information on a card in your pocket and wherever you go this card has all your details and [00:40:41]. That's not.
People lose things don't they?
Yes. But it's a way, at least it's better than relying totally on the paper records.
But members of staff in hospitals might not want their details on the patient records.
[Laughs] it could be anyway.
You could have very famous people that happen to be in that, they would not want everyone, you know, I'll just have a little look at Gary Lineker's, or whoever.
Yes, I understand. Yes, quite risky, and you can't keep copies of all your records with you all the time, it's the same. But it's really hard. I can't imagine how they used to treat patients on a paper based record before. If it's in the one centre it's so challenging, how would they do it across different organisations?
It's always, there's delays. I think, particularly the GP is so disadvantaged not getting timely information.
And the thing is there is a lot of communication between the Velindre NH Trust, the specialist and the general hospital, for example, and how quickly is that information transferred? I don't know how they refer patients. If they have a patient here who needs a

surgery, I believe the surgery is done in a general hospital, so how long does the process of sending the letter, getting the letter, putting it into the system, scheduling an appointment?
It's got to be a week at least, a minimum, hasn't it?
I believe so. But what if the case is urgent and the patient needs to do the surgery in less than a week?
I suppose they might take verbal requests.
But is that reliable?
But yes, the safety is not so.
What's my last question? Is there other information you would like to have in the system? That's a question [laughs]. Can you think of anything, more information that the system could?
I think from, again from a palliative care aspect, the issues that we're trying to look at is coordination with primary care and with ambulance control in relation to decisions about resuscitation, about advanced decisions, so that everyone is in the loop about what decisions that patient has made so that they do not receive inappropriate treatment.
So the involvement of the.
So that linking in with primary care and with ambulance is really important. You don't think perhaps of ambulance,
Yes, I've never thought of ambulance. But is it ambulance care, is it the emergency ambulance or is it the regular?
Well, the regular plus the emergency need to know because if the individual had a sudden event while they were in the ambulance the ambulance crew need to know what level of care that individual patient has requested, and if they do not want to be resuscitated we need to respect that decision.
Yes, I never thought of the ambulance, maybe basic things like blood type, to be prepared in the hospital or [00:44:46]or the patient is diabetic or.
They need to have that kind of information. Particularly perhaps going out, what do they call them? The paramedics. Sorry. The paramedics having some initial information could be critical.
Yes. That's interesting. That's another view. You've widened my view today [laughs]. Really, thank you very much. I can see that this is promising and I believe that there is a huge extension that could be made when this goes in, and in a million years I wouldn't have thought of the ambulance, for example. But being involved in these details help a lot in appreciating, I believe it's complex but it's really more complex than I thought it was, and there are many different services that need to be considered and involved in the flow.
Yes.
But I think the best thing to do is to, I mean speaking to you, giving me more insight into the existing system and how much it does provide and the gap between what I am proposing and the current system is how much I see this proposal as useful. So a general feedback would be yes, you see this as useful and beneficial to the system. Is it one step or how far is it from the existing system?
I don't know. The ability to actually extract all these alerts and have them all is quite a huge step to me.
[Laughs] if it goes live and, maybe the idea of seeing it, how it operates and works is, would you be interested in seeing some of the screen shots? I did implement a toy to demonstrate how [00:47:49] prototype, just to show how it might look. But of course we don't get the

chance to, we're proposing the idea more than how it will actually work with the system. But it shows the hierarchy of the flow, the milestones and you actually can, with an engine code the timer, the rescheduling, that stuff. So it's doable, but of course when you make it live with the existing system involving all the complex organisations it's another story and we don't know. But up until now I believe it's possible and it could be done. But reality is another story [laughs]. So thank you very much for your time.
You're very welcome.
This is very, very helpful.

A.1.3 Interview with Dr. Jason Lester

Dr. Jason Lester - Consultant Oncologist (Lung & Urology)

So as Dave said, I'm a PhD student at Cardiff University and a part of my work is, I need the evaluation to know much clinicians or consultants see the idea as beneficial to their work.
Okay.
If we look at the bigger picture, and what we're looking at is we know there are guidelines or the Map of Medicine integrated care pathways and patients are supposed to follow a similar path or something along the same line. So what we 're looking at is how we support the team work, the multidisciplinary care team dealing with a patient throughout the care pathway that the patient is going through.
Okay.
We believe that there is a need for managing changes happening to the patient throughout the care pathway and the patient needs to be associated with the care team members, dealing with them to make sure that you inform the right person about what's happening to the patient.
This is the example we're looking at, which is diagnostic breast cancer. I got this from the Map of Medicine. It shows that at the clinic the history is checked and there is a triple assessment here, examination, imaging and fine needle, for example. Then at a certain point where the multidisciplinary team meet, there is a decision made whether the patient, if there is a positive finding, no abnormalities, or there's more tests needed. This is the change point we're looking at, so if the multidisciplinary decide that there is a positive finding and the patient has cancer, then we believe at that stage not only the GP, here it says, inform GP, but not only the GP needs to know that the patient has been diagnosed with breast cancer, but all the team need that are involved with the treatment.
Yes, I can see that.
So what we're thinking of doing is managing this change points, plus whenever a patient visits let's say the oncologist, then we know the oncologist who is dealing with the patient and make sure if a change happens in any other medical problem then.
They would know about it.
The oncologist would know about it.
Yes.
So the main motivation is the patient centric and the idea of clinicians and the care team members needing to work as a team and we believe that every care team member dealing with a patient needs to be aware of the patients different treatments, notified about the patient progress, the treatment progress, and alerted if there is anything new happening to the treatment or that needs to be noticed.
You might not agree with this but we think, or how we see it, we're hoping that this might reduce your workload and save some time, saving some time by reducing the workload. If we make the information more visible to the clinicians that might save them some time searching the case notes.
I can see that. Yes, I can see how that would work.
And supporting the decision making process. So if you have all the information in front of you, aware of the different problems, aware of what's new, then that might help you

decide or make a decision at the clinic. The driver is the e-health, the extension to the e-health. What we're focusing on specifically is a better access to medical records, so we believe at some stage information will be accessed by the clinicians, or it might accessed in one way or another, but maybe we're trying to help provide a better way of accessing the information and a better way for exchanging the information, so a better mechanism, and we're proposing a new approach.
We believe that the communication is achieved in one way or another but the coordination is still missing. So we hope we can improve the coordination and the focus is making the system more proactive so it doesn't just provide the information but does something whenever something happens. We're hoping that it can do a context based action, so by understanding the history of the treatment and the anticipated pathway, so what might happen at the current stage, different problems, who's involved and the changes whenever something happens.
How we see us doing this is, luckily we have the Map of Medicine or the guidelines so we know that each patient's journey is different and unique. But there is say, a big line that the patient might, I don't know, maybe you can tell me better, but around this flow, so it's maybe not exactly but it's going to mix and match but with the same stages.
Yes, I would agree. Yes.
So by mapping the integrated care pathway there's work flow technology available so you have each stage as a process and then you do the flow between the processes. So we believe that the workload could be incorporated into the existing Canisc information system to improve care coordination so it could detect the change triggers, so whenever there's a change happening, identify the involved carers, who is involved with the patient and then do one action according to that. So to involve the carer and do the action, the care team members.
With Canisc it's not about proposing a new system, it's keeping the system as it is but adding some more tools to visualise the data and access the data, a more proactive system that is event driven so, notification, alerts, update, referrals, control timelines and scheduling. I'll show you an example of that, it's a scenario, a breast cancer scenario. Okay, this is a general thing, just an idea of the simple, if we can call it simple, but this pathway and how much the workflow can provide to this flow.
So this is the diagnostic breast cancer which we were looking at just now, and these are the treatment options, so at some stage the patient might prefer the chemotherapy, surgery, for example, etc. First of all maybe the General Practioner wouldn't be referring the patient to the special centre, [00:07:54] Velindre for example, and then when the patient does the examination, imaging, and fine needle aspiration, for example. Then along the way the case will be discussed in the multidisciplinary care, and here are the care team members who are going to link to the patient, for example. So at this stage there is a notification needed, you need to grab all the information, make sure that it's available for the multidisciplinary team at this point.
Then if there is positive finding and the patient has cancer there's an alert here and in this alert you might need to inform everybody who is involved in the case that the patient has cancer now. If the patient is doing radiotherapy then you have to be careful, I think there is a lot of adverse reactions that might happen if the patient is taking different medications, and then the chemotherapy, if the patients is having both I think there is a rescheduling here.

There should be, I think two weeks between each treatment, something like that. Then for example, if the patient had surgery then there is a recovery time before the patient is referred to, maybe the oncologist again to see him again, so there is a timer which you can set to make sure that the system, there is the referral when the patient needs it not earlier than the message, they might not schedule it or it might be forgotten or something.
I see what you mean, yes.
So this is an example. This example shows how much we think the workflow can provide. Okay. Do you have any questions?
No. I got the gist of it, yes.
Okay. So I would like to ask you some questions here about the care system you're using, if you have any problems with it and then how much you think this proposal might help.
I think it would help a lot. I think, I can only speak for my practice but if I see a new patient they would have had often a biopsy, often a scan, they would have been examined by a surgeon and it's not necessarily the case that all those pieces of information are available to me when I see the patient. So it would be good to have a system that you can easily access that the first time I see the patient.
In addition to that, to have a system when I have seen a patient that would red flag any decisions that we make back to the surgeon who referred to the General Practioner perhaps, to specialist [00:11:04] in the community, I think would be very good, sort of instantaneous. A plan, if you like, which may include information on treatments and prognosis which may be very relevant to the patient. It would also be good to know as the patient passes through their journey with me, if they seeing perhaps a dietologist* or a cardiac specialist or perhaps even going back and seeing the surgeon, and decisions made that affect my treatment, to know about that as they happen would be very, very useful.
So currently not all the information is there?
No. We spend a lot of time still looking for information even though there are various databases that hold the information, a lot of it is electronically held, it's still very difficult and time consuming to put it all together.
Good. So using the current system do you have any problems with not getting the information? And we got that answer. Getting the information late, does it sometimes, is it?
Yes it does, particularly if someone has seen a clinical colleague and either the transcript from the notes is delayed or the [00:12:15] hasn't been typed up or simply the fax hasn't arrived. So often information does get there late. A lot of information is still not held electronically. I think at Velindre we forget that we have case records which are electronic but I don't think any other district general hospital has that facility in Wales. So I won't know for example, what the neurologist found if he examined the patient a week last Wednesday because I will have no access to that information.
So it's limited to the information in Velindre?
More or less. Yes, more or less, and there are databases which I don't have access to. I don't have access to the Bridgend, the [00:12:51] database, or anything west of there or anything north of Gwent really, so there are whole databases which I don't have access to and I rely on faxes and my secretary having to chase down results and reports, which don't always get there. This morning for example, we were looking to schedule a patient for an operation but we were missing two vital bits of information and we didn't have an hour to spend on the phone trying to track it down, whereas if we had access, if that information was there and made readily available it would have made life a lot easier.

Okay, and inappropriate, do you get inappropriate information?
I think there is, you mean information from the wrong patient, is that what you mean or?
No. I would say information that is not, not enough information. So you have information but you need details.
Oh yes, often. Often, yes. Often the detail is inadequate, because often it's a summary of what the patient's had done. The clinician will do a summary of a CT scan and perhaps a [00:14:00] but won't put all the details down then because they don't know what you need or whatÕs relevant to you. Whereas if you had access to the source data quickly you wouldn't need a summary because it would all be there for you.
Okay, yes. So the problem with the summary you get because they don't know exactly what an oncologist might need?
No, exactly. For example, a bronchoscopist may not think that I need to know the tumour was four centimetres from the cornea. But we do need to know that so often that information is not included in referral letters so you then have to go back into the notes and troll around and try and find the bronchoscopy report, if it's there, if you can find the notes and that whole process obviously takes time and is resource intensive.
Yes, I see. During medical decisions using the current system how often do you become unable to make a decision?
Do you mean from lack of information?
Yes.
Quite often I would say. Well, this morning we had a case in point. So I would say in around probably 10% or more of new patients you don't have enough information to hand to make the decision that you want. Likewise patients that you have on follow-up who might have seen a colleague from another specialty and have something done which is relevant to their cancer care, you often don't know exactly what's happened and you're relying on word-of-mouth for the patient to tell you.
Do you rely on patients as a source of information?
Yes. Yes. Yes you do. You do rely, you say to the patient did you see the cardiologist? Yes. Did he say your heart was okay? Yes. And he did the scan on the bowels? Yes, they're fine. So you often rely on patients re-accounting details to you.
What about assumptions?
Yes, you do. Yes. You assume that if the patient has told you everything's fine and they've seen the cardiologist that it must be, because there is no way in a clinic you'll have time to track down the relevant scans, imaging's or clinic reports. It would just take way, way too long.
How much could this proposal reduce your workload?
In terms of reduce workload it may not by the clinicians workload that you're reducing, it maybe the secretarial workload, nursing and clinic, so it's the workload for several professionals I would have thought. In terms of saving time, yes, it would save repeat appointments which we sometimes have to do, we sometimes have to say to patients, we don't have this piece of information, we've not heard from your surgeon or whoever it might be, so we can't make a decision today we'll have to see you next week. Very much in terms of supporting medical decisions, I think the more information you have, the better. So I think it would be very, very helpful.
Okay. Disadvantages?
I guess like any system it's only as strong as its weakest link, isn't it? And if we are reliant on it then it has to work all the time which is the problem with it.

Yes, reliability.
Yes, it has to be 100% reliable or as near as you can get. Well, nothing's 100% reliable but you need to get it as near as you can to that because it's very disruptive if you become reliant on a system then the system fails halfway through a clinic, it makes life very difficult. So that's the only disadvantage I can see, if it works well then it should be good.
If it works like you say.
Yes, exactly.
Okay. Specific information that you would like to have in the system?
There's nothing else I can think of off the top of my head. It think it sounds like it covers most bases actually. Unless, I guess it depends on how interactive you want it to be, talking about patient pathways and patient flows and protocols for treating patients, whether a sort of schematic as to where the patient is on that journey, whether you could ally two nice guidelines or something like that. But look at putting documentation around the patient on the system. Do you see what I mean?
Yes.
So for example, if they had a stage three adenocarcinoma of the lung and there were various clinical guidelines relevant to the patient, to have that resource available to you quickly and easily might be quite useful.
So you mean the alternatives are the different, I might not get what you mean?
I mean this is probably a blue sky thinking, but if the system was to recognise using your breast cancer analogy that you had a stage two breast cancer, it would then link into the NICE clinical guidelines or management of stage two breast cancer so that you'd have a reference document there for you. Does that make sense?
Yes. So you would like to have the, if we're linking this to information you need, you need to have the pathway, you mean?
Yes, exactly. It might be quite useful to have it, I mean it's not essential but it would be quite useful to have.
A question that came into my mind now, do you think that clinicians, I mean you can tell that this information oncologists always need.
Yes, there's a baseline. Yes, a certain amount of information you need, yes.
So it could be specified before doing this and then grabbing this information, having always accessible, visible to the oncologists.
Yes, you could do that.
Okay. That's it.
I think it could be a good project.
I hope it can be implemented.
Very complex I would have thought.
We can do it like a toy prototype just to show how much it can do. But linking it to the exact system and getting it running, we can't do that. But we will have a session with the developers here the Canisc system and we're hoping that they might tell us more about the integrating and how this system can operate on top of the existing systems.
Will it be like the current system though, you'll still require human beings to input data onto the system, won't you?
It should be intelligent plus, an intelligent system that does understand and has the map in the underneath engine so it knows how the process should work. So it can detect that a change happened because it knows that this is a change point and this is a multidiscip-

linary meeting, it is an important stage in this process and the result is, I mean changes need to be triggered and hopefully do the right action. So it might request, it shouldn't be controlling patients, I mean it's not making decisions for the patients but it might request, it's not going to make a referral without the clinician confirming that he wanted to make a referral, for example. But it might help in suggesting that.
So there will be template referrals, it will be automatically, presumably if I wanted to send, or the breast surgeon wanted to send the patient to me, the system could automatically populate a template with biopsy results, clinical investigations, CT scans, etc?
And it should know who you need to send it to.
That will be useful.
So it will suggest and then if you agree then you can continue, otherwise you can do it your way.
Yes, that would be useful.
We believe that if the patient had surgery and then the patient might need to have another, I don't know, but maybe the same surgeon. I don't know how it works in the N.H.S but the system should have a record of who did it the first time so maybe the same surgeon can.
Right. At least you'll have the option of sending it back to the same surgeon.
Yes.
Yes. That will be really useful because often you do, you're referred patients and you don't know who performed the initial diagnostic procedure or surgical procedure, and you spend some time trying to find that sort of detail out.
Yes. This is one of the questions, do you know who treated the patient for other problems?
Not always. No, you don't. If the patient doesn't know and it's in another hospital it can be actually quite tricky to find out. So it would be useful to have that information.
So the linkage is not there?
No.
Definitely the coordination.
No, the linkage is not there.
Okay. Good. Thank you very much.
That's all right. I hope it goes well.
Thank you very much for your time. I hope I didn't take.
No, no, no. It's very interesting. If you need my help in the future let me know.
Thank you very much. Thank you.
I hope it goes well.
Thank you very much for your time.
Are you seeing anyone now?
No, I'm leaving.
You're leaving. I hope you have a good afternoon.
Thank you very much.
Take care.
You too. Thank you. Bye.

A.1.4 Interview With Dr. John Staffurth

Dr. John Staffurth - Clinical Senior Lecturer in Oncology/ Consultant (Bladder & prostate)

Ok. I am a PhD student from the Computer Science Course and we are looking at information systems and how we influence the systems used in the hospital trying support the work, so the bigger picture we are looking at is the integrated care pathway and the idea of teams needing to work. Clinicians as a team that need to work together as a team, clinicians need to work as a team once you have seen a patients, so they need to be, and we believe that the integrated care pathway or the multidisciplinary care pathway need to be managed. There are some change points that patients pass through and whenever these change points the patient accesses or passes through these change points an appropriate action needs to be taken and we believe that we need to keep a record of who are the different care teams dealing with the patient, so you can know who to notify for example or who to update about the patient case. This is an example that we are looking at, this is from the map of medicine, and I chose the diagnostic for breast cancer clinic. You can see the

Can you make the screen any bigger?

Sorry, no. It just shows you the diagnostic for breast cancer and then the history and then there is the triple assessment here, so that is the examination, the imagining and the *fine needle* aspiration. Then at a certain point there is the multidisciplinary team, here where they make a decision whether there is a positive finding from [00:03:30] tests are needed or there is no abnormalities. So whenever this is a change point we are looking at and we believe that if the patient, for example, there is a positive finding and the patient has cancer, so cancer is confirmed, and the map medicine they say inform patient GP. But we believe that not only the GP needs to know that patient has cancer, but all other care team members dealing with the patient need to be aware of that. So it is the idea of knowing that a change point happened and you can keep track of who is dealing with the patient and informing whatever they need to know about the updates and the condition.

The motivation is the most to the patient's centric, the idea of care teams working around the patient. We believe that they need to be aware of their patient's different treatments, notified about their patient treatment progress and alerted if anything new happens to the patient.

Ok.

The aim, we believe that this, we are hoping that this could be achieved, you might disagree with some of these points, we are hoping that it is going to reduce the work load, and that is hopefully by saving them time looking for the information, if you could buy the system that makes the information more visible and clinicians can see what the information is that is related to them or what they need is visible in the system, and support decision making process, so if the clinicians have all the information available hopefully a better decision is going to be made or an easier decision is going to be made. The drivers, the e:help and the move to the e:help, we are looking at here, in specific, a better access to the medical record, so if at some stage the clinicians can access the medical records, but maybe through this, our proposal, information could be accessed easier and the exchange mechanism, it is going to be better, so there is a, what we are trying to do is a more pro-active system so it

is not just a system that has information but it is exchange [00:05:56], I am informing you that this is happening to the patient.
So it offers information on distils.
Sorry, yes
Offers it alarms distils
Yes and new approaches are being introduced the way we believe it could be done. So the need we believe that if there is communication, I mean the information could be accessed, that is of course, the communication. But there is the coordination so these teams who need to work together the care needs to be coordinated through them, so we are hoping that we can improve the coordination and the focus in making this is so more proactive, take actions, considering the treatment history, the anticipated pathway, what should happen next, the current stage, different care team involved, different health issues, the patient has angry changes, and any treatment followed. So, the patient is not having radiotherapy any more, having chemotherapy for example, that change might be informed to the clinicians.
So the proposal, the technicality is we believe that there is work flow management system and the whole process is a work flow.
We understand that every patient pathway is different, so it is unique depending on the combination of the problems and the whatever other attributes that makes the pathway unique, but there is a flow of processes that the patient usually goes through, so there is a main stream and there is deviation according to the case or whatever.
Yes.
So we believe that knowing, having, like they have in the map of medicine or the clinical guidelines available that could help the system detect the change triggers, so it kind of knows that this is a critical point and that changes might be happening so the decision needs to be triggered and therefore this is to need to take appropriate action. I then define whenever a change happens identify them both care team members, so who needs to know, and send the right message to the right person and manage changes so that there is a need for an alert or notification or something on the system might hopefully take the right action, and to [00:08:21] it is not, or to any system it is not proposing a newer system, it is like a layer or something that can be attached to the existing system, but make it more proactive. So in, does it summon up kind of identification, alert, update referral and control timelines and scheduling? I will show you an example here it will just explain how much this proposal can provide to the map of medicine, the flow. So this just an example, this is the diagnostical treatment we are looking at just now, and here are the treatment options so the radiotherapy, chemotherapy and then he lists the surgeon, and these are the roles, so I am going to link each process with the role who is taking care of it, and I would say this is the general practitioner referring the patient first to the oncologists, so that is a referral, one of the actions that the system can do.
Right be it a surgeon for breast cancer? Diagnosis is done by surgeon.
Yes, but here it is before I think this is a referral before even deciding whether, before, and making sure that there is a question whether the patient has a cancer or not, so he is then referred but the cancer is not confirmed yet.
They go and see a surgeon not an oncologist.
Oh, ok. So.
You do not have a surgeon on here do you?

[00:10:11]
OK, good. So that is the first step, the referral from the GP to the surgeon and then there are the tests here, so that is the examination and then the imaging and then the fine needle aspiration for example. At some stage the case will be discussed in the multidisciplinary team and then here is an action that could be taken which is the [00:10:39] so make sure that all the information is available for the MDT when they make the decisions, so that is another action. Then here this is the example of the patient, the multi-disciplinary confirmed that the patient has breast cancer. In this case, ok, that is an alert, so that sends an alert to the care team members involved with this patient to know that the patient now has cancer.
Ok, if there is non-surgical options, if the patient is taking radiotherapy then there is a notification should be flagged, if the patient is taking both radiotherapy and comeotherapy then there should be a schedule a reschedule in here. I do not know why this has stopped working.
What do you mean by rescheduling?
I am, the [00:11:47] and that, I am not sure, but there should be like two weeks between each, radiotherapy and chemotherapy patient, the assistant should not schedule for chemotherapy if the patient just had a
At the moment, say in this hospital that would both be organised by the oncologist, so.
Yes
The chemotherapy and both heavy scheduling is already organised by one team member?
Yes, I understand, so no mistake might happen because it is controlled by the
Well, it is within their organisation, so it is not across organisational issue, it should not be.
Yes, I understand, yes. So you believe that the rescheduling of, this is an example, cannot you think of another example that might need scheduling and rescheduling or as long as it is in one organisation there should not be any issues of.
Yes, there are lots of issues, yes. Yes there are issues when you go on to reschedule, yes.
There are.
Yes
Can you, do you have an example in mind?
Yes. If you have patients in having chemotherapy before surgery, and the chemotherapy is delayed and the surgery needs to be put back.
Ok, there is also this example of.
Is this having, radiotherapy and chemotherapy in Velindre are both delivered in Velindre, they are primarily managed by one care team, within Velindre, they have got there own internal systems to managing that, and having a new system coming in to manage it would seem, I am not sure it would be needed.
Yes, I understand you, but you can, I mean, but this case, but there is and maybe in other cases for not in radiotherapy and chemotherapy, but there is sometimes a need for rescheduling within the process that the patient goes through.
Yes, that is true.
But I need to correct my examples, because, you know how they have the medical background, but this is what trying to extract this.
Yes and this is very important to get the names right and to know who is in charge. So you need to know that a new breast cancer diagnosis goes to the surgeon, because it is
Is it oncologist surgeon or?

Well he is an oncological surgeon but he is not an oncologist, he is a surgeon.
Ah yes, the names yes.
It is critical to understand, I think to design, if you can find and design a system you need to understand how things actually work, and if you look at how things work in *Cardonvale* that we work very different from in Royal Glamorgan or Gwent.
Yes I understand. The problem is with the, of course, you need clinicians involved in the planning for this, but of course the map of medicine notes does not tell enough about what or who is taking care of each process.
No.
But I believe if a clinician is involved in the, or a specialist is involved in the planning process then that, it I mean, they easily can tell who is in charge in each. If they are involved in the, with developers and the process planning then these could easily read and write and to who.
Yes they can be made correctful.
Yes, I was talking yesterday to Dr Jason.
Yes, *Jason Lester* yes.
And we were talking about the idea, I was asking him if there was a specific set of information that the oncologist might need, and he told me that there is, it could be clearly, clinicians know exactly what information they might need from the patient records and I believe using the system if the clinicians tell the developers what kind of information they need, then if I am saying better information access or better visibility, a better information exchange or a better visible data visible in a better way, if you can tell me what information you need then the system can easily extract this from the
Well it can at the initial diagnostics stage. So if you had a person when they are first diagnosed, then this is all nicely, easily and clearly demark it, but a lot of our work and more complex work is often people who have elapsed and that is often much harder to map.
Yes, but
So the easy part of our work is a new prostrate cancer diagnosis comes to the neurologist, has his tests, has entered an MDT, two options are decided, the patient discuss them, treatment decided to come to the NHS pathway, that is easy, but that is easy, we do that already. We do it as an MDT, so it may be that the information that we give to the GP might be slow going out because it is a letter getting out, but it is fairly, it is easy mapped, but the hard work is when we get a relapsed patient who may be mapped in two or three different hospitals and trying to retrieve the data is difficult, but it is going to be very difficult for this as well because there is no, unless you, I am not sure how many triggers are later on down the line. Do you understand? So you have mapped out the easier situation there.
Yes I understand.
What you really want to do is say right, what are the difficult situations that might be helpful.
Yes I understand you. So the past does not follow the anticipated care pathway, yes but I mean is it still a set, a clear set of processes, not a clear but predefined, so the patient might go again to the tests but these processes that the patient goes through is so within the map, but
Possibly yes.
But not necessarily following the lines and this is the idea of the system it is not pushing it through one way but if the processes goes in a different direction then it tries to catch any change triggers and take an action, so if there is more tests are done then there is definitely

Yes, it depends on when you say it can change trigger. That would suggest it has got to be a something you can define is going to be important later.
Yes.
And that is not always, it is only when I go back and think oh what happened then that I realise that it is important, so that might be a problem.
Yes I understand yes.
That there might be issues that are important for me as an oncologist managing the patient who is recurring that actually at the time of diagnosis for a difficult, so that might be a problem.
Yes I understand.
If you are really going to try and make this useful, so you do not have to go to anywhere else, you need to make sure that the trigger points are quite clearly defined thinking what you might need in the future, but also I think they need to be clearly defined in a way that are not going to produce so many alerts that the alerts just get ignored.
Yes I understand. This is one of the trickiest things is not overloading and sending what exactly only what needs to be sent to the care team member. But if I can have a set of, I mean if I understand right, then you might say it is normal to do a certain test at the beginning, but if there is something wrong happening with the patient then we might ask for more tests. So the first time it is not a change it is something normal, but the second time that was then because there is something wrong happening. Is it?
Yes, it may be something like, I am trying to think of an example, I am not sure I am going to have a good one, but you may have a person who has managed aggressively and then has a repeat scan at twelve months which is borderline, which then becomes abnormal, and there maybe, I am not sure I can come up with an exact example, but maybe a blood test value that in retrospect was abnormal but at the time thought to be within normal, they are, I am not sure I can give you an exact example.
Yes I understand you. But what if the system provides a tool to help clinicians, I mean if it is not within the flow, you still have the option so you can accept or redo, let say an alert or a message or something. So you are at the stage where these are not going to be fired unless you confirm that you want it to be fired and this alert is not going to go out to everybody unless the clinician confirms that I want this, it is user driven system, it is not a system that is automatically.
So I have got to decide what information for my patients gets flagged out to everybody.
Yes.
So is that not more work to me?
We are hoping that the system will suggest and then you are just going to accept it, we are not going to ask the clinician to do the whole thing. Like the referral, it is going to have the ready forms, you would say yes or no, it is trying to support because it does understand the flow. But everything is going to be user driven so it is not.
But if I have see ten patients in a clinic then later on there is a flag on one of them I am not going to have to go back and check which one it was and remind myself of the details, because the patients often have very similar clinical details.
Yes, but I mean, we are hoping that when you see a patient right now you often, I do not know how, do you open the record on the screen in front of you. If there is an alert
Yes, I work into two hospitals, so I am quite easy. I work here and I work at *The Heath*, and *The Heath* has got clinical portal, [00:23:35] scope, so I might have both systems open, I tend to work mainly on *Canis* [00:23:45], and I do not tend to use the clinical portal very much

unless I am seeing a patient for the first time at *The Heath* when I need to get access to all The *Heath* stuff.
We are hoping that the alert if you open the patient record from a point of view if the alert, if there is messages that we believe that, or that has been specifically sent to the oncologist then you will have them flagged in front of you, so you will be aware of this information while you were dealing with the patient or while you were talking to the patient, and then when you make a decision the system might say yes breast cancer is confirmed, it is going to give you the option to alert the involved care team members with the patient or not. So it is going to suggest then the clinician can accept or not accept and the alert should be linked to the patient record whenever you are dealing with the patient you will have the information in front of you, so it is.
Ok,
It is not a number of alerts that the clinicians get them then the clinicians then kept to the patient, it is
They are all linked.
Yes.
Ok.
So do you think that is going to overload or help, or is it still a concern.
Yes, I mean it is always quite difficult to actually see how it is going to be used. I mean in this situation when we come in here the multidisciplinary team review, positive findings so we only really deal with patients. I personally see to patients who have been diagnosed with the diagnosis of cancer, in my case it is primarily prostrate cancer and bladder cancer. So I come in here and that is the first time I would see a patient and I guess we are then talking about options and managing the options. So I guess at the moment when I first see that patient, I would look at the patients' notes and I know the six main pieces of information I want to know, I know they are kept in three different places. So an MR scan result a blood test result and a detailed review of pathology that is all I really need to know. So I know where they are.
You know where they are but they are not ready for you to see.
Yes they are, well yes they are all already. By the time I see the patient they have already been to MDT, so they have all been done.
Yes, but I mean.
And they are already on clinical portal, so it is a question of, well it is not it is a question of looking at clinical portal notes and looking at three areas.
Is it time consuming to link to the words clinical portal and then switch for the information, or is it.
It is not Welsh clinical portal it is the clinical portal in *UHW*, it is *Cardonvale* clinical portal.
Ah ok, sorry.
So it is not *Welsh* clinical portal. Is it time consuming?
[00:26:59] [Laughter] Yes
It would probably be balanced. There may be, there are things like previous medical history or current drugs which might be useful to have, at the moment you have to ask patients for that or you have to go through the notes looking for it, so if that was coming in from elsewhere then that is the sort of thing that might be useful, because patients are not very good at remembering that sort of information.
Yes

And those are the easy ones. Because our clinical systems and our MDT's are designed around making easy management of newly diagnosed patients and that is what the last ten years has been about, we have been trying to streamline that system, so I am not sure how this would help that.
Yes, one of the questions that we
That is just my practice, I do not, sorry.
It is one of the questions that I was having as, I have a set of questions at the end as how often do you in the clinics do not get the information? Do you want me to show you the specific questions that I have in mind?
Yes, I am happy to, tell me you want? How often do I not have the questions I want answered? That is a good question.
Here is the set of questions that I have in mind.
For my newly diagnosed patients, very rarely.
Newly
Yes newly diagnosed. From my practice it is usually there, I tend to do *power-up* clinics with the surgeons and I tend to only see patients that are fully worked up.
But deemed all the information, how do you get the information, is it passed from the general hospital, the general practitioner or?
I tend to, it is a good question again, it tends to come from the urological surgeon, so the oncological surgeon. So most of the patients are under a specialist cancer surgeon who has seen them, done the history, organises the evaluations, would then have brought the tests, reviewed the tests showing as cancer, then they come to me.
Ah so,
So I am very lucky.
Yes, so the surgeon, the consult surgeon he is the one who deals with all the headache of collecting the information, getting the information to the different resources and those staff.
Yes.
Yes, so.
At it would be the same with Dr *Lester* I would have thought, because he, oncologists do not tend to diagnose patients. So his lung cancer practice would generally they would have gone to a respiratory physician who will have done the various investigations and then come to Dr *Lester*. It maybe not it maybe that the lung cancer they come from many many different sources, but for my practice in bladder cancer and prostate cancer they nearly nearly always come through one of the few urologists at the.
Ok, you get all the information you need, is it sometimes there is some bits that are missing you might need extra information about this.
Sometimes yes, we might need to arrange an additional scan or something. It may be that we get the pathology reviewed, so if the patient has been diagnosed elsewhere we might need to get the scans up to have a look at them, or the pathology up, but generally not.
Generally not.
Generally not.
So it is not uncommon in part.
Not for me, but I guess the idea of talking a lot to different people you get [00:30:57].
Dr Lester told me that there is some detailed information that is not there and sometimes they need to reschedule things because for example the size of the tumour is not written or

where the location, the exact location of it, something like that.
Yes, but if it is not written somewhere then this system is not going to make the report better. The report is still accessible it is just they have not reported the right thing.
Yes, but if, I believe, if you as a clinician knows what the exact information is that you need, so with Dr Lester, I think, he knows that he need the size, he need, there is a specific attribute, so if you know that these need to be filled then you can ask the one who is filling it to put these details or fill these gaps, just make sure that you pass it. Because what
He could do that already if he just spoke to them.
Yes, but if they are referred from different places and there is.
That is a problem, I agree. Yes, if you get multiple sources coming in then that is a problem. It does not tend to be for me.
Yes, maybe because you were getting it from one source and it is a strict.
Yes, and that, so we have got quite a unique practice maybe. We just tend to be working with one team.
Any problems getting information late or being in the clinic and not having the?
Yes, in patients who are on follow up or the more complex patients, you often have blood tests prior to clinic appointment to assess how they are going to go on and that PSA may be done by GP anywhere around the practice.
So you might not be
So having universal access to all of the blood results would be good, and so I guess you could argue that anyone under me who has had a PSA getting alert that it is there is useful. It is but what happens in Velindre in ninety per cent of the time, all you need to do is the patient is coming to clinic in a couple of weeks anyway so you do not need to action anything, so having that for all my patients across South East Wales might be a bit too much work for the benefit. But that is the one thing, it sometimes it is quite tricky to track down a blood test result.
Yes I understand you.
It is primarily on follow up.
I think this just answers the first, you answered the inappropriate information if it is from different resources yes, but if not it is then it should be straightforward.
It is generally ok, there are individual cases where it is problematic but I would not have thought it was worthwhile designing a whole system on the [00:34:08] difficult ones.
Yes I understand you; it is not a [00:34:11].
Personally.
Yes. I understand. Ok, during medical decisions using the current system how often are you unable to make a decision or an assumption. I mean relying on patient information, or information from patients or.
Oh, that is a good question. Unable to make a decision? Not very often. The lack of decision making is usually because the patients have choices and they cannot decide. How many times do I not have information available? To my fingertips I need to use the patient's information. It does happen and it tends to happen from other medical issues which are not directly related to the cancer we are dealing with, so it may be a person who is going to have chemotherapy who has had a lung problem or a heart problem, completely unrelated that might influence what I do and I have to say I am not sure, let us wait and decide.
Is that information available what other medical conditions or problems or?
Yes, it might be the patient saw a doctor a week ago in clinical and the letter has not come out, or that the letter would not come to me it would go to a GP, so

Is not that critical, is it not a problem?
Yes it is. It is not that often. Yes, and again for other commissions it may become more, be much more important, just happened to me, it is not that much of an issue but it certainly does happen occasionally that a patient is being managed by another clinician who would not think to inform me and I have to go and chase it.
Yes I understand you. But if you are aware of that, that the patient has seen that clinician, but if you are not aware of it that patient has seen that clinician, because if the patient does not tell you then.
If the patient does not tell me that I am not the primary carer of the patient, the GP is, so the NHS at the moment information everything goes to the GP, but an oncologist who is a specialist will not know automatically what is going on within the other specialist fields. But do you think that the wait is now is ok, or do you believe that as a clinician do not have rely on only what information that is passed by the GP because the GP might not.
The GP's do not pass very much information on, very rarely, very very, the number of letters I get from GP's telling me all your patients, something important is happening to them is almost zero. The only time I get communication from GP's is nearly always if they want me to review a patient quicker.
A request more than information.
Yes, can you please see the patient earlier, or when you next see this patient can you please be aware that his pain is worse. Very rarely do I, I do not think I have ever had a letter saying this gentleman has just been diagnosed with a new bowel problem or a new kidney problem can you please case. That never happens.
Are you saying maybe in most case?
So that way you are completely reliant on the patient as the source of information. Certainly in terms of medical things that happened within a period of a week, only the patients will tell us.
So there is a weak?
So there is a weakness there.
Yes.
Balanced against the potential information overload if every specialist managing a patient gets informed about all of the medical occurrences that the patient occurs.
But if you have the highlights like the clinicians has diagnosis and has a heart problem and just be headlines just to make sure that you are aware of these things.
But I know that, that should be for the medical history and that should be within the notes. So you should be able to get that. But that yes, certainly a highlight would be useful, a summary, but, so that's, I mean doctors have always relied on patients as a source of information and that's what medicine is. The most important thing about it is the history, they have always said that.
Yes, but are the patients, all the patients people, I mean we understand what they are talking about, we know what the details of the information.
Some patients are unreliable with stories.
Oh ok.
Yes, but that is the problem at many levels, including the precise decision making about their disease and also what else is going on in their life and that is always difficult to manage. So you do have two bits of information, I mean you have three bits of information I guess you rely on, you have a detailed history of their ongoing problem, you have sort of the previous history of their other medical problems and their drugs which is important, but you also have short term changes in medical problems like if he has had a heart attack or had a stroke.

Do you need that information?
You do you get the information, but there is no automated system going round at the moment, there is no good, there is no reliable way of being given that information.
So apart from the change triggers, if this system can provide a summary for the clinicians with the details that they need, then can you see that.
Yes, I can see that any patient being admitted to hospital would be a useful bit of information, any time my patients are admitted to another hospital would be, could be useful, not always, but it certainly could be, because obviously the patient has been admitted to hospital probably they have had a heart attack, so any Accident and Emergency attendance, but you will also have within that a lot of rubbish, like I have hurt my toe, I have you know.
Yes ok.
So there are problems with that, it is how to you sift through the important information. At the moment we tend to use the patients to tell us what is important.
Yes I understand.
Do you understand?
Yes, it is still the worry of the information overload and [00:41:32]
Yes, balance it, but then I guess that is what that will be what we care about your system, is how do you balance it right.
I mean if it works closely with the clinicians and understand their exact needs then.
It can be individualised, yes, or it could be a very quick summary that you can just flick off and never need it again.
And maybe if each user can specify their needs and as you customise your screen so you get these information points.
Yes, you have to do that, I would want.
Yes, but would you use it. If it is customised and you know the set of information such as, you show me always this and this and this for my patients.
What I would want I think, I think I would more like, I do not think I would want to have an alert on each patient any time anything bad happened, but I think it might be interesting on the patient record to have a button you could flick on and off which basically if you flick it on gives you everything that has occurred. So it was not automatically telling you everything every time anything bad happened, but that you could, on your one percent one patient in clinic who has not turned up, you could click on the button and you would know what has gone on, that might be useful, I can see that, that is what I prefer. So something that I activate, a system requesting all the information is out there, all the alerts out there, rather than me having it automatically, because you never automatically you will just switch them all off, you will never look at them.
Yes I understand. So you can control the screen and say what you want, right, but would you like to specify what kind of information or just get the alerts for whatever you feel alerting alert now?
I think I would probably need to work with the system, pilot it, and then to see what I liked.
Yes, I understand, yes.
One of the very important bits of information which does not come through automatically is if the patient on some, people on chemotherapy can get very ill very quickly with infections and can end up in hospital, and often you do not hear about it, so I think the other thing there might be patients that we should know if anything happens with them, so people on chemotherapy will be put on active treatment radiotherapy and chemotherapy, I think we should be told immediately if they get admitted and we are not. Some of them get admitted to my hospital and

I do not know about it for a week. So I think that is a, there is a different thing where I could imagine wanting to actively switch a button on which says please alert me for everything that is happening with this particular patient, and may have it switched on for three months then switched off, so you have

You have the option, yes. Yes I understand. So you see the benefit but not with overloading, with my control it could be yes?

I can see a [00:44:35]

If I am selling this to you I mean.

Yes and I think you would say, what you asked me is, is this system perfect? No, in many parts of the system work as well as it is ever going to work and I am not sure that computerised centre of control is not going to make it work better but there are two or three areas where a centralised system could improve it.

Yes.

Could improve it, and it would be great if it could, I mean, you know anything improves patients care and our life is greatly appreciative, so.

Yes, I understand. I just have two more. How much could the proposal reduce the work loads, save your time and support medical decisions?

I do not think I spend a lot of my time chasing these things. But sometimes when you really want the information if you cannot get it, it can be fairly frustrating, it can just happen if you are in a busy clinic and you cannot find out, it can be very frustrating. So probably it would not reduce a massively amount of time and workload, but it might do it, it might reduce the stress, it might just do it enough on one clinic every couple of months. You might think ok that was, it was really nice having it. So I would say not massively but occasionally it would be helpful.

And the medical decisions?

Again I do not think very much really, I think the.

So you are saying once every couple of months then it is, rarely happens then.

Yes, it happens occasionally I would say. That is for my practice. [00:46:40] would be different; I mean I have a particular group of patients so.

Yes, but what happens if you do not have the information and you have the patient, do you reschedule?

Yes, you would have to. I mean, I think at the time you have to decide whether the patient has to be treated or delayed, if in doubt you delay it. It does not happen in my practice very often.

So what is the disadvantage and you mentioned a couple?

The disadvantages would be requiring changing the way we work at the present to populate the system that no one uses. So if I have to press a button that is a trigger point, or I have to spend hours mapping out my cancer management systems and never getting benefit from it. If I have to spend lots of time reviewing meaningless data just because it has been sent to me then those would be, and if it is expensive to do that then it is a waste of resources, those would be the main disadvantages.

Yes I see.

I guess the other potential problem is if the system is not perfect and you end up relying on the computer system more than your current systems, or if there is only partial uptake so that if it works in *Belindra* and *Cardonvale* but Royal Glamorgan and Prince Charles do not do it then you will have two systems running.

Yes I understand.

So if it is going to work it is going to have to be everywhere.

Yes
And that is a big challenge.
That is the biggest.
Have them everywhere at the same time.
Yes. It is just an idea that you make sure that you get the information from everywhere, if you get it from some of the clinics/places and not getting it from the other locations then it would be, yes, it is not going to mean anything.
If it gets a, I think with the system there is no risk there, we have lead things like electronic sign off that once it has come in there are occasional errors within it, and so if you got a, there is always a thing there would be errors, and there is human errors and computer errors. Once we know how to use it, it is great, and I really like it, so again with this, so you can imagine in clinic you are going through, you have got a patient has not turned up, you might have asked the nurse to ring up the hospital to find out where he is, he just click a button and know where he is, you can see that being advantageous, so it must not be more time consuming than it saves I guess.
Yes I understand. So would this active system, not very active system constructive information and controlled by the users and you can see this do-able working?
Do-able yes.
Alright, thank you.
Is that ok.
Yes that is all that I needed. Thank you very much for your time.
It is a challenge. It is a big challenge.
It is a big challenge, but you know I looked at something, I saw something today, a sign on the wall saying if you have initially this.
[00:50:10]
Gwyneth is Jo coming, lucky I was nice about here then.
Yes, this is a sign on the wall which I saw and I believe that
Ah yes
So that is one of the benefits I see from you having the system. They know they need to know this information then why is it not in the system when they have to ask the patient and what if the patient does not see this sign, or have not been asked.
Yes I can see, yes that is a good one. [00:50:47] and I am sure there are others due to that. But you see that is cardiac so it is nothing related to cancer.
Yes I understand you. But there should not be a cancer specific system it could be anything but the area of you as a professional knowing well
They had had a pacemaker, yes that is true. Yes and I am sure there are other things like having maybe heart valve replacements if you are having chemotherapy are important, or if you need to have an MR scan and you have got metal implants, like pacemakers, you cannot with metal implants, so I am sure there are areas, but to construct a really complex system just to find that out, well that is easy all you need to do is go to all the people with pacemakers in, and say can you please make sure that you know, did you develop a pacemaker registry.
Yes I understand.
So there will be, if you can find a hundred examples then you lie, if you have just got two or three examples then it is probably better just the content of those. So this pacemaker that is one of several checks we had along the way, so we you know, it is on the referral form probably, I do not know the example, but the patients probably go to two or three processes and may asked

at each tab point have you got a pacemaker, so that may be one of three or four checks.
Yes I am sure. I mean not knowing this information
Pregnancy in radiation and chemotherapy are incredibly important. So you could say well anyone who has ever positive pregnancy check should come through. Yes, that is the sort of thing, that is real time you see, because it is really quick, you might have a pregnancy test in the morning and get diagnosed with cancer that day, you might not come through, so there are things that you would say right this needs to be really flagged up. Pregnancy is much much more important than that.
Yes, alright, thank you very much for your time.
That is ok, I am sorry about that.
I know you are very busy and you are upset today, thank you very much.
Ok, nice to meet you, are you ok.
Thank you very much. I will just shut down everything.
Ok, your way out is just out here.
Alright then.

A.1.5 Interview With Dr. Mick Button

Dr. Mick Button - Consultant Oncologist (Lung & Urology)

Okay. So what we're looking at is the guidelines, the integrated care pathway, let's say best practice and knowing that or having that might help in making this more proactive, these actions. First of all I'm a PhD student at Cardiff University Computer Science School, and the bigger picture is that we think that the teamwork along the multidisciplinary care pathway or the treatment pathway needs some support, and support the workflow process that the patients go through, make them manage the changes that happen to the patient. What we mean by changes is updating the treatment or the medication, and we believe that we need to associate teams with the patient, so you need who is the oncologist looking after this patient, or who is the GP, for example.
This is an example of the integrated care pathway. I got this from the Map of Medicine. It shows the diagnostic of breast cancer, at this stage the history is checked and then there is the triple assessment, the examination, imaging and fine needle, for example. At some stage, at this point for example, the MDT meet to review the case and then they decide whether there is a positive finding or if more tests are required or if there is no abnormality, and this is what I mean by the change point, so at this point if the patient, for example there is positive finding and cancer is confirmed then here it says, inform the GP, but we believe that not only the GP needs to know, other care team members looking after the patient need to be aware of that.
So the motivation of this is the idea of patient centric, care team members needing to work together as a team and we believe that means they need to be aware of their patient's different treatments, notified about the patient's treatment progress and alerted if there is anything happening with the patient, so alerted about the changes, for example, the patient is under chemotherapy now so they need to know that.
WeÕre hoping that this, but you might disagree [laughter] might reduce the workload and save your time, and maybe it would reduce the workload in looking for the information, so if we know what the clinicians or the oncologists need, then you might make it more visible in the system and easier to read and access, and hopefully supporting the decision making process, so if you get all the information maybe a better decision is made.
So the driver is the e-health expansion and all the projects that are happening now. With the context of my project I'm focusing on hopefully better access to the medical records, better information exchange between the clinicians and the care team members and we're proposing a new way of doing it.
What are you proposing?
It's the idea of, it's going to come here, it's the idea of if you know the workflow and you know the progress then hopefully you can if you map this into a workflow system which can work on top of the existing system, so it's not a new system, but if the system understands how the system should go, we know it's restricted to one flow and that each patient's pathway is unique, but if it knows that, and this is a change point and the patient is going through this pathway for example, then the system might be more intelligent and take action.
So the next step is having a proactive system or context based actions, it takes actions according to the context, what's happening with the treatment. Hopefully it considers the

history, what should happen next, so the anticipated pathway, the current stage that the patient is at and who is involved, the different issues, because the patient might be following more that one pathway for example, and changes in any treatment followed by the patient. If the patient has cancer, if cancer is confirmed then inform [00:07:11] who is involved in the treatment, and the proposal is mapping the integrated care pathway.
Luckily we have the guidelines, for example Map of Medicine or the NICE guidelines which could help detect the changes, identify who is involved and manage the change process. So to Canisc, it's just not proposing a new system, we believe that we can have this as a layer that can work with the existing system but make it more proactive. IÕll show you some examples of notification alerts, updates, referrals and controlling timelines and scheduling.
So this is the diagnostic for breast cancer which we were looking at just now.
So thatÕs the same one we just saw?
The same one, yes.
So this kind of maps, if a lady comes to the clinic with breast lump, what processes to go through to as quickly as possible get that breast lump worked on, so we can reassure the lady that there's nothing to worry about, or is there is anything to worry about get her on treatment as soon as possible to minimise any delays and distress.
Yes, this one shows the treatment options. So there is radiotherapy or chemotherapy or, I don't know how to pronounce these, but if it's a surgical option then there will be a surgery. So the patient, and it shows you the people involved or the professionals involved in the treatment. So if the patient is here the GP will refer the patient to the special centre, so that's a referral, one of the things that the system or having the workflow management system can support. So the referral, and then if the patient is going to have test, so that is the examinations, a document will be produced out of that, and then the imaging and the fine needle aspiration.
Then when the patient goes to the MDT and all of these people will be involved then another action that the system can do is notification, so collect all the information and make sure it's available for the MDT when they need it, and then here the example of if there is positive finding and the patient has cancer there is an alert that should be sent to involved carers or care team members.
If non-surgical options are carried out then there is, if the patient is having radiotherapy then you need to be careful with the medications that are taken. If the patient is having chemotherapy and radiotherapy then there is a rescheduling, I think there should be a two month delay between these two. Then finally, let's say if the patient goes to have a surgery then there is a timing that you could set to the system to make sure that the patient after recovery is seen by a specialist.
So this is one of the examples and it shows how much we believe that having the integrated care pathway mapped to the system, how much benefit it could provide. So this is the idea and I would like to know from you as first of all, a clinician who needs the information to make decisions, plus a user of the existing system. So using the current system, which is Canisc, do you have any problems not getting information?
Yes, we do, because our patients often have the scans and biopsies at other hospitals, there isn't an easy link between Canisc and those other hospitals. We can often access reports, radiology, but to actually see the images requires an email to the radiology department here to say, can you physically import data to Canisc? And reading the reports is very important but I think us

looking at the images in terms of our management of the patient, because we know the patient and for us to look at the radiology images as well is critical, and that's quite frustrating and quite time consuming and puts a delay on decision making because it will take twenty-four, forty-eight hours for the images to be imported and so you'll be doing a job twice effectively, because you're thinking of a patient, you want to look at the results and then you can only action the results two days later. It would be lovely to be able to see things upfront. So accessing information is quite difficult in certain things.

Okay. So there is the not getting it at all or it is always just about the timing and the delay?

You can usually get it but it can take some time, and that can be the same as not getting it at all because that time is critical and that delay may make it, you may then make the decision without the information you need to make a decision quickly. So it can transpire that you don't get the information at all in a timely way.

So, inappropriate, is there sometimes?

Yes. One example that we had recently was a patient who has two different cancer diagnoses. He's got lymphoma and he's got bladder cancer. The lymphoma is in the background, it's not an active problem, and he's seeing one of my colleagues for the lymphoma and seeing her in a clinic and not having any treatment. But his bladder cancer is very active, he's having a lot of treatment for that. But all the electronic results that we have on Canisc they're all going to the non-active team member.

So I think he's got two diagnosis and two registrations. I don't know who takes priority on those but although I'm requesting blood tests on him and scans, they're being logged on Canisc under this other doctor so she's getting a lot of information that she knows nothing about, which is very inefficient and difficult for her because she doesn't know whether to sign these off and authorise the results because she doesn't know the context, and I'm not getting that information which makes it difficult for me to manage the patient because if I had that information it would keep the patient progressing through, it would act as a bit of an alert.

So I don't know whether that comes into active or inactive team members, and you were saying it was important to inform the team members appropriately. So it comes back to this definition of whoÕs in the team? What's active and what's inactive and where should the results go to?

Yes. Okay. Good. During medical decisions using the current system how often do you become unable to make a decision according to the lack of information?

Yes. Probably not very often at all because if something's important you insist that you get it. So it is very rare that you are unable to make a decision. You might be delayed.

Yes. Okay, and how often do you delay a decision?

Probably a couple of times a week. It's not clinically significant delay that happens that frequently. One thing that we do is we plan radiotherapy for patients with prostrate cancer and it's very helpful to have the MRI available when you're planning the radiotherapy because the MRI gives a lot more detail, so you can plan radiotherapy on that. You don't plan it on the MRI but you have the MRI open and a CT scan open, because all my patients have the MRI done in a different hospital you have to ask for it to be imported and so there's an extra step in the pathway, an extra step in the process, which if that doesn't happen when you go down to the radiotherapy planning department and the MRI's not there you have to say, I can't plan the radiotherapy, I'll do it later, and that happens probably at least once a week.

And do you make assumptions sometimes?

No, I don't make assumptions, I say I'm not going to do it until I get the MRI. It means I timetable, I know what's going to do planning, and then I can't complete all the planning, and

then I have to go back and do it again another day, which just adds inefficiency as another tie.
What about relying on patients as a source of information?
Yes, we do that. **100%?**
Well, we do rely on patients as a source of some information and you ask them what medications they have or what allergies they have and often they will give us a list of medications. They might bring in a print-off from a pharmacy or they might just remember their medications. We rely on them to say what they're on.
Most of the time is it reliable or?
Yes. You can make a judgment when you're talking to a patient, about how sensible they are. If they're confused and muddled you wouldn't rely on it. But a standard question would be, do you have any past medical history or do you have any allergies? And if the patient says, no I don't have any medical allergies, I would not go to the GP and double check, I trust them and if they didn't inform me then potentially that can be difficult. Yes, we're constantly relying on patients.
Yes. So how much could this proposal reduce the workload? I mean if the oncologists specify what they require to know and then we make sure that the system whenever the oncologists, or any specialty, if you know their requirements then you make these accessible and visible for them and hopefully avoid needing to ask the patients for the information.
I think it would be, it looks very elegant when it's structured with the patient flowing through on the pathway that you've put on the screen, and I think a lot of patients do go through very well worked out pathways, cancer diagnosis is one of those. The patient goes to a GP with a lump, get's referred, and you do go through that for probably the majority of patients.
But there are a lot of patients who come in in random ways. A fallback of this might probably be that it works very well for a group of patients but it might not pick up those other patients, and I think it's those other patients who come through in a non-defined pathway who will benefit most from something to structure it because they're the ones who have the least structure. We do see in MDT's that patient comes up for a discussion and the pathology isn't ready or scans haven't been done yet, and that put's a delay because most MDT's are once a week and so you're instantly put seven days back before you can discuss it again.
If it's clinically important you'll then have a discussion outside of the MDT, so it shouldn't impact clinically. But probably I'd say every week there's a patient, at least one patient on the MDT where there's some lack of information which means we have to bring them back the following week, and if there were these kind of clocks and alerts so the pathologist would know what timeline is, the radiologist would know what the timeline is, the clinician would know what the timeline is, they can all see that and they can work towards the same date and time and then the patient wouldn't be put on the MDT until everything was ready.
That wouldn't reduce my workload I don't think because it's not me that prepares the MDT and puts everything together, but it would improve the efficiencies of the system and IÕm sure it would reduce workload in the NHS overall. It would make things a lot smoother, save duplication and save admissions and delays. So I think it would save time across a team.
Yes, and in medical decisions? I think it would support those nicely. The availability of information is critical to decision making. The better the information you have, the better decisions you can make.
Okay. So what do you think are the disadvantages that this proposal might? Patients who don't fit into the pathway neatly may throw up problems, and patients are all unique and there's always variances or reasons why the pathway doesn't apply to a specific patient and it needs

to have the flexibility to account for that and still be helpful. One potential problem might be, just thinking off-the-cuff, it goes back to your thing about who's alerted appropriately about information, because if I get a lot of alerts about patients that I don't need to have those alerts. I don't really need to know whatÕs happening for some patients in the build up to the MDT, the MDT coordinator needs to know that but not me.

Yes, I understand.

So I don't want to be inundated with lots of noise, if you like, that I then have to filter out the key messages, I only want to see the things that are important for me to see.

So if you specify your requirements and the system can make, I mean if you have the ability to customise whatever you need to know and then the system sends only that information to you, then that would help make [00:21:39].

That sounds very good, yes. Whether that works or not I don't know, but it sounds good.

Appendix B

Evaluation Session with CIU Team

Overview

An evaluation session has been conducted with four members of the CIU at Velindre to discuss the proposal. The session lasted for an hour and fifteen minutes. The members attended the session are David Howells and Rhodri Evans; who are Principal Software Developers, Hazel Bailey; a Principal Support and Business Analyst, and David Morrey; the head of the CIU at Velindre. Full Transcripts of the session with the CIU team is in this section. The session was led by the author and the transcripts was done by Isabel's Typing Services (http://www.isabels-typing-services.co.uk/).

B.1 Setup Evaluation

I'll just introduce you. Hessah has been working on a PhD and it's largely around the area of workflow technology and the last bit really is it's application to healthcare, isn't it?
Yes.
We set the scene that the workflow wasn't really fully in Canisc, in that Canisc is very largely a system where clinical information is put in by doctors and other health professionals and then they look at that information back and make decisions around it, and maybe that the future might be to look at where the system or other systems, clinical portals or whatever things, how things work out in the future, how they become perhaps a little bit more active? In other words, to use the information to bring various things to various people's attention and make things happen.
There's a previous little bit of work from Alisha who was working on a similar area and her particular focus was on role based access and looking at how people's different roles and changing roles in the team, really on a Wales wide basis, might effect the information, was really brought up before then. You're looking at security, aren't you? And some of the security aspects.
Yes. Security issues and when information is being exchanged and how we can sustain the protection wherever it goes around among the team, really.
Got you. Right. Yes. Hessah, as well as looking at the literature and other ideas, she's done a little bit of evaluation work with some of the clinicians, haven't you?
Yes. I met five clinicians and posed the ideas and so if they find they would like to have such functionalities in the systems they use. Obviously Canisc is providing a lot for them but they are, I won't say it's complimentary but what I'm proposing is an approach to make this more proactive so they can access the information maybe through the Welsh clinical portal or Canisc. But how can you make the information visible to the user so they are aware of the achievements progress and the different medical problems that the patient has.
So we're talking about presenting the information that's recorded about the patient, in a way that's relevant to their position throughout the pathway?
Exactly. Exactly. So I did.
Sorry Hessah. I keep interrupting you. We pose a situation that a few years down the line when we've got a larger implementation of Canisc like systems and different clinical specialties, that you flip over from the current problem of, we can't get this information, we can't get that information, to suddenly, well we've got access to all laboratory results from all over Wales. We've got information about all the cancer patients, palliative care patients; we've got heart patients on all the general records. So at that stage you have the inverse problem that you have potential information overload. So again, that was part of the role based research work, to say, well, as soon we get to that stage how can we perhaps focus on what we present? So yes, that's the sort of background.
Thank you very much.
That's okay.
I did prep the handouts if you prefer and what I did is actually I have some questions at the end of the presentation. I thought it maybe would be that we can't tell who said what. So I have these questions that maybe you each can just tell me their opinion on. Just to start off I'm going to present what I'm trying to do. It's the idea of, we're looking at using the workflow technology in the healthcare domain and what is the impact of that, what could the impact be for the decision makers or the healthcare providers?

So I'm going to talk about the motivation, the proposal, the approach, how we see it, the architecture. We took a scenario; we marked it on a process map in a workflow management system. I'll show you some of the screen shots just to show you what I think, my view of this and way of the existing systems. So what is motivating this is the idea of the need to implement the patient centric.
In order for the healthcare providers to implement the patient centric they need to work as a team. So they need to be aware of the patient's different treatments, notified about the progress of the treatments and alerted about any changes that happen to their patient's treatment. The driver is the fact that e-health is expanding and projects are looking at better access to medical records, better information exchange mechanism and new approaches are being introduced, and here we're looking at the workflow technology. So what we're looked at is the integrated care pathway [00:09:36] the different stages that the patient goes through and throughout the implementation of the integrated care pathway or the guidelines, which are unique to each patient, we believe that each stage needs to be identified, the requirements of each stage needs to be provided to the user of the system and changes that result from this treatment stage need to be managed.
An example here of an integrated care pathway. I got this from the Map of Medicine. It shows the diagnostic of the breast cancer clinic. Here the history is checked, after the referral from the G.P. the history is checked by the oncologist and then the patient goes through three, they call it the triple assessment, three assessments, which are the examination, imaging and finally the aspiration.
At some stage an MDT meets to discuss the results of these tests to say whether there's positive findings or more tests are needed or there's no abnormality, and then the positive finding could be benign or malignant. So this is just the example that I use throughout, the prototype I implemented.
So what we believe is needed is to improve care communication. They need to communicate together and care needs to be coordinated according to the guidelines. My focus on making the system more proactive is by making more contact spaced actions, and what I mean by contact spaced actions is the consideration of the treatment history, the anticipated care pathway, what might happen, current stage care team members involved, different health issues and the changes in any treatment followed by the patient. So if the patient is under chemotherapy maybe the other doctors, not only the oncologists need to be aware of that but maybe other healthcare providers who are looking after the patient need to know this information.
So what we're proposing is mapping the integrated care pathway or the national guidelines into our workflow management system and incorporating it into existing systems. So it's not a new system, we look at it as an independent layer that can interact with the different hospital information systems or applications within the hospital information system. What we're hoping for is integrating the interface of the workflow management system into the legacy systems, have the section which shows the workflow and the process of what's happening with the treatment.
What we believe is, what we've found by mapping the integrated care pathway into a workflow management system, these functionalities could be achieved. So you can formalise the treatment of the process. We understand that each treatment is unique and each patient is different, but anyway you can help follow the guidelines, ensuring care continuities. It happens that sometimes a patient gets lost in the system, the patient didn't go back for a followup or just did not continue a treatment, so the system can alert or show that this is happening.

Filtering and gathering the medical information from the independent databases, so the multiple databases that are distributed all over the place, hopefully this information could be filtered and gathered according to the needs of the user. Proactive through changes, this includes the examples within the integrated care pathway that we looked at. This includes referral, alerts, notification, scheduling and setting timers. I'm going to show you an example of these in a minute.
So what we're looking at is an independent layer that interacts with legacy systems, evolve the functionalities by having the interfaces integrated. We believe by having this system the workflow will construct a virtual organisation so everything will get together, let's say like a ' that links everything together, and then whenever a process or whenever a patient is treated, a unique virgin of the pathway is created for each patient which is managed separately.
The architecture, as I said is like the idea of having the workflow management system as a ' linking the different organisations. This is the user interface and this is the workflow management system layer and here is the legacy systemÕs interface. So it's going to be like an interface between the user and the legacy systems, but I should really put an arrow that the user accesses both interfaces through the legacy system's interface, and here are the different systems that are accessed, sorry, the databases are accessed by the legacy systems.
This is the breast cancer scenario which we looked at just now. I highlighted within this scenario the different stages that require attention. So this is the G.P. referring the patient to the oncology, this is the same pathway that we looked at just now. This is the oncologist, this is the patient and whenever the G.P. refers the patient to the oncologist this is one of the actions that could be done automatically which is the referral. Along the treatment the patient might do these examinations, so this is the examination and a document or a summary is produced out of each of these stages. Whenever the patient is revised at the MDT these documents need to be gathered and the team needs to be notified about the results.
So this is another example. Here, whenever there is a positive finding and the MDT decide that the patient has cancer and it's confirmed, then we need to alert the involved care team members, or whoever, it's the idea of where in the system can I identify which of the care team members need to know about this update, for example. If the patient is undertaking chemotherapy then I think there is a lot of restrictions here, medications that are prescribed to the patient need to be, this patient being under chemotherapy needs to be notified whoever is going to prescribe medication for patients, for example. And if the patient is under chemotherapy and radiotherapy there is a delay of two weeks that need to be met in between, and the system can ensure that this is satisfied and this is all according to the national guidelines. So whenever the patient is between chemotherapy and radiotherapy that is another support.
Here, they're setting the timers, these are the treatment options and if the patient goes to surgery, after the surgery there is recovery after a couple of weeks or something, so this is one of the functionalities that could be provided, setting a timer and referring a patient to the oncologist or the MDT again after the recovery.
This is the scenario I looked at and if I go back to my slides. What we did is we mapped the scenario into a workflow management system. We used Alia*Systems, the company is called Alia*, it's called State Frame and they have this mapper which is on Visio* where

you can identify the different stages and really detail the stages within the flow. So this is an example of the MDT, you can have referral. Here I choose case summaries; this is an automatic agent that [00:19:30].
This is a selection of the process map; I have the whole process map if you'd like to take a look at it. You select the different stages and guide it through. So here for example, this is the MDT part of the workflow, here is an automatic agent which does collect the case summary and makes sure that all of the documents are available before the MDT meeting is scheduled for the patient, for example. These are collected here and whenever that's done the MDT review is scheduled for the patient and at the meeting a decision is made on whether it's positive, no abnormality or more tests are needed. If it's for example, positive, here a decision is made on whether it's malignant or benign and here informing the G.P. for example if it's malignant.
So I'm going to take you through this process and show you what these screen shots look like in the prototype implemented. Would you like to take a look at more of the maps? It's here; I did divide it into different pages on the Visio. This is the diagnostic. This is the beginning and identifying the patient. I made it by role, so this referral to radiology and these are the different stages within the referral to the radiology, and these are the icons that they provide in the system. It shows ASP activity which is an automatic agent that does things without needing a user interaction, and here the prompt is when a decision is made and where, a clear decision is made and which are the ways to follow, and this is an icon for referral, for example if you would like to send a message to a specific user or a department.
So these are the process maps. Next to my slides are I think, the screen shots. So that's the process map and next is the screen shots. I have some of the screen shots here. Okay. So this is me for example, logging them onto the system. Okay. That's me logging onto, I am an oncologist.
Instant promotion.
And here I chose any cases visiting. So this is the name of the patient, I'm searching the patient and along the process you can see here that the hierarchy is presented, so the different stages the patient went through. I can play with these icons to show whatever is done is checked and whatever is in process I use another icon, and here is where I actually do the alert. I'll show you that in a minute.
So here I recorded the history and then the triple assessment starts. I did the examination, completed, and then the core biopsy. What I do here is I did actually copy whatÕs in the guidelines, so it could help really tell, for example here, I don't understand most of these things, but examination for example, perform something examination, and it just guides the clinicians according to the guidelines. So this is the core biopsy. This is the triple assessment and then the patient is referred to radiology for the imaging, for example. Then the radiology logs in, the patient's [00:24:50] is referred to the radiologist, and then here, this is one of the examples that could be done automatically but I didn't implement it, which checks, the age of the patient is checked, whether the patient is younger than thirty-five. The patient should do a mammogram I think if the patient is older than, there's another examination that's done or imaging.
It's got gremlins. It's going on its own [laughter].
[Laughter] what's happening? It's actually a set of screen shots which.
It's the slide show is progressing.

Oh, okay. I shouldn't make it automatic.
There's probably a pause button on the top or down the bottom or something.
Okay. I can just do it manually. I wanted to enlarge the images for you. Okay. I'll try to control it. That's me and then the patient, I start a new case, that's [00:26:09] of the patient and then [00:26:14] this is the check history, so you record whatever you want to record about the history as an oncologist. Then the examination is done, record the results, and this depends really on the resources, whether the core biopsy could be done or not, I think, it's a resources thing, and then the core biopsy is recorded.
The patient is referred to radiology for imaging. The radiologist and the radiologist's in-tray, that's the patient, [00:26:48], referred, and here the progress can be seen. This is where you say the age which can be done automatically, checking the age. A mammography is done. Refer to MDT. You can see here that the names of whoever is dealing with the patient or who dealt with the patient is also visible in the hierarchy.
That's the examination so I can do, if I check the examination, the history or I want to check it all then it's available for the MDT meeting. A decision here is made, if it's positive for example, then you can change the icon to say there's to be an alert, it's going to go on. These are the screen shots mainly, but it just shows, how I can see it is the interface of the legacy systems having this as part of it. That shows the hierarchy of the patient's treatment progress, and there is a lot that can be done using this technology because you know what might happen and what's happened already and all of that is recorded within the workflow management system's database.
One of its features is that it can deal with heterogeneous systems and this is the problem really with the legacy systems, as an independent layer you change the [00:28:34] that has for the different systems. Hopefully it's that easy, but I know it's not that easy, but this is the vision really, on how to use this approach.
This is it. I want to ask you some questions about the usability, the challenges and the approach. First of all, would you like to comment on this?
I think the process engine looking at the recognised pathways would be useful for Canisc. I'm not sure that I understand altogether what you're trying to do. The way you presented it, it implies that there's a rigid approach that never changes and I suspect that not withstanding recommendations it's always going to change, every person's an individual.
It depends how high a level you view it at.
Yes.
You'd have to pitch it at a high enough level. Let's say 80% of the patients are going to go down what we've perhaps referred to as the 'happy pathway' [laughter] is what we intend to call it. Which is not necessarily [00:30:21]. But it's, if you want to say, the normal route you'd expect most patients to go down, you'd pitch it at that level where you'd get an 80% pathway, and is that where you'd drive to put your system in place?
It should be at an abstract level. But the thing is when I did the evaluation with the clinicians they told us there's certain information that they know up front, that they need to know whenever they're seeing the patient, which they do not necessarily get in the referral letters they get. So I think if we get the clinicians involved with the workflow management system you can really get most of what they need to know in the system. And as a clinician dealing with a patient then you know that this information is important then you will highlight it for the next to see it's visible in the flow if it's not automatically spotted as an important decision that needs to be notified to everyone.

Is that where the role based, so that you're ensuring that the people who need to know have that information, well, that theyÕre alerted to it.
Yes, we certainly want to [00:31:57] is to the medics, she was saying Rob, part of what I'm presenting to you is based on role based access, but inevitably I'm folding over to the next project which is going to come along [laughter] which is Hessah coming along because you start having an interaction between the two because once you're presenting and where you are in the process engine will depend on who you are and what's happened to the patient. So it's partly user driven so that what you're presenting or using the workflow technology for is partly role based and also partly patient based because depending on what the results are that have come in from the previous stage then you decide whereabouts you go presumably in the workflow.
I guess if you've done enough abstracting in terms of the process flow and I suppose that's what Map of Medicine was trying to do, wasn't it? To make it sufficiently generic then you just use those and that would be the starter. The final bit may well be the clinicians saying well, that's fine so far but from what I've got here, I need to do something else or something on there.
Well, this can be the start and then hopefully with the involvement of the users we can get more out of it.
I suppose it's a bit like the functionality in Canisc. You have a perceptive model of how things should be brought up and grouped together and then you demonstrate it and prototype it and then you alter it don't you because it doesn't quite satisfy the requirements.
No, it usually satisfies the requirements, whether it will satisfy the needs.
This is the problem, I think.
It's the age old problem. How do you counter the possibility that, how do you find the balance between presenting the right information at the right time and the risk of information being withheld, because obviously you can't show everything.
That's one of the problems that we've always had in Canisc in that we don't know what the consultant needs to know.
And we can't write a system that will make decisions for them.
Yes. This stresses on the fact that it supports the decision making process but never makes the decision for them.
It can alert them that information is available but it can't act on that information and it can't decide whether that information is relevant or not, just that information of a certain type is available. Is that?
It should identify whether it's relevant or not but, sorry, what was the first part of the question?
It was more a statement. Roger* was saying that Canisc now alerts consultants to data being available, test results coming in, that sort of thing. But.
We've no idea if that's relevant.
We don't know whether that's relevant and we cannot know whether that's relevant.
But that's what the workflow should [00:35:32].
So there will have been clinicians who will have designed the workflow to say "we're only interested in this, this and this result. Is that what you're saying?
Yes. But I'm not really looking at, as a future work I'm interested in looking at how they want it to be presented and maybe giving them one of the things that they highlighted for me. I don't want to see everything, I want to customise it to my needs and that's something that would be nice to have.
But I suppose part of it would be implementation because if you talk about it as a layer on top

of Canisc according to the process mapping you present what the process map tells you need to do and the clinician says “yes, I know it’s what I said but I actually want to look at something else.You then flick from that layer into Canisc and youÕve got the full clinical records.
There’s always going to be the risk that the process has said - I’m interested in results A, B and C, but the patient’s also got one on D thatÕ’s not on the process but you need to be able to get that information. So that’s my concern.
So perhaps they need to know that.
There’s non-pathway information available.
That information is available and they do need to know the other information’s available even though they don’t necessarily don’need to go and look at it.
Yes. But if I were to look at it as how can it be, what can you get out of a system that knows where you’re coming from and where you might go to. This is the main benefit that we can see. Yes, you have cancer and you’re getting this treatment and you’re following the cancer pathway but you have other problems that need to be shown in the system and if it’s in one engine that has all these patients related information then the system can provide all the relevant information, the cancer relevant information to the healthcare provider and this is what I think is the, the heart of this is you understand where the patient is.
But you’ve still got to find the balance between providing relevant information in an easy readable format at the time that it’s relevant, during the pathway, against the fact that there may be other information concerning the patient that the clinician needs to know about that’s off the pathway and that the pathway isn’t necessarily going to encompass all of that.
It’s important that it doesn’t hide information, it just.
Hides the presentation.
Yes. It just shows you what you definitely need to know and shows you that there is other stuff available should you want it.
I thought there was a certain similarity brought to mind when Hessah was showing the pathway and you were going down the various bits, there’s a certain similarity between Canisc and the summary which a lot of people.
Or indeed the MDT summary screen.
I haven’t seen that very much. You guys have seen that.
But also the designs. Do you remember the designs with the pathway across the bottom?
ThatÕs right.
Yes.
And Amber* is a very much more of a workflow process, the little I do know of that which is not very much, that’s Amber* role based.
Yes. So it’s down to bringing [00:39:39].
I don’t know whether [00:39:42] is the same. But certainly Amber* has got that.
It’s not quite the same.
Because that produces a kind of.
Yes, because again, from that summary, the existing hub in Canisc, you know where you are in the process which probably [00:39:59] the idea was you could click on that to produce [00:40:03] couldn’t you? Sorry?
I thought it was Wayne’s*
Wayne’s was it? Okay [laughter].
But he only thing that we’ve got close is the MDT summary that is trying to cram everything that they need to know for an MDT into one screen.

:40:22
know this stuff but they have to think to look elsewhere and that's just common sense, isn't it?
Well, we do tend to have the top three most recent and then the list of there is information in these areas available.
I see [00:40:40] one of the questions there, I see one of the issues around this is it's a little bit like the chicken and the egg, in that the clinicians at the moment are not used to thinking or expressing their business requirements in terms of an event driven system, are they? They're used to, as a more passive system.
They still in the kind of data set times.
Yes. Exactly.
The old [00:40:08] rather than.
Yes. But it is like the chicken and the egg. If the medics start looking at that and saying "well, actually that's the way we'd like to do, we accept your design idea then you've got then more of a chance to say "well actually that would be better rather than picking of piece meal bits of development and doing them in the traditional way, is implementing the process engine to actually help some of those requirements.
If you look at it as extending what they have ready now and your adding to the functionality but they still have what they have now in the system.
It's an additional layer on top.
Yes.
The thing that was worrying me was you might become too rigid and too tunnel vision, you look just at what you're given and decide everything purely on that.
There would be clinical risks involved.
There would. Probably it's [00:42:32] and it probably isn't even 80%, it probably 95% 96%, 97% of things, you'll be fine.
But that's where the risk is higher because as you say 96% of them sail straight through along the pathway, are they going to remember about that 4% or 5%?
I think you're probably worrying too much though, because when you talk to Tom [00:42:58] they tend to look at set pieces of information anyway and not look for those other things that you're talking about.
Well, the risk's already there.
The risk is there basically, yes.
Yes. But Tom keeps hammering on all the time because whenever we get into arguments with the information governance people, he's "what you people don't realise is that it's us constantly making decisions where we don't have all the information, we're constantly doing that, it's a far more worse risk stopping us from looking at these things. That's a separate argument but it emphases your point that they're constantly scanning for certain things and summarising things in their head about what they want to see.
This is merely transferring the existing pathway to an electronic fort.
I think it's a bit like, if you think of implementation maybe being on the ideas that's the screen of Wayne's where you've got stuff along the bottom and you're moving through that process which is mapped as a summary, when you need to look at anything else you've got the ability to just press the button and that takes you through to traditional Canisc which says on the process flow "what screen should I now display within Canisc to bring that information and any other supporting information there? [00:44:20] maybe transport back into quickly.
You're thinking of a new layer on top, is data stored in this new layer on top apart from the process or does it just refer to the other systems?

It should be the detail that is linked to the workflow management, so the process is linked to it and the rest just stay where they are.
I was looking at the data that you put in the MDT, that was going into his was it, rather than into your system?
You're helping support the system but it's what the healthcare provider is going to record at that stage linked to their databases. So if that's an oncologist using Canisc for example, and when the oncologists do the examination [00:45:46] and what do they usually do, how do they store the examination results? This is it, but because I'm not linking it to the system, but what I'm trying to show here is that you can guide the clinician through the process but oncologist's data is stored in oncologist's databases as it is in Canisc now, but the process information is stored in a process database and we have Alisha's database which is the coordinating database which links the patients to who is involved. So that's the processing of the workflow but the medical information that is related to each of the systems is stored in its own databases.
So really the answer is the end of line data is in Canisc or whatever [00:46:41] so what you're doing is you're presenting a process interface to Canisc or whatever and then ideally you won't be able to click between there and then go to the end of the line traditional view of data for break points.
Canisc sort of has the basis for this process.
Yes. Palliative care screens that you can click between the two, you've got a wet layer over the top of an older technology.
Yes. You're right as you mentioned it's been Wayne's idea, now you mention it there is some similarities in what was suggested and you can see its worked and similarities with the summary are there as well, aren't they?
Yes.
Looking at your questions here and considering work that we've got lined up still for the future is the MDT module within Canisc. It's extremely relevant to that.
That's good.
It actually.

Yes. I suppose the advantage is if you could just find the right project with the right money then probably the process engine would help and when that's available and you start seeing it then it's boot, putting stuff on your bootlaces and then you can see that and it's the same with other things.
Isn't it, because you can tailor it to every [00:48:14] you can tailor this to each MDM* and that becomes [00:48:18] everything, can't it?
But MDM's* are also very much about presenting the information so a decision can be recorded.
Yes. But they're all process driven, aren't they?
Yes. We need to know this piece of information at this point in time.
As he pointed out.
Yes. That's where it's ideally suited to in terms of our system.
But can you spot other parts of the system that are?

The one I mentioned earlier was the one they used in radiotherapy Canning* which we call the IRMER* module. I can't remember what that actually stands for.
It was ionising radiations medical exposure regulations. But yes, it's just a way of planning what radiotherapy you're going to give to patients and prescribing it for that processes.
But that is actually process driven.
That encompasses both a process and it's role based as well.
Yes. But then again this would have been perhaps a better way of doing it because then we could have transferred it to Swansea like they wanted.
Whether it's similar with chemotherapy [00:49:36].
But again, you could apply it to that.
Well, any planning process for any treatment really, isn'it?
Is there anything like this in the Mosaic* system that we were buying?
Not that I know of. No. I don't know the system in detail.
That's the new.
Yes, I can ask Alison.
That's the new chemotherapy.
Yes. But the new user training is happening next week so they might [00:50:09] their way with it based on what they've been told so far. That's a bit like the chicken and the egg, trying to configure the system based on the fact that they don't really know how to fully use it. So now they're going to go back and the first couple of days in the week will be spent on configuration and then after the configuration then it's user training. So I might know a bit more about that from there. I'm not sure if there's any process flow technology within the system. I suspect it's a bit like Kevin's*, there may be elements done but not necessarily where there's a workflow engine, [00:51:00] available because it has a functionality which would allow it to be used as a electronic record.
I'm trying to think if there's any barriers to its implementation. The first one a year or two earlier which is the ability of the clinicians to describe things [00:51:20].
Yes. We've got the [00:51:24] maintenance so that work's already been done.
Or at least start the discussion.
They will of course, change it.
Naturally. But it's getting into that mindset to put the requirements in this format.
The actual biggest barrier is the time you need to set it up.
Yes. Well, I think there is an incremental step here with the idea, the barrier would obviously be cost and having the specific requirement which is going to justify that cost and the learning process and everything else. Once you're over that step then you may will be able to direct user's requirements and say, "well, I know you've said that that's what you want, but maybe if you thought more in a workflow based way then you might then be able to use the engine to

make things more efficient ".
It could be very complicated. Maybe I'm not thinking about this is the right way, but it could be very complicated interfacing into all the other systems because you are going to have to put triggers on the other systems to say when things are done.
Is the trigger at your end going to keep pulling that system to say "have you got something for me, have you got something for me" And keep.
I didn't really think about how technically that is going to work.
Well, is it a push or a pull?
It should be a pull, I think. I thought about pushing and pulling [laughter].
Yes. I think it probably should be a pull. And again, we used to do exactly that for Canisc. Back in the ESGO* days, somebody would come to clinic and the day somebody would come to clinic ESGO* would go and look at the UHW pathology systems and say "have you got anything on this patient?"And drag it all back.
Yes. I suppose that's fair to say. Yes.
So that's how we got UHW results in Canisc.
Conversely we then had the interface with Prince Charles Hospital where they push the results for their patients to us. Admittedly that push is dependent on the list.
They're partially dependent. We tell them what patients we want and they send us all the results for those patients. But not filtered.
So it really could be the way that you agree with them how to pass the information.
But that's not going to be a trivial exercise interfacing to any machine.
Not to mention all the different interfaces. You would like to think that.
Even if you say they're all HL7, you've got the different versions of HL7 and even within one version it's how specifically have they engineered it to that.
Well, turn it on its head. Is the workflow technology better implemented in something like the Welsh clinical portal which is supposed to have access to all those other systems?
I thought it was sitting at that layer already. It is on top of all the existing systems.
It doesn't store any data.
It's just a presentation layer, isn't it?
I think it should take advantage of the Welsh clinical portal if it stores the information and has it, but it still can interact at a lower level [00:55:20].
Yes, which is what the Welsh clinical portal is doing, is supported to do that.
But are we saying that's probably the right place for this work?
It might well be actually because since the portal will be available to everybody and should have interface to every system, you don't want to do that twice.
Of course. Yes.
Right. So you do it at the portal.

Because it has the access you need to implement their workflow.
Who's in charge of the portal?
It's an organisation called NWIS.
Yes, I know it's NWIS, but.
Stuart.*
Does that portal belong to Stuart?*
Yes.
Stuart's* in charge of us as well. Us that is, not [00:56:16].
Rob's your design man though, isn't he?
Yes, he is.
The architecture man, isn't the?
Yes.
Who? Rob Jones?
Yes. He would be the person to, so that's Rob Jones at [00:56:31] not Rob Jones, actually I don't know if he's still at [00:56:33].
It's a pity the, who's the chap who's gone to Australia who was very much at the inception?
We can probably see it being used as a certain functionality within Canisc [00:56:57] retrospectively like IRMER* and things, which are process driven in oncology and the like, but you maybe see it as more generic in Welsh clinical portal simply because you're able to leverage the interface that is supposed to be there with the portal to the other systems.
Technically it would be easier to do it there because the interfaces will already be in place. The interface for Canisc isn't there yet, but it should happen sometime and if you do it in the Welsh clinical portal then it's not restricted to Canisc, it's everything. So yes, I can see the need for it and I can see the need for it in cancer and yes, we could put it on top of Canisc, but I'm not sure it's the best place to put it overall.
You don't need generic MDM's [00:58:05] solution then if you've got the portal, [00:58:07] use the MDM.
Yes.
But that first step is the recognition that it's licensed by NWIS and then used in the appropriate place. If you sit around Canisc SNB and you say "well, we actually need that"then that requirement would then be pushed into NWIS wouldn't it? And then we'd have a look at that, well is that cost effective on just the Canisc thing or is it actually more generic in terms of the portal it's in? And then the technology then should be available for use at whatever level is appropriate.
How are you going to do the answers then? How are we going to do the answers?
I kind of alluded to some of the answers because.
It's three, but the thing is I want to know each one is your [00:59:20].
Yes. Shall we put them in an email? It won't take long to do that, will it?

Whatever suits you. I've recorded everything so I have this discussion. But I think we went through most of the questions, but things like the, discussed the advantages and disadvantages. But I think I'm fine. But you don't need to worry about it.
Does it require re-engineering, would it be a radical change to implement that layer, do you think?
If you were trying to implement it within Canisc, yes.
Well, you wouldn't do in Canisc; you'd do it on top.
Yes, that's the thing.
But yes, the interfaces are not going to be easy. That's what worries me.
Canisc does not have the interfaces, that's why we've said the portal is probably the best place for it.
But even so, you're still going to have problems. It's a non-trivial problem that the interfacing and you know me, I tend to say things are trivial very easily and other people then tend to disagree with me. If I say something's non-trivial it probably means itÕs not going to be easy.
Well, that may be one of the barriers of implementation. You've got to be sure that a particular project, before you do it you've got to be sure that the particular project you're going through is [01:01:00] of palliative care and of sufficient benefit to then invest in a product and actually re-engineer that to do it.
But in terms of if you were specifically engineering it under Canisc would. Well yes, [01:01:18] the web layer, you wouldn't start doing anything in the old system that would have to be a web layer.
I suppose looking at Canisc SNB again in the context of the re-write of Canisc which is supposed to of happened for the new functionality as opposed to going back and re-writing an agreement on there, that would be sensible, that's the way to do it, the palliative care incent, that's a completely new project, it's supposed to have its own development resources and things on the budget and it's going to be different to the old one and you engineer it in a better plan.
I'm thinking in terms of adding it into Canisc now. You have to put the process database in to get there.
It's some kind of engine, isn't it?
Yes. So you've got that in possibly a different database in sequel [01:02:26]. What you do is do a halfway house and have processes in one database and then the data associated with it you just [01:02:55] so you've got to let a table pointing out which you're on and where you are in the process and which boxes have been checked, etc.
I think we've established it's a fairly non-trivial exercise.
So it's both a yes, to does it require engineering and what are the barriers?
It could be fun.
It could be fun, yes. There's a new meaning of fun.

Anything involving Visio is always appeals to me. It's the visual.
At least you haven't given us a mind map.
That can be arranged.
Whereas with me anything that involves visual pictures of it, I say "yuck, give it to me in text."
A word is worth a thousand pictures. Okay. Well, I'm going to have to run off but I'll.
No, don't worry about this, we've discussed this and this is the most important part.
But perhaps the others can email you some answers, some quick answers to these to supplement to what we've got on the tape.
Do you mind if I put in, I'm [01:04:15] and I'm not sure if you don't mind if I put your names on these?
Not at all.

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