

Supporting the Information Systems Requirements of Distributed Healthcare Teams

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2011

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

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Dedicated to the memory of

Professor Nick Fiddian (1948-2010)

"Happy is the man that findeth wisdom, and the man that getteth understanding. For the merchandise of it is better than the merchandise of silver, and the gain thereof than fine gold."

(Proverbs 3:13-14)

Abstract

The adoption of a patient-centric approach to healthcare delivery in the National Health Service (NHS) in the UK has led to changing requirements for information systems supporting the work of health and care practitioners. In particular, the patient-centric approach emphasises teamwork and cross-boundary coordination and collaboration. Although a great deal of both time and money has been invested in modernising healthcare information systems, they do not yet meet the requirements of patient-centric work. Current proposals for meeting these needs focus on providing cross-boundary information access in the form of an integrated Electronic Patient Record (EPR). This research considers the requirements that are likely to remain unmet after an integrated EPR is in place and how to meet these. Because the patient-centric approach emphasises teamwork, a conceptual model which uses care team meta-data to track and manage team members and professional roles is proposed as a means to meet this broader range of requirements. The model is supported by a proof of concept prototype which leverages team information to provide tailored information access, targeted notifications and alerts, and patient and team management functionality. Although some concerns were raised regarding implementation, the proposal was met with enthusiasm by both clinicians and developers during evaluation. However, the area of need is broad and there is still a great deal of work to be done if this work is to be taken forward.

Acknowledgements

It is with grateful thanks that I acknowledge:

- the unfailing patience, help, support, and advice of my supervisors Professor Alex Gray, Dr. Omnia Allam, and the late Professor Nick Fiddian,
- the many hours of advice and enthusiastic support given by Dr. Dave Morrey, Mrs. Hazel Bailey, and Mr. Tony Bater as well as their patient explanations of the NHS, CANISC, and working practices at Velindre NHS Trust,
- the many other members of the Velindre staff who so kindly gave their time and insight to this project,
- my sponsors, Cancer Research Wales,
- Mrs Margaret Evans, Dr. Pamela Munn, and Mrs. Helen Williams, without whom I would have given up long before I reached the end
- my fellow PhD students for their support and commiserations throughout this project, and
- the many others who have advised, supported, encouraged, informed, and tolerated me over the last five years but who are too numerous to name.

I would also especially like to thank Dani for the many, many hours she has spent discussing research with me which is completely unrelated to her own, Steve for putting up with me through all of this (as well as for everything else), and all of my loved ones who have waited so patiently for me to come home.

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

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Acronyms

C-TMAC Context-based Team Access Control. 79

CANISC CAncer Network Information System Cymru. 17

CfH Connecting for Health. 12 *Connecting for Health can refer to either the organisation or the lifelong patient record project. Here, we will use CfH to mean the lifelong record project.*

CSCW Computer Supported Cooperative Work. 36

DBMS DataBase Management System. 93

ECS Scottish Emergency Care Summary. 18

EPR Electronic Patient Record System. 16

GP General Practitioner. 3

HCI Human Computer Interaction. 36

ICT Information and Communication Technology. 8

MDT Multi-Disciplinary care Team. 6

NHS National Health Service. 2

NICE National Institute for health and Clinical Excellence. 12

NPfIT National Programme for IT. 12

NWIS NHS Wales Informatics Service. 12

RBAC Role-Based Access Control. 63

SSM Soft Systems Methodology. 48

TMAC TeaM-based Access Control. 79

TMAC04 Team-Based Access Control 2004. 79

TRBAC Team-and-Role-Based Organizational Context and Access Control. 79

VO Virtual Organisation. 54

VOICE Virtual Organisation access to Information sources and services in a Collaborative Environment. 62

WCP Welsh Clinical Portal. 16

Chapter 1

Introduction

'But I don't want to go among mad people,' said Alice. 'Oh, you can't help that,' said the cat. 'We're all mad here.'

-Lewis Carrol

In the late 1990s the National Health Service (NHS) in the UK formally moved from a disease-centric approach to healthcare delivery to a patient-centric one [1]. The patient-centric approach emphasises viewing the patient as a whole and considering interactions between different aspects of the patient's healthcare. This requires a higher degree of teamwork and coordination than earlier healthcare delivery models. More than ten years after the adoption of the patient-centric approach, healthcare information systems do not yet provide the support necessary for this cross-boundary teamwork.

One of the main challenges to providing improved support for healthcare practitioners is that the picture of what is required is both unclear and continually evolving. That healthcare information systems should provide cross-boundary access to patient information which is collected and stored at different care sites *is* clear [2]. However, because there is such an emphasis on obtaining cross-boundary information access, and because this access is so challenging to achieve, there has been relatively little focus on what will happen *after* information access has been achieved and what other requirements might exist for healthcare information systems. This research aims first to identify what requirements and challenges will exist for supporting the work of healthcare practitioners working patient-centrally once shared electronic patient record access has been achieved, and then identifying a possible approach to meet these needs.

1.1 Research Context

Healthcare is a continually and sometimes rapidly evolving field. Changes to what constitutes clinical best practice drive changes to work routines and practice which in turn drive changes to requirements for support of clinical staff. In the late twentieth century the move away from a disease-centred approach to healthcare delivery towards a patient-centric one has caused a major shift in working practices and, as a result, has had significant impact on what clinicians¹ want and require from their healthcare information systems.

Prior to adoption of the patient-centric approach, healthcare practitioners often worked in relative isolation, each within his or her area of speciality. Limited consideration was given to outside factors, such as other conditions the patient might have and their treatments as well as interaction between treatments. In contrast, patient-centric healthcare emphasises taking a holistic view of the patient considering all factors which may impact treatment, including mental and social factors as well as other conditions and treatments. In order to achieve this, the patient-centric approach requires a far higher degree of interaction and teamwork among clinicians than was required in the disease-centric approach. In the case of a chronically or otherwise

¹Throughout this thesis the words clinician and practitioner are used interchangeably to mean clinical healthcare professionals including doctors, nurses, allied health professionals, and all other clinical staff.

seriously ill patient this can be a major challenge. Consider the case of a cancer patient who is unexpectedly admitted to hospital. The admitting doctor needs to be aware that the patient is undergoing cancer treatment as this will impact both the interpretation of the patient's symptoms and his treatment plan. The patient's cancer team will need to know about the admission as well. The hospital stay may disrupt the patient's scheduled treatment and, because cancer treatment is often time-sensitive, the patient's overall cancer care plan may need to be re-evaluated and rescheduled. The oncologist should be contacted should the hospital require advice regarding the patient's treatment or symptoms. From a purely operational standpoint, the cancer centre will wish to cancel outpatient appointments that the patient will not be able to attend so that those appointments can be offered to other patients. When the patient is discharged, his General Practitioner (GP) and cancer team will wish to be informed so that they can ensure that he receives proper support and that the outpatient cancer treatment is resumed as quickly as possible [3]. In order to accomplish this level of teamwork, healthcare information system users require communication and collaboration support for cross-boundary, distributed care teams.

Unfortunately, this is a problem that is both broad and vague, and what is required to address this problem is unclear and changing. Healthcare involves a huge number of specialities and professional roles, each with a different set of support and information requirements, a wide range of working practices, and myriad opinions on what constitutes 'the best way forward.' A great number of projects have considered a narrow slice of the problem and some projects have attempted to address larger portions (e.g. [4, 5, 6, 7, 8]), but as yet there is no one clear and comprehensive view of the research area, let alone an agreed approach on how to address it. This thesis will investigate the requirements of providing appropriate information and collaboration support to healthcare practitioners working collaboratively to provide patient-centric care and will consider in more detail one possible approach to tackling some of these challenges.

1.2 Research Hypothesis and Aims

The main goal of this project was to improve teamwork support for healthcare practitioners working patient-centrally. Towards this end, currently identified requirements and proposals were investigated, along with the unique requirements of teamwork and collaboration. Emerging principles in computer science were also considered to determine how they might contribute to a potential solution. The results of this analysis were developed into a proposed solution which uses team meta-data, role-based access control, virtual organisations, and a service oriented architecture to meet the identified requirements.

The main aims of the research are:

- to improve understanding of the information and communication challenges and requirements associated with team working in patient-centric healthcare, and
- to develop a possible solution that can meet the identified requirements.

Towards achieving these aims, it is hypothesised that:

A healthcare information system that organises and manages data around care teams will have the capacity to provide more effective support for collaborative working within distributed care teams than current approaches are able to provide. Specifically, a team-based framework will allow for pro-active, role-based support for individual care team members, providing improved efficiency of information access and exchange through targeted, tailored, automated communication and information access. This will be demonstrated through:

- automated generation and sending of communications and alerts,
- provision of information organised and tailored to the context of access including factors such as patient condition and professional role of the user with that patient.

1.3 Research Scope and Achievements

This research focuses on the communication and collaboration aspects of information systems supporting healthcare practitioners working collaboratively across organisational boundaries. Because the author is not a healthcare professional, it was decided that the research should emphasise the technical side - the ability to send and filter information and communications - rather than on the more clinical aspects of teamwork, such as when communications should be sent and what information they should contain. Additionally, the work emphasises primary information usage and the work of clinical staff above the needs of administration and secondary data usage. Specifically, the work focuses on general requirements and functionality such as organising patient information so that relevant information is easily accessible without contributing to information overload, the need to be able to identify fellow team members, and the ability to selectively send messages directly to those who need information.

This somewhat high level approach does have implications for the results of the research. As a Cancer Research Wales (CRW) funded project, the research has centred around cancer care, but the high level approach has allowed for generalised results to be identified which do not constitute a case study and are not cancer specific. Similarly, the proposed solution is not architecture dependent and could be applied to either a federated or centralised system.

The main achievements of this work contribute to the overall picture of improving patient-centric teamwork support in healthcare information systems by considering these systems, and the clinicians who use them, from the team perspective. Emphasising the ‘clinicians as care team members’ aspect of clinical work, this research focuses on the particular requirements and challenges of working in care teams, and proposes a novel approach to meeting these requirements. This proposal makes the care team a central object in the conceptual model and uses team meta-data to provide improved, tailored support to team members.

Specifically, the main achievements of this research include:

- identifying requirements and potential functionality for supporting patient-centric teamwork through healthcare information systems,
- identifying some of the challenges associated with meeting these requirements, and
- specifying a possible team-based solution for addressing these requirements.

1.4 Thesis Structure

1.4.1 General Comments

This thesis outlines some of the challenges of supporting patient-centric healthcare and reasons for those challenges. It identifies a list of requirements for healthcare practitioners working as members of patient-centric care teams, and proposes one possible approach to meeting these requirements. Because collaborative care teams are so key to patient-centric work, the idea of clinicians as care team members is a central theme throughout this thesis.

This Chapter sets the stage, introducing the research and providing context for the work. Chapter 2 describes the historical background of the problem, considers political aspects of healthcare information systems in the NHS, some reasons for the current state of affairs, some of the major projects which are being undertaken to improve the current situation, and the requirements that these projects are attempting to address. Chapter 2 also identifies a potential area of need in the limited scope of currently acknowledged requirements. Chapter 3 considers a broad range of literature relevant to this research from the care team perspective, including small group research, health informatics, and research on virtual teams, in order to identify a more comprehensive list of requirements for future healthcare information systems aiming to support patient-centric working. Chapter 4 considers possible methodologies for approaching the research and describes the selected methodology. Chapters 5 and 6 describe a team-based approach for meeting the

identified requirements. Chapter 5 introduces a proposal for a conceptual model which acknowledges care teams as system entities and uses team information to meet the requirements identified in Chapters 2 and 3. Chapter 6 describes a proof of concept prototype implementing the model which illustrates a range of functionality specifically tailored to team support which can be achieved through the conceptual model. Chapter 7 provides an evaluation of all aspects of the work including the identified requirements, the conceptual model, and the prototype. Chapter 8 outlines work that should be carried out in order to extend this research as well as several interesting but less critical research topics identified as part of this research. Finally, Chapter 9 brings everything together, highlighting the key aspects of the work, lessons learnt, and the insight gained into the problem area.

1.4.2 Terminology

Healthcare is continually evolving, as is what it means for healthcare to be patient-centric and how teams are used in healthcare. One result of this continual evolution can be ambiguity of terms. To avoid confusion, the usage of key terms in this dissertation is defined here.

Because healthcare teams are the main focus of this research, it is important to have a clear distinction between different types of teams. Multi-Disciplinary care Teams (MDTs) are formally organised teams consisting of healthcare practitioners from different specialities, usually formed for a particular disease or treatment. MDTs are discussed in detail in Sections 2.3.1.1 and 3.2.1. A patient's care team is the group of healthcare practitioners caring for that patient and is defined fully in Section 3.2.1. Healthcare team is used as a generic term for any type of team used in healthcare including, but not limited to, both MDTs and care teams.

This research focuses specifically on distributed care teams which cross boundaries. A team is distributed if its members do not regularly work in the same place at the same time. Distribution can be either physical or temporal. For example, team members may work in different physical locations or in the same location but at different times. In this thesis, the term cross boundary refers to organisational boundaries. With regard to care teams this mainly, though not exclusively, relates to organisational boundaries associated with physical distribution such as working at different care sites or departments. Distribution and boundaries are discussed in detail in Section 3.3.

Finally, this thesis focuses exclusively on healthcare. Unless otherwise specified, references to care refer to healthcare. For reasons of scope, both mental and social care have necessarily been omitted from this work. Inclusion of services outside the NHS is discussed in Section 7.5.2.

A Changing Model in Healthcare

Overview

The patient-centric approach to healthcare delivery is gaining worldwide acceptance, but legacy healthcare information systems often fail to meet the informatics support needs of clinicians following this approach. In the UK, the patient-centric approach is promoted by the Department of Health and the NHS and clinicians are expected to work patient-centrally. This chapter provides a foundation for discussing patient-centric healthcare in general and in the UK specifically, with an emphasis on the information systems requirements associated with patient-centric work. This chapter also introduces the question of whether current proposals for integrated patient information systems in the UK will provide adequate support for clinicians working patient-centrally. Chapter 3 considers this question from the perspective of a variety of research areas and identifies a list of requirements for clinicians undertaking patient-centric work which extends beyond those identified here. Chapters 5 and 6 present a proposal for meeting this wider range of identified requirements than current proposals have considered.

2.1 Introduction

In 1997 UK Department of Health released a white paper entitled “The New NHS: modern, dependable” [1] which outlined a radical shift in organisation and thinking in health services in the UK. The integrated, collaborative approach outlined in *The New NHS* contrasts strongly with previous, more traditional models, where practitioners worked independently. Instead of encouraging competition between agencies, it promised that “the needs of patients would be put at the centre of the care process” [1], and emphasised communication and collaboration between Trusts as well as individual practitioners. While interest in improving communication in healthcare both between individuals and through the use of Information and Communication Technology (ICT) had been increasing for some time [9] *The New NHS* formalised the vision, and government support for it, in a way that had not been done before. Since 1997 the model has been elaborated on and refined through additional papers issued by the Department of Health (e.g. [10, 11, 12]), as well as equivalent bodies in Wales (e.g. [13]), and Scotland (e.g. [14]), but the basic concept of patient-centric healthcare has not changed with these enhancements.

Since *The New NHS* was published it has become increasingly clear that existing healthcare information systems do not adequately support patient-centric working (e.g. [15, 2, 16]). In particular, it has been noted that legacy systems rarely support information sharing between care sites and that access to all relevant information is central to the patient-centric way of working [15, 17]. This noted shortfall begs the question of whether there are other problems which have not yet been so clearly identified. Will providing improved access to patient data across care sites provide the support required for clinicians to work patient-centrally, or is more required? In order to answer this question, we must first clearly define the terms with which we will be working, the state of affairs in the NHS, and ongoing projects being undertaken by the NHS to address the needs of patient-centric working.

2.2 The Old NHS and *The New NHS*

Prior to publication of *The New NHS* the health services in the UK operated under a system known as the “internal market model” [18]. The internal market model attempted to address inflexibility and “perverse incentives”¹ [19] in the NHS by providing accountability, incentives for improving efficiency and quality of care, and focusing on quality of customer service rather than budget limits. As the name suggests, the internal market model implemented a ‘free market’ within the NHS where District Health Authorities (DHAs) became “purchasers of services”

¹Disincentives for achieving efficiency caused by rewarding improved efficiency with more work and/or fewer resources.

and healthcare providers (i.e. hospitals, GP surgeries) became “sellers of services” [19]. Rather than allocating funds to healthcare providers up-front, funding was provided to DHAs, who then ‘purchased’ services from GPs and other providers through annual contracts. This model

“aimed to promote competition among providers in the hope of replicating the benefits markets have been known to bring about in the private sector: decreases in cost, and increases in efficiency, quality, innovation, and provider responsiveness” [18].

Those providers with the best service and patient satisfaction would attract more patients and consequently, more funding. Similarly, providers who improved efficiency would gain in net resources. By providing greater autonomy to individual service providers, the internal market approach also hoped to reduce unnecessary bureaucracy and allow sites to manage their own budgets [19].

In terms of its main aims, the internal market model had mixed results and it is difficult to attribute any changes directly to implementation of the market model due to ongoing changes in policy, funding, and other confounding factors [18]. It is clear, however, that the internal market model had unintended consequences. Innovation may have improved, but competition between providers meant that there was little incentive to share beneficial innovation with other providers. In general, the competition fostered by the internal market acted as a disincentive towards collaboration and cooperation between providers, especially providers offering the same or similar services [15, 20, 21]. Increased autonomy meant that providers had more freedom with regard to ICT choices while a lack of cooperation between providers meant that there was no perceived need to consider compatibility or interoperability when making purchasing decisions regarding information systems. The continued use of pre-internal market model systems further exacerbates the problem since these legacy systems were also developed for a disease-centric approach to healthcare that did not prioritise the ability to share patient information across organisational boundaries. Taken together, the result is that legacy healthcare information systems in the NHS are, in general, designed as data silos without the ability to easily integrate or interoperate with other systems. This problem is pervasive. It is often the case that a single hospital will have multiple information systems, all of which contain patient health information, but which do not interoperate because they were set up to support different areas of patient care.

2.2.1 *The New NHS and Patient-centric Healthcare*

The drawbacks of the internal market model were highlighted by the Labour Party when it came to power in 1997 in *The New NHS* [1] which outlines intended changes to the structure

and functioning of the NHS. In particular, it criticises the internal market model for:

- “wast[ing] resources administering competition between hospitals,”
- “stifling innovation,”
- “fragmentation in decision making,” and
- “put[ting] the needs of institutions ahead of the needs of patients.”

The New NHS rejects what it refers to as the “old centralised command and control systems of the 1970s” and the “divisive internal market system of the 1990s,” and proposes a “third way”- what has come to be known as the patient-centric approach².

The patient-centric approach focuses more on how patient services are organised than how funding is allocated³. In essence, the ‘patient at the centre of care’ concept means that patient information, care, and treatment should be organised around the patient, rather than by condition, as was the case in traditional models. Patient-centricity also implies that the patient will be viewed ‘as a whole’- that consideration will be given to the implications that multiple conditions may have on each other, potential interactions between different treatments, and other factors including the patient’s lifestyle and social needs.

Although *The New NHS* and later Department of Health papers and reports (e.g. [1, 15, 22, 23]) discuss a variety of issues in the NHS that need to be tackled, perhaps the biggest change coming out of the patient-centric approach is the emphasis on collaborative care. Interestingly, while collaboration between healthcare practitioners is mentioned it is rarely discussed in detail, at least not in a practical way. It is treated more as an aspect or side effect of providing ‘seamless’ or ‘integrated’ healthcare. But, from the healthcare practitioners’ perspective, the impact of the expectation of collaborative working practices implied by the patient-centric approach is not insubstantial. True collaboration requires effective and efficient communication, access to relevant information, and time.

The UK is not alone in adopting a patient-centred approach to healthcare delivery, nor are the challenges facing the NHS unique. The remainder of this chapter discusses what patient-centric healthcare means in practice, the challenges facing healthcare practitioners attempting to work patient-centrally both in the UK and worldwide, and the requirements for healthcare information systems which can be drawn from this discussion.

²Although the phrase ‘patient-centric’ does not appear in *The New NHS*, the “integrated approach” described there has become synonymous with patient-centric healthcare.

³Some aspects of the funding structure of the internal market model have been retained or modified only slightly, but the element of competing for patients has been de-emphasised [18].

2.2.2 The National Programme for IT

The New NHS reform package included a pledge to improve ICT in the NHS. In 1998, this was formalised through the publication of an information strategy for the NHS [22], “Information for Health,” which highlights the specific information and ICT requirements and challenges associated with *The New NHS*. Specifically, Information for Health proposed:

- “lifelong electronic health records for every person in the country
- round-the-clock on-line access to patient records and information about best clinical practice, for all NHS clinicians
- genuinely seamless care for patients through GPs, hospitals and community services sharing information across the NHS information highway
- fast and convenient public access to information and care through on-line information services and telemedicine
- the effective use of NHS resources by providing health planners and managers with the information they need” [22].

Information for Health also lays out five information principles, which are still central to the discussion of healthcare information systems in the NHS:

- “information will be person-based
- systems will be integrated
- management information will be derived from operational systems
- information will be secure and confidential
- information will be shared across the NHS” [22].

However, these changes have been slow in coming. In 2002, the Wanless Report pointed out that “there has been inadequate setting of ICT standards from the centre, resulting in a diverse range of incompatible systems across the health service” [15]. While the report supports the idea that improving ICT in the NHS has the potential to improve quality, efficiency, and overall patient health, it also points out that higher spending, in itself, is insufficient to resolve the problem, and recommends that “the Government and health service must ensure that they have clear and well developed views about the benefits which they want to achieve and how they will

be delivered” [15]. The report also recommends implementation of “stringent standards... to ensure that systems... are fully compatible with each other” [15].

In response to the Wanless Report, the Department of Health released a white paper specifying “four major national deliverables” which would be at the heart of the National Strategic Programme for healthcare, (more commonly referred to as the National Programme for IT (NPfIT)) [23]. These include a prescription service, a booking service, IT infrastructure, and a life-long health records service [23]. NPfIT is used as an umbrella term encompassing a variety of projects, programmes, and organisations whose aim is to improve support for patient-centric work within the NHS. At a national level, the National Institute for health and Clinical Excellence (NICE) has been formed to provide guidelines and standards for organisations and individual clinicians. In England the NPfIT ultimately resulted in the creation of Connecting for Health (CfH) [4] (see Section 2.3.2.1), while in Wales Informing Healthcare (now NHS Wales Informatics Service (NWIS)) was “set-up to improve health services in Wales by introducing new ways of accessing, using and storing information” [24].

2.2.3 Changes Under the Coalition Government

In 2010 the government changed again and, with it, the perspective on healthcare also changed. The Coalition Government has renewed the commitment to patient-centric healthcare, but in a different way. *Equity and Excellence*, published within a few months of the election focuses very strongly on the patient aspect of patient-centric care, emphasising inclusion of the patient in decision making with the slogan “no decision about me, without me” [25]. While embracing the patient-centric approach in terms of healthcare, *Equity and Excellence* also suggests a return to market driven organisation and funding. This includes a reduction in central management and devolution of power to local authorities. Towards this aim, GP commissioners will be given financial control over purchasing of services. Along with GP purchasing power comes a re-introduction of some aspects of competition between service providers and the possibility of greater private sector involvement in provision of NHS services [26].

As with all suggested changes to healthcare, the new proposals have caused a mixed reaction. Some have expressed serious concerns about the changes eroding the remit of the NHS (e.g. [27]), some believe that parts of the plan are not well developed (e.g. [28, 29]), and some have lauded it as an important step forward (e.g. [30]). It is too early to tell what the ultimate result of the *Equity and Excellence* proposals will be. Clearly, if the proposal goes forward it will have a significant impact on funding and purchasing, but at the same time the continuing emphasis on keeping the patient at the centre of care means that patient-centric healthcare is likely to remain the delivery model within the NHS. Because this research focuses on healthcare delivery rather

than funding and purchasing of services, the Coalition Government's reform plans are expected to have a limited impact on the results of this research, meaning that the research will continue to be relevant in the emerging NHS model.

2.3 Moving Towards the Patient-centric Approach

The patient-centric approach and information systems for healthcare have come a long way since the publication of the Wanless Report. The Choose and Book system has been implemented allowing patients in England to book appointments online, and NHDirect provides 24 hour telephone support to patients [4], as planned in Information for Health [22]. NICE provides guidance on best practices, and CfH in England and Informing Healthcare in Wales are developing a variety of projects to support both clinicians and patients. The new coalition government continues to reiterate the commitment to patient-centric care, and continues to emphasise the need for improved integration of services and a continued focus on support for care across boundaries (e.g. [25, 31]). However, there are still a variety of challenges that have yet to be overcome before the aim of providing information systems that fully support patient-centric care can be achieved.

Pre-patient-centric delivery models did not emphasise collaboration as much as the patient-centric approach and sometimes even provided incentives for healthcare providers to act separately, to keep data and innovations hidden from other providers. The patient-centric model encourages sharing of new ideas and improved ways of working, and it requires sharing of patient data between healthcare providers. But the legacy of prior models is that information systems in the NHS, on the whole, are not equipped to support this sharing of information which is such an integral part of the patient-centric model. Legacy systems remain in use and it is not practical to believe that healthcare can be treated as a green field domain. As a result, more than ten years after the publication of Information for Health, the NHS does not have a comprehensive shared patient record system. Progress has been made in working towards such a system, but the challenges have turned out to be greater than expected. Both the NHS in England and the NHS in Wales have undertaken major integrated patient record projects to address the goals laid out in Information for Health (see Section 2.3.2), but these are not the only steps that have been taken to move the NHS towards a patient-centric approach. This section discusses some of the NHS projects most relevant to this research.

2.3.1 NICE

Created in 1999, NICE is an NHS organisation whose aim is “to ensure [that] everyone has equal access to medical treatments and high quality care from the NHS, regardless of where they live in England and Wales” [32]. To meet this aim, NICE “produces guidance on public health, health technologies, and clinical practice”⁴ [32]. Clinical guidelines provide treatment advice for medical professionals based on current best evidence. In contrast to the government papers discussed above, the clinical guidelines provided by NICE often contain specific guidance relating to the collaborative aspects of providing patient-centric care, such as who should be involved in each collaborative team, commonly referred to as MDTs.

2.3.1.1 MDTs

MDTs vary widely in structure and working practices, usually according to diagnosis. In general, MDTs consist of healthcare professionals from differing specialities who meet regularly to determine and sometimes update patient care plans, although the term is increasingly being used for “community care” teams who are often associated with primary care and who may not meet regularly or discuss the patient as a group (e.g. [33, 34]). Secondary and tertiary MDTs may be based on a single hospital ward (e.g. [35, 36, 37]) or may consist of members from different care sites [38]. Depending on the condition, these MDT may include members of the allied health professions, such as physiotherapists and nurses, and may consist of members from secondary care, tertiary care, or a combination of the two. Primary care providers are rarely, if ever, included as regular members of MDTs other than community healthcare teams, largely because each MDT discusses many patients at each meeting, each of whom may have a different GP. Each GP would need to participate in many MDTs, each for only one or two patients, and each MDT would have many GPs in attendance. Given this, it is easy to see that including GPs in regular MDT meetings would be infeasible both for the MDT as well as for the GP. A detailed discussion of secondary/tertiary MDTs and their working practices is included in Section 3.2.1.

The use of MDTs has become widespread worldwide and examples of MDTs can be found from the U.S. (e.g. [35, 37]), Canada [36], Australia (e.g. [39, 40]), Japan (e.g. [41]), and, of course, the UK (e.g. [42, 43]), among others. However, as with many aspects of adopting a patient-centric approach to healthcare delivery, progress on understanding what models of

⁴It is worth noting that, here, ‘health technologies’ refers to medicine and treatments, including medical devices, rather than health information technologies, such as electronic patient records. This proposal does not consider health technologies as defined by NICE, but focuses exclusively on healthcare information systems which collect and store patient information.

MDT work (or fail to work) and in which situations, developing best practices, and providing appropriate support for care teams has been slow.

2.3.2 Patient Record Projects

2.3.2.1 Connecting for Health

Officially, NHS Connecting for Health is an organisation established as part of the Department of Health Informatics Directorate, whose “role is to maintain and develop the NHS national IT infrastructure” [4], but the name ‘Connecting for Health’ (CfH) is also widely used to refer to the ‘lifelong patient record’ project which was overseen by the organisation⁵. The CfH project was undertaken as part of the NPfIT. Although *Information for Health* proposes the creation of a lifelong patient record, it does not specify the details of how such a record should work or exactly what information it should contain [22]. In a written response to the House of Commons in 2004, however, Mr. Hutton talked about “providing doctors and nurses with the right information in the right place at the right time” [44]. By 2006, the project had been further defined

“The care records service will create electronic patient health records by combining central data about patients, including their identifying characteristics (the personal demographics service), administrative records, and important health alerts such as allergies, with summaries of care episodes drawn from local institution-based electronic patient records...” [45].

This was to be achieved by connecting all healthcare systems to a central record system, known as the ‘records service spine’ [45]. As of 2008, the project consisted of several distinct components, including the Summary Care Record (SCR), the Secondary Usage Service (SUS), and the Detailed Care Record (DCR) [46]. But, by this time, the project was encountering heavy opposition. Concerns centred around confidentiality and use of resources [47]. Many health professionals within the NHS felt that CfH did not constitute a good usage of NHS resources [48]. In addition to the costs associated with development, adoption of the new system, which heavily emphasised standardisation across systems, would require migration of existing patient health data onto new, “spine compliant” systems. Migration of data is resource intensive at the best of times, and in the case of the NHS is particularly difficult because information held in legacy systems may not map directly to the format of the new system [45]. In addition, there is the issue of waste with regard to legacy systems once the data has been moved to the new system.

⁵For convenience, CfH will be used to refer to the lifelong patient record project, rather than the organisation, for the remainder of this thesis.

Legacy systems represent a significant investment of NHS resources. Abandonment of them while they are still potentially useful can be considered a waste of resources. Similarly, introducing a new system, running the new system and the legacy system side-by-side, then phasing the legacy system out over time can be seen as wasteful since the two systems must be run in parallel until the legacy system is fully phased out.

In addition to the resource issues, healthcare professionals, the public, and activist groups raised serious concerns about the security and confidentiality of patient data in such a system. Gathering data on a few centralised servers was seen as decreasing physical security, while allowing universal access throughout the NHS was seen as opening the door for improper use of or access to patient records by NHS staff. Storing records on third party servers also caused concerns among healthcare professionals that they would lose control of the data [46] as well as raising questions about information availability [49]. Of even greater concern were proposals to extend access to patient records beyond the NHS [50].

In September 2010, the Department of Health published a press release which essentially ended the lifelong patient record as embodied by the CfH patient record project, stating that “a review of the National Programme for IT has concluded that a centralised, national approach is no longer required, and that a more locally-led plural system of procurement should operate” [51]. However, for the majority of this research, the CfH patient record was a central project within the NHS and, as a result, heavily influenced this research. To reflect this, CfH is included in discussions of current or ongoing projects throughout this thesis.

Although the grand scale of the centralised, national, lifelong patient record project has been greatly reduced, it is worth noting that, at the time of writing, NHS Connecting for Health continues to exist as an organisation and is still moving forward with various aspects of the NPfIT, including a summary care record and ‘Choose and Book’, an electronic appointment booking service [4].

2.3.2.2 Welsh Clinical Portal

The Welsh Clinical Portal (WCP) is part of the national applications strategy for the NHS in Wales [16] and is intended to provide an all Wales interface to an integrated, shared Electronic Patient Record System (EPR). The Portal itself is the clinician access point to a Single Integrated Health Record [52] meaning that, although the Single Integrated Health Record will actually incorporate a variety of systems, from the end users’ perspective the WCP will be synonymous with the single care record. This also means that, although the WCP and CfH both aim to provide an integrated patient record which can be accessed across multiple sites, they have taken very different approaches. Whereas CfH mainly adopted a silo approach, the WCP is

taking a federated approach, and will incorporate existing systems and services as well as newly developed ones [52]. At the time of writing, the WCP is intended to be rolled out in five stages:

- “Version 1 allows you to request tests.
- Version 2 will provide electronic clinical communications.
- Version 3 will support recording of detailed clinical assessments.
- Version 4 will allow [the user] to prescribe and manage medicines.
- Version 5 will support integrated care planning and clinical pathways” [53]

Currently, multiple pilot projects, each encompassing different aspects of the portal are in progress. As elements of Version 1, these pilots focus primarily on test requesting and reporting in different diagnosis areas [5].

2.3.2.3 CANISC

Originally developed in Velindre NHS Cancer Centre⁶, CAnCER Network Information System Cymru (CANISC) began as a shared patient record for cancer care providers. Since its original implementation, CANISC has been expanded to include a range of services both within cancer care and in other areas. At its heart, CANISC is primarily a shared patient record, incorporating data from, for example, cancer centres, Cancer Genetics, palliative care, clinical trials (Welsh Clinical Trials Network), movement disorders, and colposcopy [55, 56, 57]. In addition, a series of cancer minimum datasets have been developed as part of the CANISC project. CANISC has been accepted as the all Wales cancer system and it is planned that CANISC will eventually be incorporated into the WCP [55, 58].

It should be noted that this research has been undertaken in collaboration with Velindre NHS Trust. Throughout the project, the author has met with an advisory team from the Clinical Information Unit at Velindre, who have provided advice and support regarding the needs of clinicians, general information about the NHS including working practices, political developments, and their own experiences developing and maintaining CANISC [57]. This team consisted of Dr. Dave Morrey, Head of Clinical Information at Velindre, Hazel Bailey, NWIS Senior Information Analyst, and Tony Bater, Head of CANISC Software Development. On occasion, other members of Velindre staff participated in meetings and interviews to provide additional perspectives on working practices and requirements. Such meetings are cited individually throughout the thesis, as appropriate.

⁶Under the name ISCO (Information System for Clinical Oncology) [54]

In addition to the general help and advice of team members, CANISC has also heavily influenced this work. CANISC has been used as one starting point for discussions regarding future system requirements and is included as part of the integrated EPR in the prototype. The collaborators and clinicians interviewed as part of the evaluation currently use CANISC as their patient record system.

2.3.2.4 Scottish Emergency Care Summary

Rolled out in 2006, the Scottish Emergency Care Summary (ECS) contains basic patient health information for NHS staff providing out of hours patient care. As its name implies, the Care Summary is not a complete shared patient record. Rather, it contains only the most vital information for emergency care - patient identification, prescriptions, adverse reactions, and the patient's GP surgery [8].

Although the ECS is not an integrated lifelong patient record, it is a form of shared patient record and demonstrates that at least some of the challenges associated with developing and implementing integrated patient records can be achieved. The ECS draws patient information from multiple systems and provides that information at the point of care at the time when it is required. The ECS has also overcome other challenges, such as patient adoption through informed consent. Whereas CfH faced significant opposition because it was perceived as putting patients' sensitive information at risk, the limited scope of the ECS, both in terms of the quantity of data as well as access rights to that data, meant that it has met with far less resistance. In contrast to the heavy opposition and ultimate failure of CfH, the apparent success of the ECS [59] suggests that an integrated EPR is technically possible, but also that it will be accepted by the public as well as members of the healthcare community if it is perceived to be both ethically sound and clinically beneficial.

2.3.3 International Projects

Although this work focuses on the NHS in the UK, there has been a widespread shift towards a patient-centric approach to healthcare delivery in many countries around the world. The use of collaborative healthcare teams is common, and there is a wealth of literature examining the various aspects of collaborative healthcare teams, including efficacy studies, research on current working practices and best practices, team make up, including whether the patient should be considered a team member, and challenges to working collaboratively in healthcare.

Similarly, the NHS is not alone in working towards a shared patient record. In particular we note two open source patient record projects: openEHR and OpenMRS:

2.3.3.1 OpenEHR

Evolving out of the Good European Health Record (GEHR) project, the openEHR Foundation [6] is an international, not-for-profit company aiming to “promote and facilitate progress towards electronic health records of high quality, to support the needs of patients and clinicians” [60]. OpenEHR promotes interoperability through “a set of open specifications for an [EPR] architecture” [61]. The proposed architecture uses *archetypes*, where an *archetype* is a “thorough, distinct, and clinically meaningful concept” [62]. The openEHR project has received interest from a variety of Governments in Europe, South America, and Australia, including the UK. In 2007 a pilot project was undertaken to develop archetypes for use in the NHS [63].

2.3.3.2 OpenMRS

Created in 2004, “OpenMRS is a community-developed, open source, enterprise electronic medical record system platform” [7] which is comprised of a data model, an API, and a web application [64]. As an open source project, one of the goals of OpenMRS is to make a well implemented, effective, and useful shared EPR available to developing countries. As a result, OpenMRS is in use around the world, including several implementations in Africa [64, 65]. OpenMRS is patient-centric and aims to minimize free-text, using coded entries wherever possible. This is accomplished through the use of a concept dictionary which contains “all diagnosis [sic], tests, procedures, drugs and other general questions and potential answers” [7]. OpenMRS uses a modular design within a client-server architecture [7].

We note that each of these proposals differs from current work in the NHS. OpenEHR focuses on an architecture standard, rather than on a specific implementation, the aim of which is to allow for standardised concepts and structures across systems, improving quality and supporting interoperability. While the NHS may be able to benefit from the openEHR project, the ‘big projects’ in the NHS focus on functionality - providing new or improved services through electronic health systems.

In contrast to openEHR, OpenMRS specifically *is* an EPR implementation. However, because OpenMRS is tailored for developing countries with poor ICT infrastructure, it emphasises the use of mobile technologies. To streamline access from mobile devices and to allow for machine interpretable data, OpenMRS emphasises the use of coded entries in preference to free-text notes. However some research shows that clinicians derive more meaning more quickly through free-text fields than coded entries [66].

From this section it can be concluded that, while providing shared EPRs is a high priority, there is, as yet, little agreement on how this should be done. Any work looking at EPRs must take the

variation between models into consideration.

2.3.4 The Realities of Patient-Centric Working

Thus far, the challenges and realities of patient-centric working have mainly been considered from the implementation and legislative perspective - what the government has prescribed to the health services, and what projects and services have been and are being developed as a result. While these papers and projects certainly have an impact, they do not always reflect the realities of attempting to work patient-centrally. The NPfIT has resulted in huge expenditures in terms of healthcare IT, but communications between GPs and consultants continues to occur primarily through the postal service, by telephone and, occasionally, via e-mail⁷ [67, 68]. However, there are areas in which the legislative perspective considered above can be seen to be reflected in working practices in the NHS. The clinical guidelines published by NICE dictate best practices for patient treatment in a variety of areas. Because many of the clinical guidelines include suggestions regarding the use and composition of MDTs, the practice of working through MDTs has become widespread throughout the NHS⁸.

Alongside the use of MDTs is the ethos of ‘collaborative care’ - the idea that clinicians work as a team to provide the best possible care for each patient. Unfortunately, the lack of interoperability between legacy healthcare information systems means that communication and information sharing between team members is both difficult and time consuming [39, 33]. In order to work collaboratively, clinicians require access to patient healthcare information which is recorded at different care sites. Currently, this need is not being met [2]. Healthcare practitioners often express frustration about the time spent “chasing up” patient information and the difficulties of communicating with practitioners working in different locations. As a result, it is not surprising that access to shared patient records is often viewed as a (if not *the*) main requirement to be met by future healthcare information systems and that new and different approaches to achieving this goal are being considered. The emphasis that clinicians place on the need for information access can also be seen in the NHS projects discussed above.

2.4 Putting the Pieces Together

In many ways, the situation as presented in this chapter is over-simplified. There are a huge number of challenges to providing high quality healthcare information systems, and the se-

⁷Despite the fact that using e-mail for clinical communications is frowned upon because of the inherent lack of security [67].

⁸Or perhaps because the use of MDTs has become widespread in the NHS they have been adopted as part of best practice by NICE. Either way, MDTs are commonly used.

quence of events is not as cut and dried as it has been presented. For example, influence tends to be circular; clinician opinion and government legislation and priorities influence each other, rather than working as either a strictly top-down or bottom-up system. However, whatever perspective is taken, the end result is the same. The patient-centric approach requires a much higher degree of information sharing than other healthcare delivery models, which is causing challenges for healthcare practitioners attempting to work patient-centrally. As a result, information access is seen as a high priority for clinicians, and a variety of projects are attempting to meet this need by providing integrated patient records that can be accessed from multiple locations. In the UK, these efforts have been hampered by the widespread use of legacy, disease-centric information systems - patient record systems which are not interoperable - but progress is being made. If the government and the NHS continue to support the patient-centric model, then shared patient records will, eventually, become the norm throughout the NHS.

The emphasis on information access carries with it the implication that ‘if we have access to the data, the problem will be solved.’ This research began by asking the question of whether this was a valid assumption. Is information access *enough*, or does effective patient-centric healthcare delivery have other requirements? It is proposed that information access across care sites, while a necessary first step, will not in itself be sufficient to meet the needs of practitioners working patient-centrally. This proposition, in conjunction with the discussion above, leads to the conclusion that, currently, requirements for healthcare information systems supporting patient-centric provision of care are not well understood. This chapter concludes by identifying those requirements which *are* well understood and inferring additional, implicit requirements arising from the current situation in the NHS.

2.4.1 Requirements Arising from the Domain

The discussion above leads to the conclusion that ‘providing access to patient health information from multiple sources’ is an important requirement for supporting patient-centric working, and that other requirements are not yet clearly defined. But the idea that requirements are poorly understood immediately gives rise to an additional requirement: any new information system must be able to evolve to meet changing requirements, both in terms of functionality as well as operation and specification. This is additionally relevant given that policy in healthcare is continually evolving as it is reviewed and updated. Healthcare information systems must be able to be adapted to support changing policies and associated requirements. Similarly, the amount of time required to keep the system up-to-date and to maintain the system must be reasonable. Finally, as discussed in [1], the UK government has committed to providing improved information and communication technology to the NHS. Many projects have been undertaken in partial fulfilment of this promise using different approaches and architectures (see Section

Requirement	Derived From
System must be flexible/evolvable	Healthcare
System should be easy to maintain	Healthcare
System should work with existing approaches/proposals	Healthcare
System should provide access to information from multiple sources	Healthcare

Table 2.1: Requirements Derived from Healthcare Literature and Domain.

2.2.2). A great deal of money has been invested in these programmes, so it is necessary for future proposals to be compatible, as much as possible, with systems and approaches currently in use within the NHS as well as those currently in development. These considerations provide an initial set of requirements for a future healthcare information system attempting to support clinicians working patient-centrally (see Table 2.1).

2.5 Conclusion

The primary aim of the NHS has been, and continues to be to provide the best possible care to its patients, free at the point of care [25]. But, what constitutes ‘the best possible care’ changes over time. Most recently, this has meant moving from a disease-centric approach to healthcare provision, where care focused on individual diagnoses separately, to a patient-centric approach where the patient, and all diagnoses for the patient, are viewed as a whole and the interactions between different factors are considered. More than ten years after the official adoption of the patient-centric approach, however, healthcare professionals are still frustrated by a lack of access to patient information; the patient-centric approach, by its very nature, requires easy and efficient access to relevant patient information as well as clear and effective communication channels between practitioners, but information systems in the NHS have yet to meet these goals effectively. Efforts to provide adequate information systems have been hampered by a variety of factors including widespread use of legacy ICT and a limited understanding of the information systems requirements of patient-centric healthcare provision.

This chapter has set the stage for consideration of what an information system to support patient-centric working should do. The situation has been outlined and the known challenges have been highlighted. More importantly, however, the question has been raised - are the known requirements the only requirements? If they are, then the problem can be left to the developers. However, if they are not, then two important research questions emerge - what requirements have been missed? And how might they be addressed? Chapter 3 considers the first question, and Chapters 5 and 6 discuss one possible approach to addressing the problem.

Requirements of Teamwork

Overview

Chapter 2 discusses the increasing use of collaborative teams in healthcare and the resulting call for information sharing between healthcare practitioners, particularly across organisational boundaries. However, in order to determine whether providing information from multiple sources will meet the needs of team members or whether they will have additional requirements, it is necessary to understand the ways in which teams work and how working practices impact on what teams require from their information systems. This chapter examines research on team working as it relates to the healthcare domain and healthcare information systems in order to identify requirements for future healthcare information systems aiming to support healthcare practitioners working as members of collaborative care teams.

3.1 Introduction

The UK Department of Health papers discussed in Chapter 2 emphasise the need for collaborative, patient-centric, healthcare teams. However, they do not clearly define what these teams should look like - how they will be structured, who will be included, to what extent and in what ways they will collaborate, and in what way or how often team members should communicate. This is reasonable given that the goal of instituting collaborative teams is to provide the best possible care for each patient, and that what constitutes this will vary widely from patient to patient depending on diagnosis, treatment stage, and severity of the condition, as well as potential confounding factors such as other conditions suffered by the patient. The National Institute for health and Clinical Excellence (NICE) gives more specific guidelines for teams working on various diagnoses including suggested team composition [32]. However, these guidelines are diagnosis specific and do not provide an overall framework for healthcare teams within the National Health Services (NHS) in the UK. This means that there is no universal or even generally agreed definition of ‘teamwork’ in healthcare. The result of this is that requirements for effective team working within healthcare are poorly understood, despite a wealth of research in both social science and computer science on team working. It is impossible to consider requirements for information systems to support the work of care teams without first defining and characterising those teams. Small group research provides a framework for such a classification. By applying this framework to the healthcare domain, a specific definition for collaborative care teams has been generated. This definition has then been compared against potential requirements derived from the literature in social science, computer science, health informatics, and computer supported cooperative work to identify a set of high-level, long-term requirements for supporting the work of teams in healthcare.

3.2 Small Groups

In 1950, Homans defined a small group as “a collection of people, few enough in number to be able to interact and communicate with each other on a regular basis in order to reach a common goal ” [69, pg. 1]. Since then, the definition has varied, sometimes including only groups who meet face-to-face, and sometimes including distributed or virtual groups who are geographically and/or temporally distributed [70]. However, it is generally agreed that, although size is important, it is not the only criteria. Small groups must have a *shared purpose or goal*, be *interdependent* in that “the actions and behaviors [sic] of individual members both affect, and are affected by, the actions and behaviors [sic] of others in the collective” [71, pg. 1], the group must have *perceived boundaries*, and members must engage in *regular interaction* [71, pg. 1]

(see Table 3.1).

Criterion	Definition
size	the group must be small enough to meet the rest of the criteria
shared purpose or goal	The group must share “at least one common goal toward which they are all willing to contribute” [71, pg. 1]
Be interdependent	The actions of group members impact and are impacted by those of other members.
Have perceived boundaries	It is clear to group members who is, and who is not, part of the group.
Engage in regular interaction	Group members should “communicate openly and often with one another” [71, pg. 2]

Table 3.1: Criteria Defining Small Groups.

3.2.1 Healthcare Teams as Small Groups

The use of MDTs is widespread in patient-centric healthcare. As such, MDTs are the logical place to begin when considering healthcare teams as small groups. Consisting of practitioners from multiple specialities specific to a particular diagnosis or range of diagnoses, MDTs all share the goal of providing improved, more consistent, more efficient patient care [72]. Interactions between aspects of a patient’s conditions can be complex. Including a range of specialities is intended to provide a more comprehensive view of each patient and to ensure that these interactions are considered from all perspectives. Teams inform a patient’s treatment, developing a preliminary care plan following diagnosis and/or modifying it as treatment progresses. It is immediately clear that MDTs meet some of the criteria of small groups: they share the common goal of improving patient care, are interdependent insofar as treatments provided by one team member may impact on those provided by other members, and have identifiable boundaries. Although group size is variable, membership is limited. Additionally, MDTs engage in group decision making, meaning that it is arguable that they are, by definition, small enough to fit Homans’ criterion of “few enough in number to interact...” [69]. Although some MDTs do not have regular, fixed meeting times, guidelines indicate that they should [42, 32]. So, MDTs following best practices do meet the final criterion for small groups - regular interaction. Therefore, MDTs as suggested by NICE can be classified as small groups.

However, the patient-centric approach also implies a different type of team, of at least equal importance to the MDT - the team of all practitioners working with an individual patient. This

team may include an MDT if the patient is referred to an MDT for discussion, but is broader and more inclusive. In particular, this team will include individuals not normally involved with MDTs such as the patient's GP, home care nurse, and palliative care professional(s), as appropriate. Additionally, this team is more dynamic than the MDT, growing when new treatment(s) begin and new clinicians join the team, and shrinking when treatment(s) are completed and some clinicians either leave the team or become less active in it. In contrast, MDT membership is relatively fixed and is generally unaffected by the individual patients on the agenda. Finally, the life-cycle of this type of team is directly tied to the state of the patient; The team exists exactly as long as the patient's treatment requires input from multiple practitioners, whereas MDTs exist independently of an individual patient. Throughout this thesis the phrase 'care team' will be used to distinguish this team from the MDT.

To illustrate the practical differences between care teams and MDTs, consider the case of patient Jane Doe, diagnosed with breast cancer. When her GP suspects cancer, Jane is referred for tests to confirm a diagnosis. Upon referral, the practitioner(s) performing the test(s) join Jane's care team. If they have no further hand in her treatment, then they leave the team once test results have been returned and diagnosis confirmed. If Jane's case is discussed at an MDT, then the MDT members become part of her care team from the time that Jane's case is added to the MDT agenda until a suitable period after the meeting has taken place. If Jane's case is discussed at multiple MDT meetings over the course of her treatment, then MDT members may join and leave her team multiple times. It is also worth noting that some MDT members are likely to work with Jane outside of the MDT. Jane's oncologist, for example, may be an MDT member. In addition to MDT members, Jane's care team will include her GP, oncologist(s), radiologist, chemotherapy nurse(s), and others, as appropriate. If Jane also suffers from other conditions, such as diabetes, she may have other carers who are also part of her care team. If, for example, Jane sees a dietician as part of her diabetes care, then the dietician will be part of her care team, though he will not be part of the cancer MDT. Finally, Jane's care team exists only as long as Jane's treatment requires it. If Jane goes into remission, her care team reduces significantly in size. If Jane later moves out of the country, then her care team ceases to exist altogether. Clearly, such events would have no impact on the cancer MDT.

Like an MDT, the care team has the shared purpose of providing the best possible care to the patient and team members are interdependent in that decisions made by one team member impact and are impacted by decisions made by other team members. While the definition of care team implies a clear boundary - only those people working with patient X are members of the team - it is important to note that this boundary is fluid. As the patient progresses along the treatment pathway, practitioners will join and leave the team. For example, some members of an MDT may discuss a patient at one MDT meeting but never meet the patient face-to-face. These MDT members would only be considered part of the patient's care team from

the time that the patient was added to the MDT's 'to be discussed' list until the discussion has been completed and recorded. Similarly, practitioners from certain specialities, such as surgeons or physiotherapists are likely to be involved with the patient only at discrete stages of the treatment pathway. Additionally, different specialities will be more or less actively involved at different stages of treatment. For example, if a patient is in hospital, the GP will usually take a fairly passive role in the team. When the patient is discharged, the GP's role will usually become more active. Similarly, once a patient has recovered from surgery, the surgeon's role becomes less active, unless certain complications arise or the patient requires additional surgery. Although the boundary of the team is clearly defined, the potential implications of the fluidity of this boundary are substantial and must be kept in mind. The final two criteria for qualifying as a small group - size and regular interaction - are more complex for care teams than for other types of teams.

By their nature, care teams will vary significantly in size, both across teams as well as within a single team over the course of treatment. With regard to size, a small group is "a collection of at least three and ordinarily fewer than 20 individuals" [73, pg.3]. It is likely that, for a very ill patient, the official care team (including both currently active and currently inactive members) will rise above the maximum for a small group. However, the number of *active* team members at any given time is likely to be within the range to qualify as a small group. It is not feasible for too many practitioners to be actively working with a patient and coordinating treatment. Group structure may also reduce the effective group size in situations where several individuals participate in the team as a single entity. For example, ward nurses may act collectively to perform a single role within the team, due to shift working.

Group size is closely related to communication. In a small group, each member of the group should communicate regularly with all other members of the group [71, pg. 2]. As groups increase in size this becomes impractical, leading to changes in the communication networks used by the group. *Communication networks* represent communication patterns within the group - which group members communicate with each other and how they go about it. In a small group, the communication network should have all members connected to (communicating with) all other team members (See Figure 3.1(c)). Other communication networks include all team members reporting to a single team leader (See Figure 3.1(a)), or hierarchical (See Figure 3.1(b)) [74], for example (see Figure 3.1). Care team members communicate when necessary rather than regularly, and use multiple types of communication networks. It is likely that some sub-groups of the care team will communicate regularly, and others will communicate only rarely, depending on the interconnectedness of different aspects of treatment, location, the team member's role, and other factors. In some cases, two or more team members may communicate directly, and in others a hierarchical, dissemination approach may be taken. For example, an MDT (whose members communicate regularly at MDT meetings) makes decisions about pa-

tient treatment. These decisions are then disseminated to other team members, as appropriate.

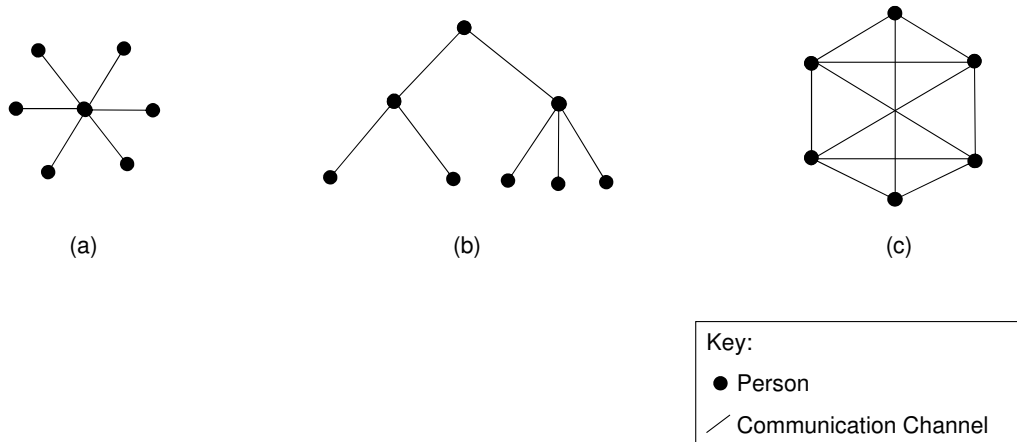


Figure 3.1: Some Possible Communication Networks (Adapted from [74, pg.92]).

3.2.1.1 Analysis

It is clear that care teams do not meet the standard definition of a small group - their size is likely to be too large and their communication patterns, as a whole, are too limited (members communicate selectively). However, if the focus is restricted to those practitioners *currently* playing an active role in the patient's treatment at a given time, the definition is met. The set of *active* team members will be much smaller than the total care team and members playing an active role in the patient's care are far more likely to require communication with other team members, and are therefore more likely to communicate regularly. Additionally, the need for information access identified in healthcare literature (as discussed in Chapter 2) indicates clinicians' desire to increase communication between team members beyond what is currently practised. So, while care teams as a whole do not currently communicate as small groups, they *require* the ability to do so. Viewed in this way, it can be argued that, at any given point in time, a care team *behaves*, or wishes to behave, as a small group. Information systems should support the team's desired way of working; thus, small group research can be applied to care teams in order to better understand them and as a tool for better understanding their future support requirements. However, the uniqueness of the domain and its working practices must be taken into consideration. Care teams cannot be treated as generic or traditional small groups.

3.2.2 Care Teams Versus MDTs

Both MDTs and care teams are important groups in modern healthcare and both types of team require information systems support to achieve their aims efficiently and effectively. As discussed in Section 1.4.2, because the use of teams in healthcare is evolving, the terms used to describe them are evolving. As a result, the author and her academic supervisors initially believed that care teams and MDTs would be similar enough to have similar requirements and that support for one type of team would translate into support for the other. After attending an MDT meeting, however, it became clear that this is not the case. While there is some overlap between requirements for the two types of team, it was decided that focusing on one type of team would provide better results than trying to accommodate both simultaneously. Although MDTs are currently the preferred way of viewing patient-centric collaborative work in the NHS, they are less suitable for this research on multiple grounds.

First, because care teams revolve around an individual patient and MDTs serve multiple patients, care teams can be considered more patient-centric than MDTs. Second, care teams are more inclusive than MDTs and, in fact, subsume MDTs. Third, care teams are ad-hoc; membership is defined by the requirements of the patient. In contrast, MDTs are more likely to be structured, both in terms of having pre-defined membership and operationally. Intuitively it would seem that defining requirements for a more structured group should be easier than for an ad-hoc one, but this does not turn out to be the case for MDTs. Although MDTs are more structured than care teams, they are disease or condition specific; as a result, there are many different types of MDT with different structures, meeting schedules and styles, and ways of working. Although care teams are more flexible and less structured than MDTs, the result is that they are more easily generalised. Healthcare practitioners from any speciality may join a patient's care team, and there is no fixed term of membership. Care team members may join or leave a team at any time, as required. Care teams are distributed, do not meet as a whole group, and they may cover any condition (care teams are characterised against small group criteria in Section 3.3.2). The generalisability of care teams over MDTs was considered a factor in favour of focusing on care teams.

Finally and, perhaps most importantly, this research is concerned with information systems to support patient-centric healthcare teams. The inherent distribution of care teams versus MDTs necessitates greater reliance on mediated methods of communication (telephone, computer, mail, etc). This means that care teams will be more dependent on information systems than MDTs, making this research more meaningful for care teams than for MDTs. Ultimately, care teams were chosen over MDTs as the best focus for this research based on generalisability and potential impact of the work.

The aim of this chapter is to identify a set of requirements for information systems supporting the work of collaborative healthcare teams. This section shows that care teams can be considered small groups and identifies care teams as the type of collaborative healthcare team chosen for this research. The remainder of this chapter considers research from a variety of areas pertaining to the support of small groups and identifies high level requirements applicable to care teams from each of these areas. The compromise with this approach is that greater breadth necessitates less depth. Completing an exhaustive literature review for each of the areas discussed below would have been impossible in the time available. However, it was decided that considering care teams from multiple perspectives would allow for a more comprehensive list of requirements and a better understanding of the associated challenges than would have been achievable had research from only a single discipline been considered. Similarly, the requirements identified here are high level. By considering the problem from multiple perspectives and focusing on high level requirements, it was hoped that the identified requirements would be broad enough to be generalisable yet focused enough to be useful in system development¹.

3.3 Characteristics of Small groups

Once defined, a small group can be further characterised by a variety of criteria including structure, cohesion, norms [74, pp. 5-15], organizational context [75], autonomy, diversity, fault lines [76], task complexity [77], life-cycle, and member roles [78]. If virtual or distributed teams are being considered, then distribution, both physical and temporal, communication style, and boundary spanning [78] may also be included. Considering teams in healthcare, Øvretveit (1996) adds degree of integration, extent of collective responsibility, membership, client pathway and decision-making, and management structures [79] (see Table 3.2). However, not all of these characteristics provide meaningful information regarding information systems requirements generally or care teams specifically. Further, many of the characteristics are closely related and influence each other. For example, boundary spanning is often linked to distribution since team members who are distributed are far more likely to span organisational boundaries. Similarly, distribution has a direct impact on how, when, and how often team members communicate.

Additionally, while small group research in the social sciences has historically focused on co-located teams who regularly meet face-to-face, developments in computers and ICT in the late

¹Although the high level requirements presented here are organised according to the literature, they were identified, refined, and validated through a combination of literature review and conversations, both formal and informal, with a variety of developers, healthcare practitioners, and health informatics professionals over the lifetime of the project (as discussed in Chapter 5)

twentieth century have changed the way that people interact and communicate. These new technologies and modes of communication have allowed for the creation of distributed teams that behave as small groups. In response to this, the way that researchers view groups has changed and the study of virtual or distributed teams has become prevalent in a variety of areas. MDTs may be distributed between team meetings, and care teams are, by nature, distributed. Therefore it is worthwhile to consider any extra implications of distribution on team characteristics and team working and the resulting affects on information systems support.

3.3.1 Virtual Teams

Defining virtual teams as “groups of geographically and/or organizationally dispersed coworkers [sic] that are assembled using a combination of telecommunications and information technologies to accomplish an organizational task” [80, pg.17], Townsend, et al identify several challenges that impact virtual teams more significantly than traditional, co-located teams. Bell and Kozlowski formalise these challenges into a typology of virtual teams using temporal distribution, boundary spanning, lifecycle, and member roles to distinguish between different types of virtual team [78] (see Table 3.2). They also discuss the concept of task complexity as it relates to distributed teamwork.

Although Bell and Kozlowski [78] emphasise implications for leadership, the characteristics they have defined are also of particular importance to information system requirements for distributed teamwork. For example, teams that are not co-located are forced to rely on mediators, such as telecommunication and information systems, to support communication. Teams that are temporally distributed engage in asynchronous communication, increasing the reliance on information systems even further. Boundary spanning introduces challenges related to group norms and member roles. The more boundaries a team crosses, and the stronger these boundaries are, the less likely it is that all team members will have the same expectations.

For completeness, each of the general team characteristics has been defined in Table 3.2. However, development of a complete classification of teams in healthcare is more suited to a Social Science study and is an area for further research. Instead, a generalised description of how care teams operate was created from healthcare literature and personal communications with healthcare professionals to develop a characterisation of care teams as a type of small group. This characterisation was then used to identify an initial list of information systems requirements needed by care teams.

Characteristic	Definition
Autonomy	“The freedom of a team to make decisions about objectives (‘what’), work methods (‘how’), planning issues (‘when’), and/or the distribution of work among team members (‘who’)” [76, pg. 5]
Boundary spanning	The extent to which the team crosses organisational and other boundaries [78]
Client pathway and decision making	The interaction between the team and the client’s care pathway [79]
Cohesion	The extent to which “individual members believe themselves to be part of the team” [76]
Communication Style	The means of communication (i.e. face-to-face, telephone, etc) [78]
Degree of integration	How closely members work together and to what degree an individual’s work is affected by the team [79]
Distribution	The extent to which members are co-located and are working at the same time [78]
Diversity	“...attributes of individual team members, such as age, skills, or personality traits where it is not supposed that the team members share these attributes” [76, pg. 8]
Extent of collective responsibility	“The extent to which the team as a collective is responsible and held accountable for providing a service” [79]
Fault lines	The extent to which certain members of a group share similar sets of attributes [76]
Life-cycle	Length of time the group exists, usually in non-quantitative terms (i.e. permanent work group versus a team created solely to solve a particular problem) [78]
Management structures	The way team members are managed and the way the team is led [79]
Membership	“Who is and is not a member of the team, and what membership means” [79]
Member roles	How clearly defined or ambiguous a member’s role is with respect to the team [78]
Norms	“Those behaviors [sic], attitudes, and perceptions that are approved of by the group and expected... of its members” [74, pg. 11].
Organizational context	“Relevant features of the organization external to the work team, such as reward systems and training resources” [75, pg. 121].
Structure	“The way groups are organized and how various positions in the group are related” [74, pg. 5].
Task complexity	The level of interdependence between work/tasks performed by different members of the group [78, 76]

Table 3.2: Summary of Characteristics for Classification of Small Groups.

3.3.2 Small Group Characterisation of Care Teams

Each care team relates to an individual patient, exists as long as that patient requires care from multiple practitioners, and covers all diagnoses and condition(s) relevant to that patient. Care teams are always distributed and will, in general, never meet face-to-face as an entire group, although some team members or sub-groups may meet face-to-face regularly. Because team members will go through active and inactive phases, and by the nature of medical work, the team will be distributed temporally as well as physically. Team members will be working with the patient at different times as the patient progresses along the care pathway. This will occur in the short term, such as with different shifts on a hospital ward or clinicians working at an out of hours clinic versus a GP surgery, and in the long term as the patient moves through the care pathway. Team membership will vary depending on the patient's state and condition, but will span multiple sites including primary and secondary and, in some cases, tertiary care. In contrast to MDTs, the care team will always include a GP.

Viewing the above description as that of a small group we note that care teams span boundaries, both organisational (across sites) and cultural, since different sites will have different working practices and cultures. As a result of boundary spanning, care teams will experience both physical and temporal distribution, which necessitates extensive use of mediated, asynchronous communication. This leads to low cohesion within the group as a whole (members are less likely to feel 'part of the team'). However, individual clinicians may go through periods where they are not actively involved with a patient, then suddenly become central to the patient's treatment as the patient moves along the care pathway, or as the result of a complication. How actively involved a team member is at any given moment is likely to have a significant impact on how she perceives group cohesion and the extent to which she, herself, feels 'part of the group.' Distribution combined with an overall lack of cohesion can lead to problems with group norms which may be unexpected to an outside observer. While it would be unreasonable to think that group norms are severely lacking in care teams - in many ways procedures and best practices will be the same in different care sites - still, there is a surprising range of instances where group norms may not exist. For example, in a study of information sharing requirements between GPs and other members of cancer teams in Wales, Allam notes that there is little understanding between members of different specialities of what information other specialities require [81]. This illustrates a lack of norms regarding communication; there is no shared understanding of expectations regarding what information should be shared, with whom, and when. Similarly, while a team member's role within the group will be defined by his area of speciality, and this definition will be generally understood by other team members, working

practices will vary somewhat across organizational boundaries. This can lead to the problem of team members believing that a group norm exists when, in fact, it does not. For example, it may be standard practice in one hospital to post a notice directly to a patient's GP when the patient is discharged whereas another hospital may give the letter to the patient. In this case, the GP may not know whether to expect the letter in the mail or to request it from the patient. Worse, he may expect one situation and encounter the other. Cott points out that, even in the same hospital, team members may not "share understandings of roles, norms and values" [82]. Lack of group norms, especially when it is unexpected, can in turn reinforce fault lines. Fault lines appear when certain team members share a set of characteristics and identify themselves as a subgroup based on these characteristics. For example, fault lines may occur between 'the men' and 'the women' in a group, or between 'junior' and 'senior' team members [76]. In care teams, fault lines are likely to occur along levels of care (primary/ secondary/ tertiary), professional classification (e.g. doctors versus allied health professionals), by site/Trust, across disease boundaries, and as a result of familiarity or past experience of team members with one another.

Task complexity impacts on the level of communication and coordination required by the group. Rothrock et al. propose a "three-dimensional task complexity space" [77] using characteristics of scope, structurability, and uncertainty to define the range of task complexity. Task scope is "the breadth, extent, range, reach, or general size of a task" [77], structurability "represents how well-defined the sequence and relationships between subtasks are" [77], and uncertainty is defined by "the degree of predictability or confidence associated with a task" [77]. In contrast, discussing virtual teams specifically, Bell and Kozlowski use task interdependence to define differences in complexity between tasks. Task interdependence defines how much interaction is required between group members to complete a given task. Tasks with low interdependence "require minimal collaboration and information sharing among team members" [78] while tasks with high interdependence require "greater levels of synchronous collaboration and information sharing" [78]². Using either measure it is clear that, in care teams, task complexity will vary depending on both the patient's condition and the current stage of treatment. Some treatments are straightforward with limited scope, are very structured, and rarely vary from the expected structure, while other treatments, such as some cancer treatments, have a broad scope involving many people and an extended time frame and are prone to unexpected changes to their structure. Similarly, treatments which are carried out by a single team member, prescribing antibiotics, for example, may have low interdependence (although it may be important for other team members to be aware of the treatment, they are not actively involved in it) whereas others, such as cancer treatments involving a combination of radiotherapy, chemotherapy, and surgery will have high interdependence and need to be coordinated and timed carefully to achieve maximal efficacy. It

²For a complete discussion of the impact of task complexity on distributed teams, see [78].

is worth noting that timing is often a key factor influencing the interdependence of healthcare tasks.

Øvretveit indicates that his criteria (degree of integration, collective responsibility, boundaries, and management structures) may not be suitable for classification of the ‘client’s team’ [79, pg. 164] . This assessment holds true for care teams as defined here, since they are closer to what Øvretveit terms a ‘network’; care teams have a low degree of integration, low collective responsibility³, group boundaries are well defined, but are not determined by group members, and management structures are not impacted by team membership. As a result, these criteria were not considered while determining support requirements in this research. Table 3.3 provides a summary description of those characteristics which were used to define care team requirements.

Characteristic	Application to Care Teams
Autonomy	Constrained by guidelines and available services/resources
Boundary spanning	Extensive
Cohesion	Low
Communication Style	Mediated
Distribution	Extensive temporal and physical distribution
Fault lines	Caused by professional identification, familiarity/past experience, and co-location of some group members
Life-cycle	Defined by patient condition; generally long term
Member roles	Clearly defined to each individual; lack of group norms may cause confusion with regard to how group members perceive the roles of others
Norms	Clear in some cases, in other cases not well defined
Task complexity	Variable; will depend on patient diagnosis

Table 3.3: Characterisation of Care Teams.

3.3.3 Requirements Derived from Small Group Analysis

Section 2.4.1 defined an initial set of requirements for care teams. From the characterisation of care teams as small groups in Section 3.3.2, three additional considerations for defining requirements for information systems aiming to support care teams can be derived (see Table 3.4⁴). First, the system must support asynchronous communication. Second, system design should consider group norms. In some cases, it may be possible for a shared information system to

³That is, the group is not responsible for allocation of group resources.

⁴Requirements defined in the current section are listed in bold.

support group norms through standardisation of communication and interface across the organisation. However, this may not always be desirable. System design should consider whether standardisation or flexibility is more important within each functionality and the user interface should reflect this. Finally, task complexity directly impacts the amount of communication and information sharing required by team members. The system should provide appropriate information sharing and communication facilities for individual team members based on the various tasks they will be engaged in, and the complexity of those tasks.

Requirement	Derived From
System must be flexible/evolvable	Healthcare
System should be easy to maintain	Healthcare
System should work with existing approaches/proposals	Healthcare
System should provide access to information from multiple sources	Healthcare
System should support asynchronous communication	Small Groups
System should support standardisation of information and communication	Small Groups
System should provide information/communication support that is appropriate and relevant to the user's current task	Small Groups

Table 3.4: Requirements Derived from Healthcare and Small Groups Research.

3.4 Information and Communication Technologies

The same developments in ICT that paved the way for the widespread use of distributed teams also sparked a plethora of research into how information systems can support the work of these teams. In particular, the fields of Computer Supported Cooperative Work (CSCW) and Human Computer Interaction (HCI) have paid special attention to requirements and design factors for collaborative information systems. Health informatics research covers both design and implementation but, obviously, specialises in the unique complexities of the domain. This section considers what additional requirements can be drawn from these research areas.

3.4.1 CSCW, HCI, and Health Informatics

CSCW, HCI, and health informatics research all emphasize the importance of considering the human element as well as the technical elements when designing computerised systems. As a result, these fields have identified a wealth of factors contributing to a system's success or failure, reaching beyond technical specification and performance. Here, we will focus on those

lessons which are most relevant to healthcare. Because the lines between these disciplines are blurred (HCI merges with CSCW when it considers groupware, for example, and all of the areas become health informatics when they consider applications to healthcare), this section will discuss all computer science related disciplines together.

In the seminal work “Groupware and Social Dynamics: Eight Challenges for Developers,” Grudin [83] identifies eight problems specifically associated with developing software to support collaborative groups⁵. These include:

1. **Disparity in work versus benefit.** Groupware applications often require additional work from individuals who do not perceive a direct benefit from the use of the application.
2. **Critical Mass and the Prisoner’s dilemma problems.** Groupware may not enlist the “critical mass” of users required to be useful, or it can fail because it is never to any one individual’s advantage to use it.
3. **Disruption of social processes.** Groupware can lead to activity that violates social taboos, threatens existing political structures, or otherwise demotivates users crucial to its success.
4. **Exception handling.** Groupware may not accommodate the wide range of exception handling and improvisation that characterises much group activity.
5. **Unobtrusive accessibility.** Features that support group processes are used relatively infrequently, requiring unobtrusive accessibility and integration with more heavily used features.
6. **Difficulty of evaluation.** The almost insurmountable obstacles to meaningful, generalizable analysis and evaluation of groupware prevent us from learning from experience.
7. **Failure of intuition.** Intuitions in product development environments are especially poor for multiuser [sic] applications, resulting in bad management decisions and an error-prone design process.
8. **The Adoption process.** Groupware requires more careful implementation (introduction) in the workplace than product developers have confronted” [83].

As with team characteristics, however, some of these challenges, such as failure of intuition, do not directly provide requirements for information systems and, as such, are not relevant to this discussion. The challenges most relevant to care team requirements are discussed in more detail below. Since Grudin’s challenges were published in 1994, researchers have added to and refined his list. For example, Pratt, et al discuss accounting for incentives structures which is an extension of Grudin’s disparity in work versus benefit, understanding workflow which is an extension of Grudin’s exception handling, and add a new challenge, *awareness* [85].

⁵See also [84]

The idea of *incentives structures* is that “not making life harder” is not the same as “making life easier” and that users will not be inclined to use a system unless they perceive benefits from doing so. Pratt, et al point out that different members of an organisation will have different reasons for wanting a system, different goals for the system, and different reasons for using the system. In particular, they note that there is likely to be a divide between what the administrators in charge of paying for the system hope to gain from it and what the clinicians using it hope to gain from it, and that if proper incentives do not exist for the end users to use the system, then it is unlikely to be taken up. That is, if the end users feel that they are not benefiting from the system in some way, then there is likely to be resistance to adoption. The example provided is that “having physicians enter their own notes has a financial incentive to the institution in terms of saving transcript costs, but it also acts as a disincentive to the physicians who are unlikely to work as efficiently” [85]. To address this issue, they suggest that it is necessary to provide “direct incentives (e.g. time or effort savings in some part of the daily work)” to end users. In the results of an empirical study on MDTs in long-term care, Cott points out that, for healthcare practitioners, this means a system that helps them to ‘get the work done’ and to do it well [82]. ‘Getting the work done’ is providing the best possible patient care. People and systems that help to achieve this aim are viewed positively, while those that interfere are not. The lesson to be drawn from this is that any new information system must, from the point of view of the end users, help professionals to complete their work or it will not be accepted. Personal communications with clinicians in the UK support this view, indicating that a feeling of being able to provide measurably improved patient care would be considered a significant incentive towards system adoption⁶. It is also important to note that, as use will be different for different user groups, appropriate incentives will need to be considered for each user group.

Workflows analyse the methods and stages of an entire process from its start to finish, whereas *exception handling* highlights the fact that, in teamwork, exceptions and improvisation are common. Understanding workflows highlights multiple issues: that modern workflows are often used to standardise or streamline processes but that it is necessary to ensure that the group retains the ability to handle exceptions, that computerised workflow systems may not reflect the actual flow of work between team members, and that by over structuring work processes, standardisation (whether through the use of workflows or otherwise) may impede the team’s ability to work effectively [85]. Workflows can provide standardisation and support norms, but can also be restricting and, if not carefully implemented, may not reflect the reality of work practices. The same argument applies to over-structuring any aspect of the system. For example, implementing a fully structured interface with limited or no free-text in it may be seen as a benefit as it makes the data more accessible for secondary usage, such as research, auditing, or billing. However, over-structured data is limiting in what it can express and does not allow for

⁶For a complete discussion of clinician responses to the identified system requirements, please see Section 7.3

the exceptions and caveats which are an important part of the patient record [86].

Finally, we consider *awareness* of the work of other team members with whom one's work must coordinate. Awareness, it is argued, improves collaboration by allowing team members to organise their work around the work of others. For example, by maintaining awareness of the work of others, one can avoid interrupting a team member at an inappropriate time. In distributed teams especially this may also work in the opposite way; team members may wish to intentionally schedule overlapping or consecutive patient visits in order to discuss treatment with other team members [33]. In co-located teams, physical artefacts such as paper notes and public displays support awareness because they carry meaning beyond the data they display. They can indicate at a glance, for example, that work has been completed, a bed is available, or that a backlog of patients is building up [87]. Bjørn and Hertzum point out that whiteboards, in particular, support awareness "by amassing and broadcasting selected information about the collaborating actors' joint work" [88]. This highlights the fact that one factor in making artefacts so powerful with regard to awareness is their shared nature. Multiple people contribute to a shared artefact and multiple people draw information out of it. Shared artefacts inherently carry information about the work of other team members or the team as a whole. Every team member accessing the shared artefact then has access to that information, improving awareness. In distributed teams, however, sharing physical artefacts and making them accessible to multiple people simultaneously is more difficult. Thus, it is more difficult for distributed teams to maintain awareness of the work of other team members. Design of information systems serving distributed teams should consider this loss of awareness and should consider ways in which awareness can be supported for despite distribution. Although their work focused on the use of informal conventions in medical work, Cabitza et al [89] suggest functional requirements for supporting awareness among collaborating practitioners: "the system must be able to display text messages on top of the electronic document" [89], "the system must be able to highlight specific data values" [89], "the system must be able to highlight data structures such as fields, sections, sheets [sic]" [89], and "the system must be able to flank either data values or data structures with graphical cues" [89]. Pinelle and Gutwin also suggest specific functionality for supporting awareness: a flexible tool to illustrate intended and completed patient visits, 'flagging' or labelling data as high priority, and internal messaging [33].

3.4.2 Requirements Derived from ICT Research

The above discussion gives rise to yet more potential requirements and considerations for care teams. The general moral obtained from health informatics and ICT research is that the needs of and impact on the end users must be given high priority when designing systems. Purchasing and/or implementing a new system is only beneficial if it is fully accepted by users. In

the case of healthcare especially, a new system will not be taken up or fully used if it interferes with the clinical work of the end users - healthcare practitioners. More specifically, health informatics and ICT research highlights the need for appropriate incentives to system adoption, warns against over-structuring, emphasises the prevalence of exceptions in teamwork, and introduces the need for particular attention on how awareness is maintained between distributed team members. Specifically, we interpret these requirements as: the system should benefit those who are asked to do increased work, the system should be able to handle exceptions, and that the system should support awareness of other team members' work (requirements 8, 9, and 10 in Table 3.5).

Requirement	Derived From
System must be flexible/evolvable	Healthcare
System should be easy to maintain	Healthcare
System should work with existing approaches/proposals	Healthcare
System should provide access to information from multiple sources	Healthcare
System should support asynchronous communication	Small Groups
System should support standardisation of information and communication	Small Groups
System should provide information/communication support that is appropriate and relevant to the user's current task	Small Groups
System should benefit those who are being asked to do increased work	ICT
System should be able to handle exceptions	ICT
System should support awareness of other team members' work	ICT

Table 3.5: Requirements Derived from Healthcare, Small Groups, and ICT Research.

3.5 Derived Requirements in the Context of Care Teams

Thus far, the literature review and an analysis of teams in healthcare has provided an initial list of requirements for future healthcare information systems (see Table 3.5). But this still does not provide a complete picture. What does it mean to say that practitioners should have increased access to patient information collected in multiple locations? Should *all* practitioners have access to *all* information gathered on a particular patient? Certainly not. A pharmacist, for example, is not legally allowed to have unlimited access to the patient record [90], and information gathered at sexual health clinics is generally confidential and not shared with *anyone* outside the clinic. It is necessary, then, to consider each of the requirements in a pragmatic light- what does this requirement mean to the end user? How will it interact with and impact real-life working practices? This requires something of a leap of faith; practitioners do not yet

have the information access they desire, so how can they be expected to know what gaps will appear once it is available? In order to complete the requirements analysis, it has been necessary to imagine what users will do with increased information access and what they will want from it once they have it. The remainder of this section considers each of the requirements within the context of information systems support for care teams discusses how the requirements have been modified to fit the domain.

The first three requirements, that the system should be *flexible/adaptable*, *easy to maintain*, and should *work with existing systems, approaches, and proposals within the NHS*, have been derived from the context of the domain, so no further analysis with regard to the domain is required.

The fourth requirement, that the system should *provide access to information from multiple sources*, although derived from healthcare literature, does require further examination. As identified above, unlimited access for all users to all patient information is not legally allowable. But this is not the only concern to consider with regard to providing increased access to patient information; the potential for information overload in a unified EPR is substantial. Consider the case of a patient who is suffering from multiple conditions. For example, a geriatric patient undergoing cancer treatment who is also recovering from a stroke. It is likely that this patient will have an extremely large patient record. It is also clear that the patient's oncologist is unlikely to be interested in whether the patient had a broken leg at the age of ten. Further, it is expected that the patient's GP, physiotherapist, and oncologist will be interested in significantly different aspects of this patient's record. Simply making an undifferentiated, unified patient record available to all of these users is unlikely to meet any of their needs adequately and may, in fact, be of less use to them than their current, separate systems. Thus, simple provision of information is insufficient as a requirement. The system should *provide context-based access which is targeted, tailored, and automated in order to reduce information overload and support tasks seamlessly*.

The fifth requirement is that the *system should support asynchronous communication*. For medico-legal reasons, the system should ideally store all communication about patients with tracking meta-data. Additionally, making communications viewable from the patient record would increase their clinical usefulness [91]. So, the system should *support asynchronous communication which can be archived, traced, and linked to the patient record*.

Requirements six and eight, that the *system should support standardisation of information and communication* and *should benefit those who are being asked to do increased work*, are interrelated and, if not addressed carefully, potentially conflicting. Computerised systems can enforce standardisation of data capture and communication by limiting the use of free-text, forcing completion of certain fields, or providing standardised forms. Standardising certain aspects of

recorded data clearly has potential benefits including improved clarity of communication [81], increased data completeness, and, theoretically, increased data quality, as well as being more accessible for secondary data usage such as auditing and billing, but over structuring also has the potential drawbacks of increasing workload and impeding clinical practice [86]. Research has shown that clinicians derive meaning from the phrasing of free-text notes above and beyond the technical information recorded in the note. Similarly, what has *not* been recorded in a patient record can be as meaningful as what *has* been recorded [66]⁷. The potential benefits of standardisation cannot be ignored, but unless there is visible benefit to the end user, in this case members of the care team, these benefits are unlikely to be realised [85, 66]. Furthermore, the purpose of team work in healthcare is to improve patient care. An information system that provides standardised data at the expense of patient care is not supporting this aim. Therefore, the *system should support standardization of information and communication, where appropriate and Increases in workload resulting from the system should provide direct clinical benefit.*

Requirement seven specifies that the *system should provide information/communication support appropriate and relevant to the user's current task.* But treatment, particularly for a very ill patient, can be a complex process. What is relevant to one practitioner may not be relevant to another. Similarly, what is relevant to one practitioner at one stage of treatment may not be relevant to the same practitioner at a later stage. To address this, the system should *provide proactive, context-based information and communication support appropriate to the user's current task.* Factors that may influence context include, but are not limited to, patient condition(s), user's professional role, treatment stage, and type of interaction (i.e. Accident and Emergency, drop-in clinic, follow-up visit, etc), as well as task complexity.

The ninth requirement, that the *system should be able to handle exceptions,* refers to exceptions in a patient's treatment. In contrast to the first requirement which intends that the system should be able to evolve to accommodate organisational changes or changes to best-practices, being able to handle exceptions in the context of care teams means that the system should be able to handle unexpected changes to the patient's treatment, treatment pathway, and care team including non-standard treatment pathways or care team composition. However, this type of exception handling can be viewed as a subset of the overall flexibility and evolvability required by the domain. Therefore, requirement nine is already covered by requirement one.

The final requirement, that the *system should support awareness of other team member's work,* is impossible to analyse comprehensively at this stage. Providing integrated, tailored information access, supporting communication, and pro-active notifications all address aspects of supporting awareness. But until a system meeting some or all of these requirements is in place,

⁷On the other hand, research also indicates that different groups will have differing conventions with regard to recording and shorthand [92]. This clearly could be problematic in a distributed team, such as the ones being considered here.

it will not be possible to determine whether they are sufficient and, if they are not sufficient, how any remaining gaps might be addressed. As a result, although awareness is an important factor for successfully supporting groups, it will not be retained as an explicit, separate requirement. For the purposes of this project, supporting awareness is addressed by the requirements of providing integrated, tailored information access, supporting communication, and pro-active notifications. However, awareness as a concept is important for successfully meeting the needs of teams, and will be considered throughout the remainder of this work.

Initial Requirement	Adjusted for Domain
System should be flexible/evolvable	System must be flexible/evolvable
System should be able to handle exceptions	
System should be easy to maintain	System should be easy to maintain
System should work with existing proposals and approaches	System should work with existing systems, approaches, and proposals within the NHS
System should provide access to information from multiple sources	System should provide context-based information access which is targeted, tailored, and automated in order to reduce information overload and support tasks seamlessly
System should provide information/communication support appropriate and relevant to the user's current task	System should provide pro-active, context-based information and communication support
System should support standardisation of information and communication	System should support standardisation of information and communication where appropriate
System should benefit those who are being asked to do increased work	Increases in workload resulting from the system should provide direct clinical benefit
System should support awareness of other team members	(Covered by other requirements)

Table 3.6: Requirements Adjusted for the Domain.

3.6 Further Evolution of Requirements

As with many projects of this nature, the requirements list continued to evolve over the course of the research (see Section 4.6.1). In particular, it was necessary to distinguish between requirements that related to implementation and functionality versus requirements that concerned conceptual aspects of the system. Because implementation requirements were not discussed in detail with clinicians, they have not been altered. However, to facilitate conversations with collaborators and healthcare practitioners it was necessary for the conceptual requirements to

System must be flexible/evolvable
System should be easy to maintain
System should work with existing systems, approaches, and proposals within the NHS
System should support asynchronous communications which can be archived, traced, and linked to the patient record
System should support standardization of information and communication, where appropriate

Table 3.7: Implementation Requirements.

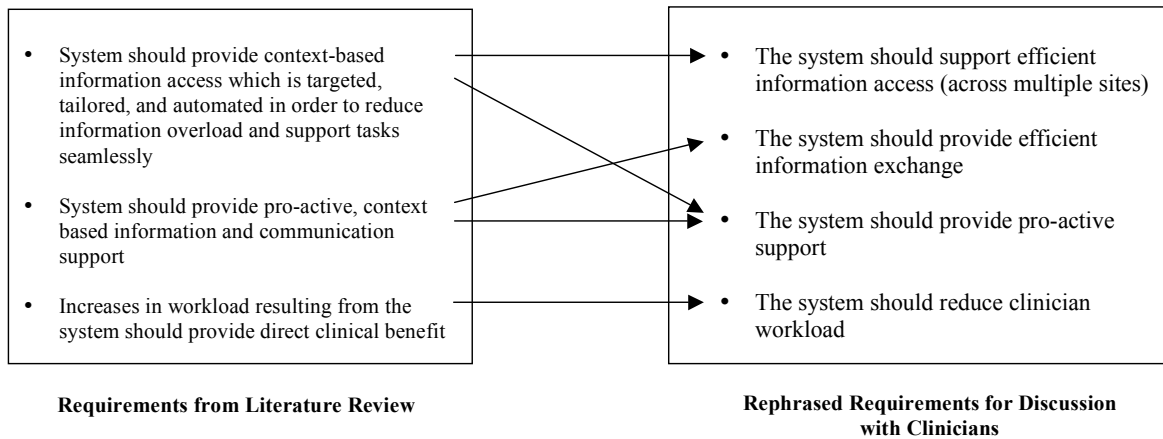


Figure 3.2: Evolution of Conceptual Requirements.

be phrased succinctly and to clearly illustrate how each requirement is related to the working practices of clinicians. Table 3.7 lists the implementation requirements, Figure 3.2 illustrates the evolution of the conceptual requirements, and Table 3.8 lists all of the requirements in their final forms. For consistency, the requirements will be discussed using the phrasing and organisation shown in Table 3.8 for the remainder of this thesis.

3.7 Conclusion

The increasing use of teams in healthcare has significantly changed what healthcare practitioners require from their information systems. However, exactly what these new requirements are is still poorly understood. The use of small group research to define qualities and challenges of care teams provides a stepping stone from which care teams can be better understood and a preliminary list of general requirements can be derived. However, small group research alone does not provide a complete picture. Many fields, especially health informatics and CSCW,

Implementation Requirements
System must be flexible/evolvable
System should be easy to maintain
System should work with existing systems, approaches, and proposals within the NHS
System should support asynchronous communications which can be archived, traced, and linked to the patient record
System should support standardization of information and communication, where appropriate
Conceptual Requirements
The system should support efficient information access (across multiple sites)
The system should provide efficient information exchange
The system should provide pro-active support
The system should reduce clinician workload

Table 3.8: Final Requirements.

have considered the needs of distributed teams. Incorporating ideas from multiple areas and grounding the discussion in a characterisation of care teams based on small group research has allowed for the creation of a preliminary list of support requirements for future healthcare information systems. Considering these requirements specifically in the context of care teams as defined here has allowed them to be further refined and adapted to the domain. In particular, the system must be flexible enough to handle both changes to working practices in general as well as on a case by case basis, should pro-actively support the work of team members without contributing to information overload, and should provide noticeable benefit to end users.

While this chapter has focused on bringing together research from a variety of fields to identify a list of high-level requirements for the support of care teams, it should be noted that this list is in no way all-encompassing. Aside from content gaps, such as data security and incorporation of external knowledge sources, the requirements list presented here ignores infrastructure and technical requirements such as hardware and software compatibility or system speed. Clearly, all of these areas are critical to the success of any information system, particularly in a life-critical field such as healthcare. However, health informatics is a huge field in a domain which is both messy and complex, involving competing requirements and often driven by political pressure. If developing high quality, effective health information systems were easy, there would be no need for this research. From the very beginning of the project the need to keep a tight rein on the project scope has been clear. In order to accomplish this, it has been necessary to limit the focus to those requirements directly related to teamwork.

Tackling the Problem

Overview

Chapter 2 discusses the decision to move to a team-based approach to healthcare delivery in the UK and identifies some of the challenges associated with providing appropriate and useful information systems support for healthcare practitioners working within this model. Chapter 3 continues this analysis, considering requirements which can be identified by looking at a broader range of research areas. Before moving on to addressing these identified requirements, we take a moment here to discuss software development methodologies considered for this research and, specifically, the methodology that was eventually employed.

4.1 Introduction

Once a problem area is identified, the next stage of research is to select an appropriate approach to tackling the problem. In this project, it was clear from the earliest stages of the literature review that three key factors impacting the research were that a) the domain is highly complex and requirements within the domain evolve as advances in medicine occur, b) different members of the healthcare community have differing views on what a team is and how they should work, and c) how care teams work in practice is evolving, therefore requirements for support of care teams are not yet well understood and are expected to evolve over time. This lack of clarity immediately ruled out traditional software engineering approaches, such as the waterfall method, since it would not be possible to set fixed requirements at the start of the project. Even a modified waterfall method which allows for iteration would not be sufficiently flexible to cope with the expected level of change [93, 94].

Because this is not a commercial development, methods which are specifically designed for commercial applications, such as Boehm's spiral model, were also excluded [94]. Many commercial developments make assumptions, such as the existence of a large development team, which are invalid for this project and make such models inappropriate for consideration here. Instead, consideration focused on approaches designed for developments involving unclear or evolving requirements, such as Soft Systems Methodology (SSM), evolutionary methods, and Agile development [94]. Each of these methods is specifically designed for 'messy' project developments where the problem is poorly understood and/or user requirements are not well defined at the start of the development.

4.2 Soft Systems Methodology

SSM or Systems Thinking focuses on what could be termed the 'pre-requirements' stage of software engineering. Geared towards complex situations in complex environments, SSM provides tools and techniques for converting a 'problematic situation' that is ill-defined and poorly understood into a 'problem' that can be clearly defined. Considering the stages of SSM:

1. "Define the situation that is problematic
2. Express the situation (top mapping, rich picture, etc.)
3. Select concepts that may be relevant
4. Assemble concepts into an intellectual structure

5. Use this structure to explore the situation (possible iteration with steps 3 and 4)
6. Define changes to the situation (i.e. problems to be tackled)
7. Implement change processes” [95]

one can see that it is only in stage 6 that SSM reaches the ‘requirements definition’ stage of more traditional software engineering methodologies, and that the rest of the development life-cycle is relegated to a single step - stage 7.

Because SSM is specifically designed for tackling highly complex, poorly understood situations in complex environments, it is in many ways ideally suited to identifying and understanding requirements in healthcare. However, the main aim of this research is not requirements definition. Rather, this research aims to *develop an approach* that could provide improved support for care teams. The emphasis within SSM on problem definition and requirements specification means that it is inadequate for handling the later stages of development. Additionally, SSM requires intensive information gathering with regard to the ‘problematic situation’ from various stakeholders. For this project, that would entail multiple interviews with members of NHS staff. Time constraints on the part of healthcare workers made this impractical. Due to the intense focus of SSM on requirements definition, the limited time available for interviews with NHS staff, and the author’s own inexperience with SSM techniques, Soft Systems Methodology was not used for this project.

4.3 Agile Development and RAD

The Agile software development model is the antithesis of the waterfall model, emphasising entire team collaboration, inclusion of all stakeholders throughout the development process, and building change into the development process. The main aim of Agile development is to build “flexibility into the development process” [93] in order to more effectively deal with changing requirements. Collaboration with all stakeholders is planned into the entire development process with implementation beginning as early as possible and undergoing multiple iterations. Iterating implementation and discussing development collaboratively is intended to provide high quality software that is exceptionally fit for purpose [96].

Agile software development is particularly useful in developments where requirements change over time [93]. This flexibility makes it suitable for a highly complex domain such as healthcare. However, as with SSM, the Agile approach places high demands on the customer’s time. More critically, Agile development is intended for large projects with a team of developers.

Agile techniques, such as pair programming assume team development. The expectation of team collaboration made Agile development unsuitable for this project.

The Agile approach is one example of a set of methodologies classified under the umbrella term Rapid Application Development (RAD). However, it clearly illustrates the problems associated with using any of the RAD approaches for this project. RAD methodologies all use timeboxing and iteration, collaboration, prioritisation of functionality, and place high emphasis on inclusion of all stakeholders throughout the development process [94]. As with the Agile method, every RAD approach requires more stakeholder involvement than was possible in this project and they are all designed for teams of developers. As a result, all variations of RAD were deemed unsuitable for this project.

4.4 Evolutionary Development

An evolutionary approach to systems development involves incremental completion of the system [94]. There are many variations to evolutionary development, but they all follow the same fundamental formula: an incomplete system (or prototype) is developed and presented to the customer. By interacting with a tangible, if incomplete, system the customer is able to explore system requirements and intended usage. Based on this exploration, the customer's requirements evolve and the customer gives feedback to the developers who then update the prototype, and the process repeats. In some cases, the system is 'phased in'; each iteration extends the previous version of the system. This process is also known as *evolutionary prototyping*. Using evolutionary prototyping allows core functionality to be implemented and made available to the users quickly, with 'extra' features being incorporated over time. Alternatively, in *throwaway prototyping* the prototype is abandoned and a new prototype written at each iteration. Throwaway prototyping allows for 'quick and dirty' software that answers specific questions [93] where there is little benefit to fastidiously coding multiple designs, as all but one of them will be abandoned in the production of the final system.

The iterative nature of the prototyping approach makes it especially well suited to developments where requirements are poorly understood. Interacting with the prototype can help both the user and the developers to clarify vague requirements and to identify misunderstandings. Additionally, prototyping makes the development process tangible. The user does not have to imagine what the system may look like or how components will fit together; the prototype makes it visible. This visibility makes it much easier for the user to provide feedback on the system.

The iterative nature of prototyping can also cause problems. Evolutionary development can lead to poorly designed and/or inefficient systems as the basic design is 'tweaked' to accommodate

new or altered requirements. Iterative development also increases the testing overhead as each component of the system must be tested at each iteration to ensure that alterations and additions have not introduced errors into previously tested system components. Additionally, iterative approaches can be difficult to manage [94]; regular changes to requirements and implementation can lead to poor documentation and, potentially, miscommunication. Methodologies such as Boehm's spiral model attempt to overcome some of these problems by imposing a more rigorous structure onto each iteration. In particular, Boehm's model emphasises evaluating and addressing risk factors at each iteration [94].

For this project, however, neither inefficiencies in the system nor testing overhead were substantial concerns. This research required a proof of concept prototype only, making coding inefficiencies acceptable. Similarly, a proof of concept prototype is, by definition, not intended to become a complete system. Even if it is developed as an evolutionary prototype it is, in the end, 'thrown away', meaning that comprehensive testing is not required. Additionally, by building modules that interact through interfaces, changes to the system do not require the entire prototype to be 'thrown away' at each iteration. Finally, because the development component of the research would be largely exploratory, reducing risk was not a primary concern.

4.5 Healthcare Development Methodologies

Formalising software development methodologies specifically designed for healthcare information systems is an emerging theme in health informatics literature (e.g. [97, 98, 99]). While the unique challenges and requirements of developing software for healthcare providers have been discussed in the literature for some time (see Section 3.4.1), until recently, these discussions took the shape of 'lessons to be learned' or 'tricks of the trade' more than formal approaches. As health informatics expands as a discipline, however, the need for development models and tools tailored to the domain is becoming more clear, although many approaches are still published in the context of individual projects rather than generalised methodologies. This is particularly true for research and other non-commercial developments. Healthcare information system development models take many different forms but, in general, emphasise end-user involvement in the development process. Although not formalised, the methodology adopted for this project falls into the category of healthcare development models adapted from existing methodologies, concentrating on requirements analysis and end-user involvement.

4.6 Chosen Methodology

Because prototyping is particularly suited to situations where requirements are poorly understood and because the nature of the project minimised concerns about problems associated with this methodology, it was initially decided that this project would be undertaken using an evolutionary prototyping approach. A proof of concept prototype would be created, then evaluated by clinicians and developers at Velindre NHS Trust in Wales. Based on this evaluation, requirements, design, and functionality would be updated and a new prototype created. This process was expected to be completed two to three times over the course of the project. Further research into MDTs, however, revealed that not only are requirements for healthcare teams poorly defined, but the way that teams work in healthcare is poorly understood and that, in fact, teams that one would expect to be similar often work differently in different Trusts. Some requirements for future healthcare information systems exist, but without understanding the way that healthcare teams work, it is impossible to determine whether and to what extent meeting known requirements will actually support the work of these teams. As a result, it was decided that creating an initial list of requirements would require substantially more research and analysis than was initially expected. This, combined with the author's relative inexperience with regard to both research and software development, meant that time constraints would make the use of a typical evolutionary prototype methodology impractical. Instead, an evolutionary/iterative approach was taken with regard to requirements specification, but only one prototype was ultimately developed. The main difference between this approach and a typical evolutionary approach is that, in this case, the 'prototype' under consideration for the majority of the project was the requirements list which was continually extended, modified, and refined throughout the life of the project.

Despite problems with the full specification of requirements, some basic requirements are clearly indicated in healthcare literature. Specifically, there is a call for increased access to patient information gathered from multiple sources, and for improved support for communication. More generally, existing healthcare information systems are not designed to support distributed collaboration. Based on this identified gap, a minimal list of requirements was drawn up. An outline for a potential high-level approach for tackling the problem was developed, and the project entered the first design stage. This initial list of requirements (as well as design and subsequent development phases) was then continually evolved as understanding of the complexities of the problem increased.

Level	Example
Problem or area of need.	Communicating with practitioners at different locations is difficult.
Complexity arising from a known requirement.	Different practitioners will have different expectations with regard to communications.
High-level requirement.	The system should provide automated, appropriate, electronic notifications/communications.
Specific functionality.	If a cancer patient is admitted to hospital unexpectedly, the patient's lead oncologist should be notified.

Table 4.1: Levels of Abstraction for Requirements.

4.6.1 Evolutionary Requirements

New requirements arose from multiple sources including literature, personal communications, presentations, and the development process itself. Further new requirements were identified at different levels of abstraction ranging from an identified 'area of need' to specific functionality. Table 4.1 illustrates the different levels of abstraction, using an example of a single requirement, as it was defined at each level. Each newly identified requirement was reviewed and refined until it could be expressed either as a high-level requirement or a specific functionality requirement supporting an existing high-level requirement. If specific functionality was proposed that could not be associated with a high level requirement, then that requirement was evaluated with respect to how it related to supporting teamwork with the assumption that either the requirement was not directly related to team working, or it suggested a new high-level requirement that had been previously overlooked. Often, the refinement process itself led to new requirements or new areas of study. For example, an initial requirement was that the system should support the work of MDTs. Refining this requirement ultimately led to a study of social science literature on characteristics of teams and teamwork which yielded several new high-level requirements (see Chapter 3). As new requirements became clear, they were phased into the design and implementation. The process of refining requirements was, itself, highly evolutionary. Conference presentations, conversations with collaborators, and new literature regularly highlighted unforeseen complexities, but transforming these often abstract concepts into requirements that were clear to all parties, evaluable, and meaningful with regard to the domain was largely accomplished through informal discussion with clinicians, developers, and researchers. This process involved noticeable aspects of negotiation where an impractical functionality would be mentioned then discussed in the context of what is technically achievable. In this way, collaborators negotiated until a meaningful but practical requirement could be defined. In some cases, this negotiation carried on through multiple sessions.

As new requirements were defined and existing requirements tweaked, the high-level proposal and technical design evolved to accommodate them. Although detailed system design was not

discussed until after implementation, at the final stages of the project, incorporating each new requirement into the system design as it was specified both reduced the likelihood of specifying impossible requirements and opened the door for a broader discussion. As expected in an evolutionary development, altering the design to accommodate one new requirement often revealed new complexities to be considered or provided inspiration for completely new requirements.

4.7 Virtual Organisations

In addition to development methodologies, frameworks suggested in Computer Science which have the potential to contribute to the solution were also considered. In particular, because this research focuses on supporting teamwork within teams that are both temporally and geographically distributed, Virtual Organisations (VOs) were investigated. Virtual Organisations as discussed in Computer Science literature are very similar to the Virtual Teams described by Townsend, et al [80] (see Section 3.3). The term Virtual Organisation refers to a structured collaboration and sharing of information between team members from different communities [100]. This may include people from different organisations, different departments within the same organisation, or even members of the same department who have different information needs. Because these teams cross organisational boundaries, there is an implicit assumption that at least some of the members are working from different physical locations at some time. Most researchers also agree that VOs consist of autonomous members, that the primary reason for creating a VO is to support communication, cooperation, and collaboration, and that they exist in a computing environment [100].

The main distinction between virtual teams and VOs is that VOs are typically used in scenarios where two or more non-affiliated (and possibly competing) businesses work together on a project. This means that VOs are usually characterised as short-term, ad hoc teams which emphasise traceability of data ownership, modification, and generation, restriction of data access, and ring-fencing of each organisation's contributions, resources, and ownership of the outcomes of the project. Additionally, while VOs will clearly have a shared purpose, competition between component organisations and autonomy of the members implies that they will have low *cohesion*.

It is interesting to note that, while both MDTs and care teams qualify as VOs, because there is no element of competition, they do not have many of the characteristics of VOs in business; they are long term, there is no need for ring-fencing, and there is no question of ownership of produce. Traceability is important, but for legal reasons rather than competition. Despite this, care teams do fit the definition of VOs, albeit non-standard ones. The differences between business VOs and care teams mean that much of the VO literature cannot be reasonably applied

to care teams. However, care teams are VOs and some lessons can be applied to providing support for distributed care teams.

4.8 Constraints and Scope

As with any project of this nature, constraints on resources were substantial. As doctoral research, the project was undertaken by a single researcher supported by a supervisory team. Although healthcare practitioners and developers at Velindre Trust were consulted, the amount of time these professionals were able to give to the project was limited.

Constraints impacted the project scope in multiple ways. Time and access constraints meant that it was not feasible to conduct in-depth consultations with practitioners and developers at multiple locations. Instead, it was necessary to focus on work in a single disease area as conducted at a single site. As a result, this project focused on the needs of care team members working at or with Velindre Cancer Centre, although practitioners and developers working in other areas and other care centres were consulted when opportunities arose. Focusing on work at Velindre Cancer Centre also led to a focus on CANISC, the main EPR used in the Trust. This focus on Velindre and CANISC provided the access to healthcare professionals necessary to this work, but also has potential implications with regard to the generalisability of the work (see Section 7.5.4).

Scope was also impacted by both resource constraints as well as the nature of the research itself. The area of providing support for cross boundary care teams is broad and encompasses a variety of areas and fields. It was therefore necessary to put strict boundaries on the project. The author chose to approach the research at a high level, rather than to focus on the details of functionality and implementation, in the hopes that this would lead to more generalisable results. Therefore, the implementation focused on the ability to provide a particular range of functionality rather than the details of how the functionality should look to the end user. For example, the prototype provided the ability to tailor access to an individual based on the user's current professional role, rather than looking at exactly what roles would be needed. Similarly, the prototype provides the ability to generate and send communications to individuals based on professional role, but does not consider exactly what information each communication should contain. This decision made it impractical to consider the user interface of the prototype in detail. Time constraints meant that emphasis on the user interface would have limited other aspects of the project and, because the research undertaken was exploratory in nature, it was decided that functionality should be given priority over user interface implementation.

Examination of existing systems and working practices was also constrained by limitations of both time and access. For ethical reasons, obtaining access to working healthcare information

systems is not a simple process. As a result, it was necessary to find a compromise between what is available, what is achievable, and what is desired. For this research, working with Velindre and CANISC provided access to healthcare professionals and a working healthcare information system which would not otherwise have been possible, but this access was not without constraints and limitations. Because access to clinicians was limited, it was necessary to be highly selective about what feedback was sought. Similarly, while CANISC is a successful and widely respected system, it is only one of many existing and proposed EPRs. It is recognised that all of the decisions regarding scope, while taken for practical reasons, do have implications for the evaluation, generalisability, and next steps of the research. With the chosen approach, it is not possible to draw meaningful conclusions about amount, style, or presentation of information. Considering aspects of the system such as functionality, user interface, and other disease areas in greater detail are important next steps if the research is to be taken further (see Section 8.2). However, conclusions *can* be drawn about whether users would like and/or require the types of information considered in this project if it were presented well, as well as some of the potential benefits and challenges of providing this information.

4.9 Conclusion

Adopting an appropriate methodology for any project has a variety of benefits. Most importantly for a research project, perhaps, is that a methodology can provide structure to the project, can help to ensure that each area of the work is given due consideration, and can suggest tools and techniques for completing each phase of the work. But following a particular methodology too rigorously can also lead to inflexibility and missing potential alternatives. This research project involved a very complex, highly dynamic, and evolving subject within a complex and rapidly evolving domain. Additionally, at the outset, the author had limited experience with both systems design and the healthcare domain. As a result, this project was fraught with changes caused by the politics of the domain, 'state of the art' in healthcare IT, the understanding of each collaborator with regard to what the project was attempting to achieve, and the needs of the clinicians who the project was aiming to serve. Constant and significant change meant that extreme flexibility was necessary, and it became impractical to commit rigidly to any one approach. In the end, an evolutionary prototyping methodology was adopted and adapted to fit the needs of the project.

Adopting a hybrid approach for this project provided the flexibility necessary for handling a quickly evolving research area and for coping with unexpected setbacks. However, adopting a hybrid model also sacrificed much of the structure that could have been achieved had a standard approach been more rigorously followed. One potential advantage to adopting a hybrid

approach is that it allows more freedom to integrate tools and techniques used in alternative approaches. In this case, incorporating some SSM tools into the initial requirements gathering phase may have helped to clarify requirements at an earlier stage in the project. Unfortunately, this opportunity was missed. As a result, the requirements gathering stage of the project was fairly ad-hoc and the requirements were not formally validated until the final stages of the project. This strategy introduced significant risk into the project - if the requirements had not been useful the results of the research would have been meaningless. While ongoing interaction with developers and end-users limited this risk, a more formalised and systematic approach would have been preferable.

Despite the sacrifice of structure inherent in adopting a hybrid methodology, the evolutionary requirements approach was effective for this project. Regular communication with individuals involved with healthcare information systems, both developers and users was key in keeping the project focused on meeting users' needs. Early in the project, the paper-based models met their intended aim of improving communication and sparking discussion. In the later stages of the project, system design and implementation highlighted both potential problems and unidentified potential benefits to the chosen model.

A Team-Based Model

Overview

Chapters 2 and 3 identified a variety of requirements for supporting the work of care teams and Chapter 2 discussed a few of the projects attempting to meet these requirements. Although the projects reviewed in Chapter 2, if successful, will be an important step in the right direction, there will still be more challenges to overcome. This chapter proposes a conceptual model aimed at providing explicit support for care team members tailored to the individual's professional role on a given team. Chapter 6 will then discuss how this conceptual model was converted into a proof of concept prototype to demonstrate viability of the approach.

5.1 Introduction

The image of clinicians grouped around a patient is commonly used to illustrate the concept of patient-centric work in healthcare (see Figure 5.1 (a)). An alternative view of patient-centric working shows clinicians grouped around an integrated patient record (see Figure 5.1 (b)). Neither of these images, however, fully expresses the interconnectedness of collaborative healthcare. A care team is more than just a group of people interacting with a patient or with a patient record. Effective teamwork requires both direct communication and information sharing between individual team members as well as an awareness of the work of other team members (see Section 3.4.1). It is this interaction between members which makes the difference between a team and a group of people who happen to be working with the same patient, yet neither of the standard models fully expresses this interaction since they each concentrate on one dimension of what is a complex, multi-dimensional collaboration. Patient data, and access to it, is central to effective teamwork in care teams. Having access to patient data allows clinicians to do their jobs - to make decisions about the patient's care and to identify when problems have occurred or are likely to occur. Therefore, access to patient data should be reflected in a team model. At the same time, Chapter 3 highlights the fact that simply providing access to patient data will not meet the needs of care teams. The interactions between team members must also be considered.

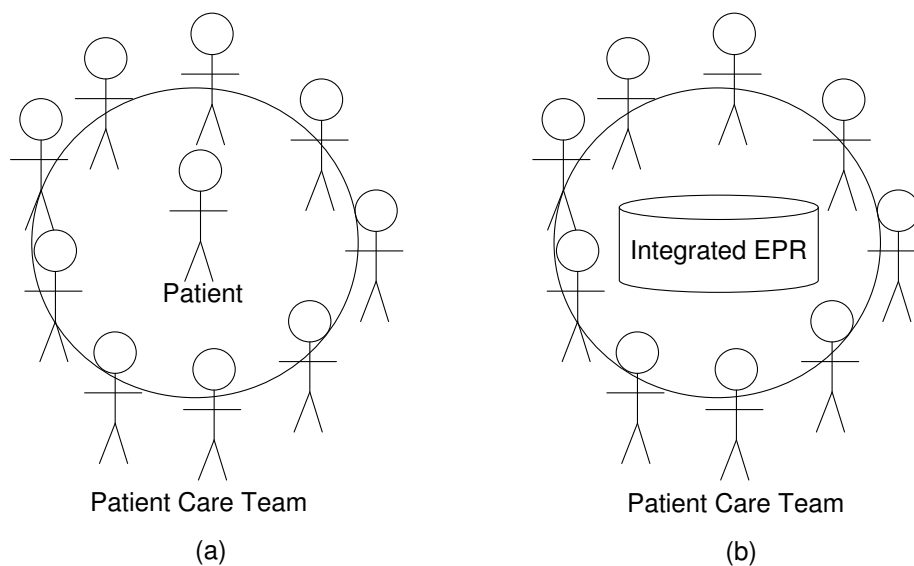


Figure 5.1: Models Representing Patient-centric Care.

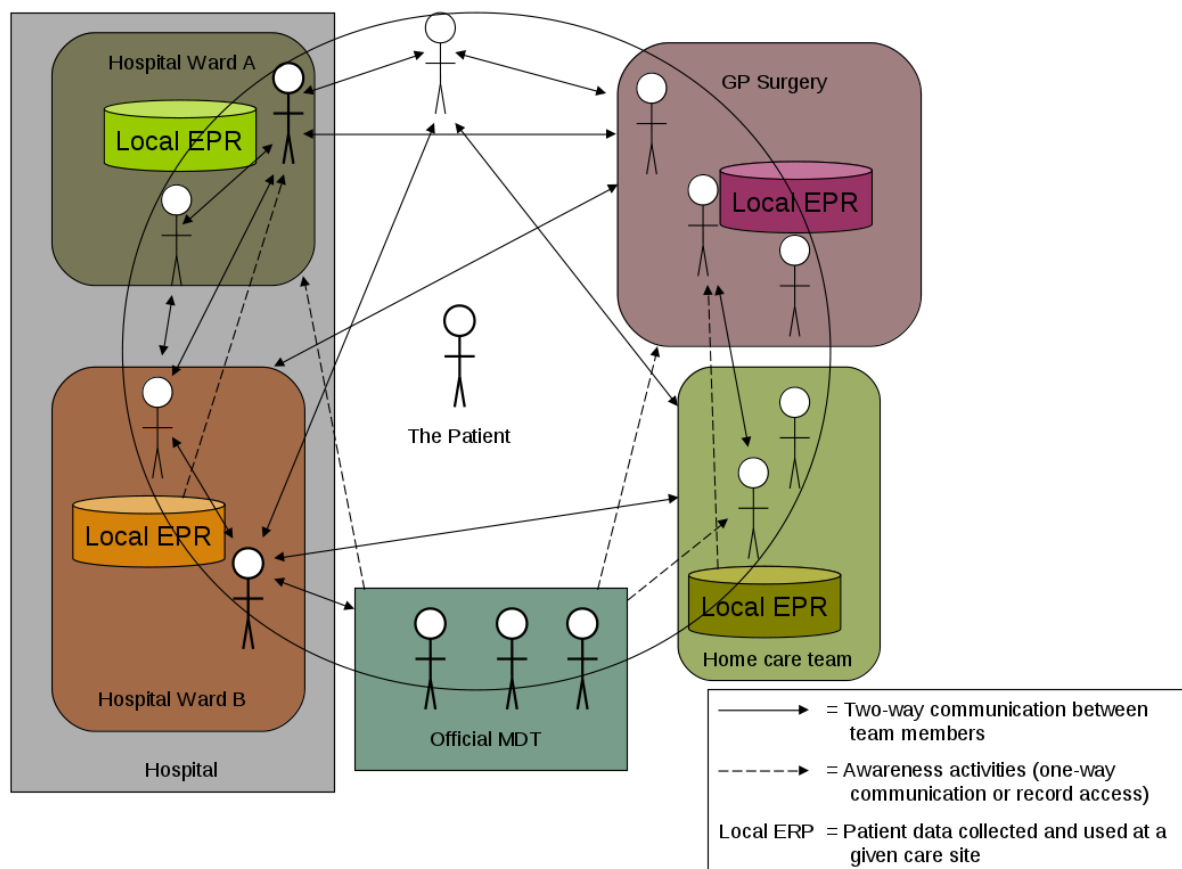


Figure 5.2: An Alternative Model of Patient-centric Care.

Figure 5.2¹ attempts to reflect the complexity of the work of care teams by highlighting key aspects of teamwork in healthcare. First, the model illustrates the communication aspect of teamwork. In a care team, each team member may communicate with a variety of other team members, but very few team members communicate with *all* other team members. Communication may be one-way or two-way. One-way communication is dissemination of information; for example, one team member informs another team member of a decision that has been made or provides a status update on the patient. Two-way communication often supports joint decision making while one-way communication relates to awareness. Additionally, team members interact with EPRs. Saving and retrieving data to or from an EPR also supports awareness. Saving data (theoretically) makes it available for other team members to view and viewing data collected by other team members supports awareness of both the work of the individual who recorded the data as well as supporting a big-picture view of the combined work of the team. In the case

¹In Figure 5.2 solid arrows represent two-way communication between team members, dashed arrows represent awareness activities (one-way communication or record access), and each 'Local EPR' represents the patient data that is actively collected and used at each care site, whether it exists as part of a shared patient record or not. To reduce clutter, interaction (saving and retrieving data) between team members and their local EPRs is assumed and not explicitly shown.

Conceptual Requirements
The system should support efficient information access (across multiple sites)
The system should provide efficient information exchange
The system should provide pro-active support
The system should reduce clinician workload

Table 5.1: Conceptual Requirements.

of a care team, the ‘big-picture view’ reflects the overall health of, and care currently being provided to, the patient. In some ways, the model is idealistic; team members want to have access to the EPRs of other team members, but this is rarely available at present (see Chapter 2). Similarly, team members currently communicate less than they would like to because communication is both difficult and time consuming (e.g. [39, 33]). However, in order to provide the support required for effective team working it is important to consider how teams *want* to work as well as how they currently *do* work. Considering only how teams currently work is restrictive. It does not allow for improvements or alterations to existing working practices, nor is it likely to address those requirements which have been identified but are not yet met².

This chapter proposes a conceptual model for healthcare information systems supporting care teams that reflects the complexities and issues illustrated in Figure 5.2. The conceptual model, Virtual Organisation access to Information sources and services in a Collaborative Environment (VOICE), emphasises team structure to support communication and awareness among team members, while bearing in mind the unique challenges of the healthcare domain. The model considers the awareness and communication dimensions of teamwork as well as the relationships between the EPR and team members and the influence of the EPR on teamwork, communication, and awareness. We take as a starting point the requirements identified in Chapter 3 (for convenience, the requirements are duplicated here as Table 5.1). Each of these requirements has at its root the main aim of the research - to provide improved information systems support for the work of healthcare practitioners working as members of collaborative care teams, specifically to help care teams to work more effectively as *teams*. In order to support these requirements, a model that explicitly views clinicians as members of care teams and that tracks and manages those care teams is proposed Acknowledging and tracking Team data - who is on a team, what role each team member plays, who the team is created for, etc. - allows identification of team members as individuals, which is necessary for providing pro-active notification and communication without contributing to information overload. Additionally, tracking a clinician’s Team Role allows for tailored provision of information, further reducing problems of information overload. Taken together, these requirements provide a foundation for supporting awareness and communication at multiple levels while taking into consideration the importance

²Indeed, even this perspective can be viewed as incomplete because it does not consider how teams *should* work .

of efficiency of use for healthcare information systems. The system should provide information to the user, but must do it in a way that is useful, not overwhelming, and is timely.

5.2 Users, Roles, and Permissions

The conceptual model proposed here involves creating associations between Users, Teams, and organisational Roles to model patient care teams. This allows for a focus on the information needs of each role. Users acquire access to patient record information through a compound association of the User's Role in a particular patient care Team. This association provides a mapping between a User and the patient record view defined for that User's current Role. Defining a User's view of the patient record using professional Roles allows for tailored information access to information needed to support the role. Specifying the User's Role on a patient-by-patient basis allows the proposal to better reflect working practices. Explicitly modelling care teams and their roles allows the model to capture associations between Users, which can then be used to support aspects of teamwork. Section 5.4 explains in detail how team information is used to meet the selected requirements and support teamwork.

5.2.1 Role-Based Access Control

The concept of using organisational Roles to define User access to organisational objects and information has been previously proposed in Role-Based Access Control (RBAC) [101]. Standardised in 2001 [102], RBAC uses organisational roles to restrict access to objects within an organisation [101, 102]. In the RBAC model, Users are associated with organisational Roles, and organisational Roles are associated with Permissions relating to organisational Operations and Objects (see Figure 5.3). When a user is assigned to a Role, she acquires the access permissions necessary to complete Operations and view Objects and information associated with that Role. This is far more efficient than assigning Permissions directly to individual Users as it allows each user to be assigned multiple Permissions simultaneously. Similarly, re-defining a single Role updates the access Permissions of all Users associated with that Role. This not only increases efficiency, but supports consistency in access Permissions throughout the organisation. It also means that, as roles evolve and change user's permissions evolve reflecting that change [101]. Allowing a single User to take on multiple Roles provides flexibility and finer granularity of Permission assignment.

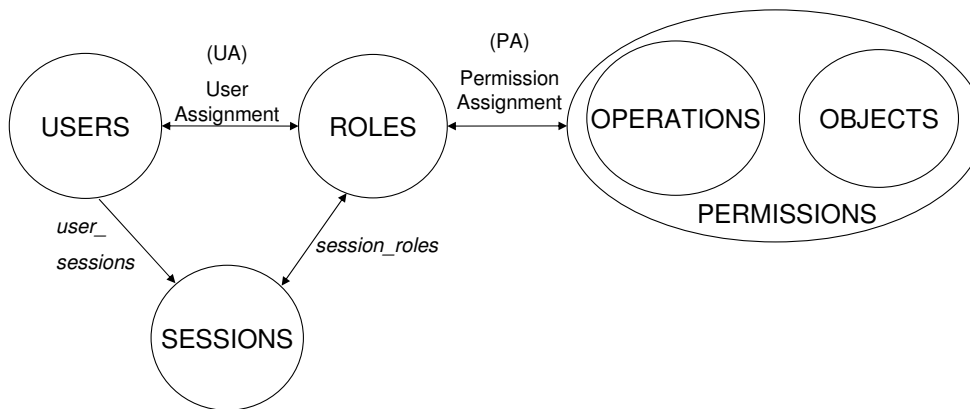


Figure 5.3: RBAC Model (Figure adapted from [102, pg. 232]).

In addition to these benefits, RBAC may also include Role hierarchies, static and dynamic separation of duty relations as well as supporting a variety of protection policies [101, 102]. Role hierarchies allow for finer grained permissions and improved efficiency of permission assignment through inheritance. Separation of duty relations are used to prevent fraud by ensuring that a single person is not responsible for all steps in a procedure or chain of activities, such as requesting, ordering, and receiving goods.

Since its introduction, many extensions to RBAC have been proposed (see Section 5.5.1), but it is important to note that these models are designed to enforce access restrictions, rather than to support teamwork. As a result, none of these models adequately support the communication and collaboration requirements determined for this project. The conceptual model proposed here can also be considered an extension of RBAC as it uses an association between Users, Roles, and the user's system view to provide tailored access to patient records. However, although the proposed model is closely related in form to RBAC and other access control models, it differs in both application and, consequently, key aspects of the model. A detailed analysis of access control models and the differences between this proposal and access control proposals are included in Sections 5.5.1 and 5.5.2, respectively.

5.3 The Model

As outlined above, the VOICE model is based on the premise that, if healthcare practitioners are working as care teams, then the meta-data associated with care teams, such as team structure, could be used to provide improved support for care team members. Once this fundamental premise had been identified, the next step was to define the various system entities implicit in this point of view, and to identify the relationships between them. Although the work is presented

here in its final form, system entities and relationships were defined and refined iteratively, as described in Chapter 4.

First, we identified Patients as those people receiving care and noted that Patient health data is stored in the system. Healthcare practitioners caring for Patients are system Users, and Users access patient health data. Users work on care Teams and each team has Members. Further, each team Member has three defining characteristics - the User who is the team Member, the Team to which the Member belongs, and the professional Role played by that team Member on the given Team. Different Users play different professional Roles. Further, a User's professional Role may change over time within a particular patient's care or from patient to patient. Each professional Role involves a unique set of Tasks which the professional may wish to perform to provide optimal patient care. Practically speaking, Tasks define the user interface associated with each Role. Finally, we noted that both implicit and explicit Policies exist within the NHS which dictate the actions of healthcare professionals. In particular, we focused on Policies relating to patient information - when and what information a person is interested in, when and what information to share and with whom, and what action to take when new information becomes available. Later, Policies relating to care team management - adding and removing Members from the care Team, updating team Members' Roles - were also incorporated. Thus, Policies are included as composite entities defined by three characteristics - when the policy should be applied (what Event fires the Policy), what Action should be taken as a result of the Event, and the Role for which the action should be taken. This analysis yields Patients (Pa), Users (U), Teams (T), Roles (R), Tasks (Tk), Events (E), and Actions (A) as fundamental entities within the model (see Table 5.2). Members (M) and Policies (P) are defined as a combination of these fundamental entities (see Sections 5.3.1 and 5.3.3, respectively).

Notation	Entity	Definition
Pa	Patient	Person receiving care
U	User	Healthcare practitioner using the system to access patient information
T	Team	Group of people caring for a patient
R	Role	Professional role performed by a system user
Tk	Task	Activity performed by a system user as part of a professional role
E	Event	A change to a patient's status which causes a policy to be fired
A	Action	What the system should do in response to a fired policy

Table 5.2: Fundamental System Entities.

The remainder of this chapter explains the proposal in terms of these entities and the relationships between them, highlighting how the model may be used to meet the requirements defined in Section 5.1, and comparing the proposal to related work. For improved specificity, aspects of the model are further defined using set theoretical notation (summarised at the end of Section 5.3). For ease of comparison, the notation, format, and conventions used in related work ([103, 104, 105], discussed in Section 5.5.1) have been followed.

5.3.1 Care Teams

Users (U), Patients (Pa), Teams (T), Roles (R), and team Members (M) model the real world relationships that exist as a result of patient care teams. Considering a care team as an object, one can see that each Team has as attributes: the Patient (Pa) for whom the team is formed and a set of team Members (M) participating in the Team. As mentioned above, each team Member can be uniquely defined by three attributes - the Team (T) to which the Member belongs, the professional Role (R) undertaken by the Member, and the User (U) who is the Member. Thus, the Member entity can be defined as a relation between Teams, Roles, and Users as follows:

- **team Member**, $M \subseteq T \times R \times U$, is a Team, Role, User assignment relation where \times represents Cartesian product. That is, each $m \in M$ represents a unique (t, r, u) triple where $t \in T$, $r \in R$, and $u \in U$ (see Figure 5.4).

If a User plays more than one Role on a given Team, then the Team has two Members for that User, one for each Role. For example, if a consultant presents one of her own patients at an MDT meeting then, for a time, she has two Roles on that patient's team - 'consultant' and 'MDT member.' Thus, there are two Member entities for that consultant on that patient's Team, one for each of her Roles. In terms of database management this is equivalent to having Team, Role, and User as elements of a compound primary key for team Member entities; each User may be a Member of a given Team multiple times, as long as her Role is different. Similarly, each Team can have multiple Users undertaking the same Role.

Allowing multiple Users to play the same Role on a given Team is necessary for practical reasons. For example, in some GP surgeries, a Patient may visit any of the the GPs, rather than having each patient assigned to a single GP. This is also the case for shift work, such as nurses on a hospital ward. Each shift may consist of multiple nurses all undertaking the same professional Role with the patients on the ward. When a new shift begins, a new set of nurses, undertaking the same professional Role with each patient on the ward, take over. It should be said, however, that this research has not considered shift work in detail. It may be that the approach presented here is not ideal for shift work and, in fact, there is some indication that it is not. Including

shift workers in a patient's official care team exponentially increases the rapidity of team size and/or team member turnover. Shift workers must either always be members of the care team (as long as the patient is in hospital, for example) or the system must update the patient's team every few hours as shifts change. Neither of these cases is ideal. Adding and removing shift workers every time they come on and off duty has the potential to significantly reduce system speed and assumes that shift workers are not interested in alerts that come through while they are off duty. Leaving shift workers on the team all the time could contribute significantly to information overload since, at the beginning of each shift it would be necessary for the user to sift through all alerts that have come through since his last shift in order to determine which have been handled and which ones still require attention. In addition to these concerns, it would be necessary to send alerts and notifications to every member of the professional role in question (in order to ensure that the communication had been received in a timely fashion and by the right person), eliminating the benefits of personalised support and potentially contributing to information overload. How the model can be extended to best deal with shift work is a matter requiring further research (see Section 8.3).

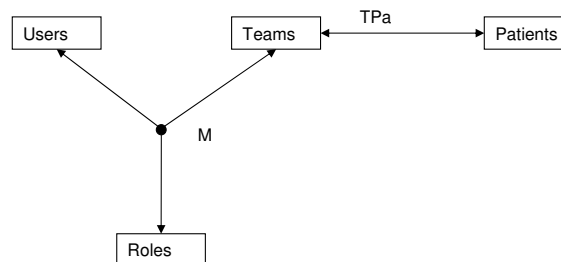


Figure 5.4: Team Portion of Conceptual Model.

For maximal flexibility, the proposal does not restrict team membership - any clinician may play any role on any care team. This means that, as the patient's care progresses, the team can evolve fluidly to meet the patient's needs. While this compound association adds greater flexibility to the system, it is also an area of potential concern. Because the relation is defined as a three dimensional mapping, the User \leftrightarrow Role relationship is not explicitly stated. This means that any User can be assigned to any Role, whether or not he is qualified or has a legal right to be given the level of access associated with that Role. There are two main concerns relating to the problem of Users being assigned to inappropriate Roles. First, an inappropriate Role will provide the User with the wrong standard view of the patient record, negating the benefits of

having tailored provision of information. Second, a User who is assigned to an incorrect view may inadvertently be given access to information that legally ought to be prohibited to that user. For example, in the UK, legal requirements limit the access that pharmacists have to a patient's record [90]. If a pharmacist were assigned to a patient Team as a GP, he would then have illegal access to patient data. The first concern is addressed in the implementation by allowing Users to switch between views while accessing a patient record (see Section 6.4.2). To address the second concern it is necessary to introduce a mechanism for restricting Role allocation and for identifying 'approved' Roles for each User. A straightforward approach would be to add a direct User-Role relation that defines a set of approved Roles for each User. However, for the purposes of maintaining a reasonable scope for this project, a decision was taken to leave the Member entity as a Team - Role - User relation as defined above. Introducing a User - Role relation would add another layer of complexity to the system and, more importantly, make the system more difficult and time-consuming to manage and maintain. Additionally, this proposal is intended for clinicians who should already have access to the shared patient record through other systems. The aim is to improve *organisation* and *presentation* of patient information, rather than either increase or decrease access. Interestingly, the issue of ensuring the correct *level* of access was raised by only two interviewees during evaluation and was not emphasised as a major concern. However, the issue of being denied access as a result of not being assigned to a care team was raised by all six interviewees and was seen as a major concern (see Table 7.5). Logging and auditing system access was recommended by NHS employees several times throughout the life of the project as a means to address issues relating to inappropriate or unauthorised system access. However, this remains an issue which should be considered in more detail in future work.

5.3.1.1 Team Inheritance

Although Chapter 3 defines a patient's care team to be "the set of *all* practitioners caring for the patient," it has been noted that, in practice, each care team may have many subgroups. These subgroups may be based on working location, active status, or reason for joining the team (diagnosis). Additionally, it is likely that these subgroups will have different support requirements, particularly subgroups defined by different diagnoses. To accommodate these sub-teams and better reflect real world working practices, team inheritance has been considered with regard to the conceptual model. In theory, each Patient has one care Team and each sub-team inherits attributes of the main Team. In practice, this is more easily accomplished by allowing each Patient to be associated with multiple Teams; each patient has one team for each of his diagnoses or, at least, those diagnoses involving multiple practitioners³. The patient's

³Given that the patient's GP is considered a member of every diagnosis team, this is equivalent to saying that each patient has one team for each of his diagnoses requiring care from someone other than his GP.

care team is then defined as the aggregation of all diagnosis-based sub-Teams. Incorporation of sub-teams into the model allows for greater flexibility and finer granularity of support for individual team members (see Section 5.3.3). The Team to Patient (TPa) assignment formalises the relationship between Patients and Teams. Each Team is associated with exactly one Patient but, to accommodate identification of sub-teams, each Patient may have multiple Teams.

- **TPa** $\subseteq T \times Pa$ is a Team to Patient assignment relation associating one Patient with each Team (see Figure 5.4).

Although the relationship between an individual clinician (U) and an individual Patient (Pa) is not explicitly specified in the model, the clinician's Membership on a team, together with the team - patient (TPa) relation, fully define the relationship between clinician and Patient, as in "Dr. X is patient Y's GP."

5.3.2 Tasks

Tasks are used to define the standard patient record view associated with each professional Role. The assumption underlying the use of Tasks is that, in general, two Users undertaking the same Role for different Patients will perform similar tasks/require similar types of patient information. Each Role is associated with one or more Tasks representing User activities, goals, or required information. This set of Tasks then defines the information, actions, and options that the system makes available to a user undertaking the given Role. If a User requires different Tasks, he may alter his view, as discussed in Section 5.4.1. Tasks may include, for example, viewing a list of current patient medications, recording a patient note, or sending a communication to another team member.

- **RTk** $\subseteq R \times Tk$ is a many-to-many Role to Task assignment relation. The RTk relation defines the standard patient record view provided to each professional Role (see Figure 5.5).

As with the clinician - patient relationship mentioned above, the RTk relation does not provide an explicit relationship between Tasks and Users. This relationship can be inferred, however, through the Member relation. First, we note that a team member - user mapping exists:

- **team member - user:** $M \rightarrow U$ is a function mapping each Team Member to an individual User. That is, a specific User u can be identified from a given Member entity, $m_i = (t_i, r_i, u_i) \in M$.

While this function is inherent in the definition of the Member entity, it is worth highlighting as it is this mapping which allows identification of team Members as system Users. Given the team member - user mapping, a team member - task mapping can be defined:

- **team member - task:** $M \rightarrow 2^{Tk}$ is a function f mapping each team member, m_i , to a set of Tasks⁴ determined by the member's Role within the current Team and the RTk assignment relation. Given $m_i = (t_i, r_i, u_i) \in M$, $f(m_i) = RTk(r_i)$.

Taken together, these two mappings provide the required relationship between Users and Tasks. Given a User, u_j , acting as part of a given Team t_i , the team member - user mapping provides the Role, r_k , that u_j fills for the currently selected Team. The team member - task mapping then provides a set of Tasks to be displayed for Role r_k :

- **user - task:** $U \times T \rightarrow 2^{Tk}$ is a relation, h , mapping a user, u_j , to a set of Tasks based on team membership. Given $u_j \in U$ and team $t_i \in T$, if there exists $m_l = (t_i, r_k, u_j) \in M$ then $h(u_j, t_i) = RTk(r_k)$ for Team t_i (see Figure 5.5).

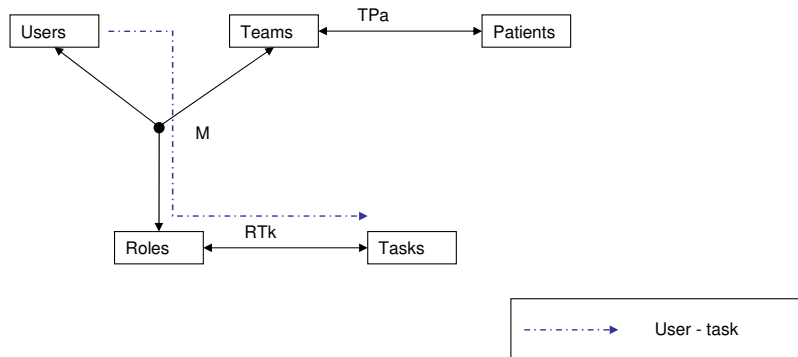


Figure 5.5: Conceptual Model Including Tasks.

It is worth noting that h is a relation but not a function. Because each User may undertake multiple roles concurrently on a given Team (see Section 5.3.1), it is possible that a (u_j, t_i) pair may be associated with more than one Role and, therefore, more than one set of Tasks.

Because the user's Role is team dependent, the user's view (Task set) is also team dependent and may vary between Teams or even over time on the same Team if the user's Role changes. Currently, the user's view is dependent entirely on his current Role, but including other contextual

⁴Where 2^{Tk} is the power set of Tk; the set of all subsets of Tk

factors to further tailor the view has been considered for future work (see Section 8.3). Additionally, if the user's view does not include an appropriate set of tasks, he can alter it through a drop-down menu, as described in Section 6.4.2. How these mappings are used to provide tailored information access is discussed in detail in Section 5.4.1 (also see [106]).

Although defining User views in this way easily allows for the implementation of access controls, restricting clinician access to patient records is a complex, controversial topic. During both the design and evaluation stages of this project, several clinicians expressed concerns about the possibility of not having access to patient information when they required it, as they felt that this would lead to lower quality patient care (see Section 7.3). As a result of these concerns, the inclusion of access restriction within the proposal has been left open - the conceptual model allows, but does not require it. If desired, access can be restricted in two ways - by allowing a Member to only access Tasks allocated to her current Role by the RTk relation, or by allowing a User to access records only for patients for which she is a care team Member. To address clinician concerns, however, the design for this project both allows Members to modify their current view and recommends inclusion of a patient search feature. How this issue has been handled within the conceptual model is discussed in more detail in Section 5.4.1. Providing flexible views within the prototype is discussed in Section 6.4.2.

5.3.3 Policies

Policies allow the model to support pro-active system actions and may include sending alerts to certain team members, updating a team member's view, or even adding a new member to a team. In order to carry out an action of this type, it is necessary to identify not only what action should be taken, but also to whom the action applies and under what circumstances it should be carried out. System policies incorporate these attributes as: (A) the Action to be taken, (E) the Event that fires the Policy, and (R) the subject affected by the Action. To allow for generic Policies, the subject is defined by professional Role and the individual User is inferred through a policy-user mapping (see Section 5.3.3.1). Events may include changes to patient status or patient care, such as a new diagnosis being made, lab results being returned, or the patient moving to a different stage of the care pathway. The Role component of the Policy can either be a single professional Role or all professional Roles, and can specify either the patient's entire care team or one of the patient's sub-teams. For example, a Role can specify 'physiotherapist(s) on this sub-team', 'all members of this sub-team', 'all physiotherapists on this patient's (entire) care team' or 'all members of the (entire) care team for this patient.' The notation R^+ is used to represent this extended set of professional Roles. Extending R for the purposes of Policy definition allows for finer granularity of control, improved efficiency of Policy declaration, and improves consistency; if a policy applies to all team members, it does

not need to be defined for each Role individually. Similarly, when a new Role is created, it inherits all Policies defined for “all roles.” If multiple Roles should be affected by a Policy, but not “all roles,” then the Policy must be defined for each Role, as appropriate. Although it may be desirable to have additional Role groups in R^+ , having too many options may detract from system usability and maintainability. Additionally, determining appropriate Role groupings requires a detailed analysis of Policies which was not possible within the scope of this project. Policies are defined formally as:

- **Policy**, $P \subseteq E \times R^+ \times A$, is an Event, Role, Action assignment relation. That is, each $p \in P$ represents a unique (e, r, a) triple where $e \in E$, $r \in R^+$, and $a \in A$ and where $R^+ = R \cup \{r_x \text{ all teams for this patient}\} \cup \{\text{all roles this team}\} \cup \{\text{all roles for all teams for this patient}\}$. Where $\{r_x \text{ all teams for this patient}\}$ means “this role (role r_x) on all teams for this patient” (see Figure 5.6)

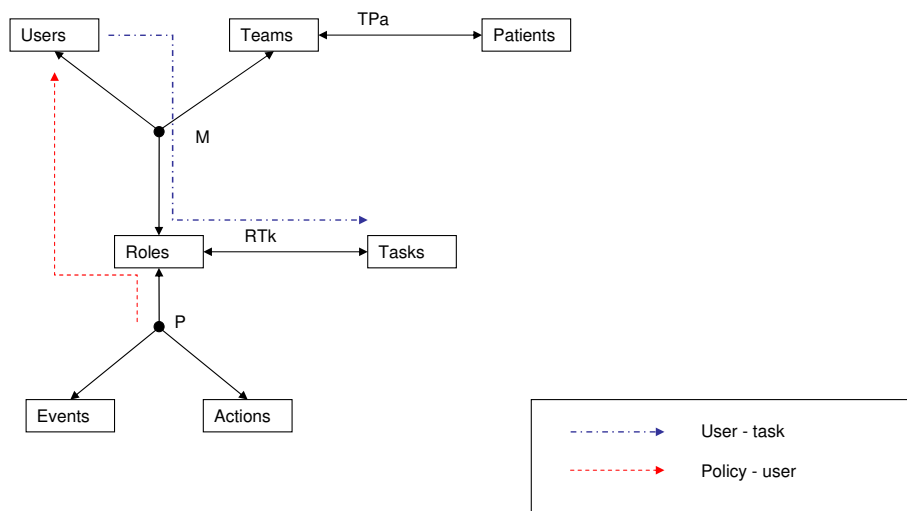


Figure 5.6: Complete Conceptual Model.

5.3.3.1 Policy-User Mapping

Policies are defined by Role, rather than by User. This keeps Policies generic enough to apply to any care team. However, in order to enact a Policy, it is necessary to be able to identify the User(s) who should receive the Policy’s Action. Because Role is an attribute of team Members as well as Policies, it can be used to provide the necessary link between generic Policies and

individual Users. Specifically, a policy-user mapping can be inferred from existing system entities to convert the subject of a Policy from a Role to one or more Users. In the policy-user mapping, information such as current Patient, Team, and team Member are identified when the policy is fired, and are used in conjunction with the Policy's Role to translate the subject from a general role to a specific individual or group of individuals during the policy execution process through the team Member entity (see Figures 5.6 and 5.7).

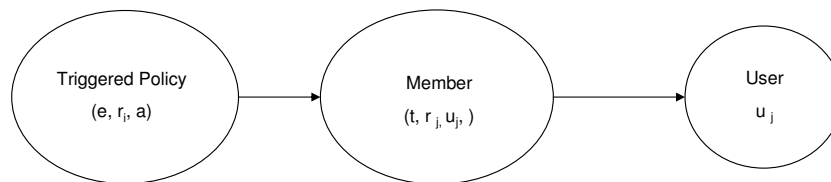


Figure 5.7: Policy - User Mapping.

To illustrate how Policies work in conjunction with team information, consider the Policy “When a new diagnosis is entered, the patient’s GP should receive a summary.” Here, ‘new diagnosis is entered’ is the Event, ‘send summary’ is the Action, and ‘GP’ is the Role. When a clinician is viewing a patient record she is identified as the current User and the patient associated with the record is identified as the current Patient. When the patient record is opened, the current Member is identified. The Member entity has as attributes the current Team and Role played by the Member, so this information is also obtained, by definition of Member. This means that, at any time, the current user, user’s role, patient, and patient team, are known. If a new diagnosis is entered, the Policy is fired. The system uses the known patient and team information to look up team members and their roles. From this list, the patient’s GP is identified by his team role. A summary can then be either automatically generated and sent to the GP, or the current user can be prompted to complete an electronic summary addressed to the GP. Because the current user’s professional role, the diagnosis, and the recipient are known, it is even possible to provide an electronic summary tailored to the GP’s information requirements if the policy is written with enough specificity.

As with Policies, a formal definition of the policy-user mapping must take into account the extra Roles defined in R^+ . This makes the formal definition of the policy-user mapping the most complex of all the model components. Again, we first note that a team member - user mapping exists which allows identification of an individual User from a Member entity. We also note that TPa is the Team to Patient relation defined in Section 5.3.1.1 and that R^+ is the

extended set of professional Roles defined for use with Policies (above). The policy - user mapping can then be defined as:

- **policy - user:** $P \times T \rightarrow 2^U$ is a function g mapping an activated Policy to a subset of Users to whom the Policy is applied for the current Team. Given current Team t_i and an activated Policy $p_j = (e_j, r_j, a_j)$, $g(p_j, t_i) = \{u\}_n$ where $u_k \in \{u\}_n$ iff $\exists m_k = (t_k, r_k, u_k) \in M \cdot \exists \cdot r_j = r_k \wedge t_i = t_k$ (see Figure 5.6).
- g is defined as follows for the special cases in R^+ :
 - If $r_j = \{r_x \text{ all teams for this patient}\}$ then $u_k \in \{u\}_n$ iff $\exists m_k = (t_k, r_k, u_k) \in M$ such that $\text{TPa}(t_i) = pa_i = \text{TPa}(t_k)$ and $r_k = r_x$.
 - If $r_j = \{\text{all roles of this care team}\}$ then $u_k \in \{u\}_n$ iff $\exists m_k = (t_k, r_k, u_k) \in M$ such that $t_i = t_k$.
 - If $r_j = \{\text{all roles for all teams for this patient}\}$ then $u_k \in \{u\}_n$ iff $\exists m_k = (t_k, r_k, u_k) \in M$ such that $\text{TPa}(t_i) = pa_i = \text{TPa}(t_k)$.

That is, in the general case, a User u_k is identified as a subject of activated Policy $p_j = (e_j, r_j, a_j)$ if and only if u_k is a Member of the current Team and is undertaking Role r_j on that Team. To illustrate the model more clearly, Section 5.4 discusses in detail how the conceptual model relates to each of the selected requirements.

5.4 Analysis

Although the basic concepts underlying the conceptual model are fairly straightforward, they have significant implications for individualising support for care team members. Tracking team data allows for provision of role or context based access, targeted and tailored notifications, and reduction of information overload. Additionally, by maintaining a link between team members and professional roles, the model allows for automation of processes that are currently time consuming and inefficient, including promoting awareness between distributed practitioners through automated updates, summaries, notifications, and alerts.

5.4.1 Information Access

The potential for information overload in a large, integrated patient record is significant. Finding relevant information in a universal view of the record could be time consuming and problematic. As has previously been discussed, practitioners working in different specialities will have

Summary of Formal Definition

Users, Patients, Teams, Roles, Tasks, Events, and Actions are represented by U, Pa, T, R, Tk, E, and A, respectively.

- **team Member**, $M \subseteq T \times R \times U$, is a Team, Role, User assignment relation. That is, each $m \in M$ represents a unique (t, r, u) triple where $t \in T$, $r \in R$, and $u \in U$. Team Members model the relationship between Users, professional Roles, and patient care Teams.
- **TPa** $\subseteq T \times Pa$ is a Team to Patient assignment relation. Although one Patient may have multiple Teams (see Section 5.3.1.1), each Team is associated with exactly one Patient.
- **RTk** $\subseteq R \times Tk$ is a many-to-many Role to Task assignment relation. The RTk relation defines the standard patient record view provided to each professional Role.
- **Policy**, $P \subseteq E \times R^+ \times A$, is an Event, Role, Action assignment relation. Each $p \in P$ represents a unique (e, r, a) triple where $e \in E$, $r \in R^+$, and $a \in A$ and where $R^+ = R \cup \{r_x \text{ all teams for this patient}\} \cup \{\text{all roles of this care team}\} \cup \{\text{all roles for all teams for this patient}\}$. Policies model automated system actions (see Section 5.3.3).
- **team member - user**: $M \rightarrow U$ is a function mapping each Team Member to an individual User. The **team member - user** function is key in determining to which User(s) an activated Policy applies.
- **team member - task**: $M \rightarrow 2^{Tk}$ is a function (f) mapping each team member (m_i) to a set of Tasks determined by the member's Role within the current Team and the RTk assignment relation. Given $m_i = (t_i, r_i, u_i) \in M$, $f(m_i) = RTk(r_i)$. The **team member - task** mapping provides the role-based patient record view discussed in Section 5.3.2.
- **user - task**: $U \times T \rightarrow 2^{Tk}$ is a relation, h , mapping a user, u_j , to a set of Tasks based on team membership. Given $u_j \in U$ and team $t_i \in T$, if there exists $m_l = (t_i, r_k, u_j) \in M$ then $h(u_j, t_i) = RTk(r_k)$ for Team t_i .
- **policy - user**: $P \times T \rightarrow 2^U$ is a function g mapping an activated Policy to a subset of Users to whom the Policy is applied for the current Team. Given current Team t_i and an activated Policy $p_j = (e_j, r_j, a_j)$, $g(p_j, t_i) = \{u\}_n$ where $u_k \in \{u\}_n$ iff $\exists m_k = (t_k, r_k, u_k) \in M \cdot \exists r_j = r_k \wedge t_i = t_k$. That is, when a Policy is activated for a particular Patient, the Policy is mapped to Users playing the correct Role on that patient's Team(s)^a (see Section 5.3.3).

^a g is defined as follows for the special cases in R^+ : If $r_j = \{r_x \text{ all teams for this patient}\}$ then $r_j = r_k$ iff $r_k = r_x$, and $t_i = t_k$ iff $TPa(t_k) = TPa(t_i)$. If $r_j = \{\text{all roles of this care team}\}$ then $r_j = r_k \forall r_k$ since, in execution, $r_j = \{\text{all roles of this care team}\}$ is equivalent to $\{r \in R\}$. Similarly, if $r_j = \{\text{all roles for all teams for this patient}\}$ then $r_j = r_k \forall r_k$ and $t_i = t_k$ iff $TPa(t_k) = pa_i$.

different information requirements [81, 90]. Additionally, practitioners will require different information depending on their current role within the care team as well as the current phase of treatment. The same clinician may play different roles for different patients, and a clinician's role may change during the course of treatment. For example, some clinicians will only be involved with some patients as members of an MDT while other clinicians may first encounter the case during an MDT meeting, but work with the patient more closely at a later stage of treatment. A single view of the patient record shared by all users will not address these issues and could lead to significant problems with information overload. The conceptual model presented here addresses this issue by dynamically tracking team members' professional roles and associating a particular view of the patient record with each professional role. As the team member's role changes, the standard view of the patient record is altered to meet the information requirements of the member's new role. To address clinician concerns regarding the possibility of not having the right access at the right time, there is scope for allowing clinicians to select an alternative view if the standard view is not satisfactory. In the proof of concept prototype, this was incorporated through a drop-down menu which allows clinicians to switch between the standard view for different roles (see Section 6.4.2). Additionally, it is proposed that the users should have the option of searching for a patient in case they require unexpected access to a particular patient's record (see Section 7.3.5).

5.4.2 Information Exchange

Supporting efficient information exchange covers multiple areas including both improving practitioner awareness and supporting communication. First, we note that having access to data is not the same as viewing data or even being aware of its existence. By presenting relevant information more prominently, tailored access can improve awareness but does not, in itself, ensure that a particular team member has viewed a particular piece of information. In fact, tailored access has *no* impact on awareness if the team member does not open the patient record and read it. Importantly, it does not provide any improvements to awareness for unexpected problems, which is where awareness is most critical. To promote awareness, the VOICE model allows for automated generation of tailored notifications to be sent to one or more team members when changes occur within the system. Notifications can be triggered by any machine understandable state change, such as alterations or additions to a patient record, alterations or additions to the team, or (as part of future work) changes to the patient's care pathway. Policies indicate which professional role(s) should receive a notification, under what circumstances the notification should be sent, and what type of notification should be provided. As with provision of tailored access (Section 5.4.1) team membership information provides an association between professional roles and individual practitioners so that notifications can be sent only to

those individuals who require them. Because both policy specifications and teams are recorded, notifications can be generated on the fly as new information is entered into the patient record or the team is updated. Where appropriate, creation and delivery of notifications can be completely automated without the need for human intervention. In cases where human input into the notification is desirable, the system can prompt the user entering data to take appropriate action, such as verifying or completing summary details, before the notification is sent.

In addition to automated notification, the model also supports user initiated communication. At the most basic level, having a record of all team members allows users to efficiently look up details of other team members which supports communication external to the system (such as phone calls). Additionally, the same mechanism that allows for automated internal notifications supports manual ones - the sender can specify professional role(s) as recipients and the system then uses stored team data to identify the individual(s) to whom the notification should be sent.

It should be noted that some manual and partially automated communication functionality, such as prompting for, partially completing, and sending referrals and summary letters electronically, are expected to be available as part of other proposals, such as the Welsh Clinical Portal. Unfortunately, as these proposals are still under development at the time of writing, it is not possible to provide a complete comparison of alternative proposals against the functionality presented here. However, other proposals are not currently expected to provide the same level of fully-automated communication functionality, or team-based communications. It is also unclear how structured electronic communications will be in other proposals; whether they will be restricted to specific usage (i.e. referral form) or whether support will be provided for completely user generated, free-text communication, as is possible through this proposal.

5.4.3 Pro-active and Individualised Support

Automated, dynamic, tailored access, together with automated and partially automated communications and notifications constitute pro-active support within the system. That is, the system moves from being a “passive repository” [107] of patient information to actively supporting the work of care team members by automating support functionality. Similarly, dynamic, tailored access, notifications, and alerts provide individualised support for each team member based on their work with each patient. That is, support is based on the current patient, diagnosis, the practitioner’s current role with that patient, and how active the team member currently is within that care team.

5.4.4 Reduction of Workload

The model allows for potential reduction of workload in two areas - improved efficiency and automation. Making role-relevant information more prominent within the record should reduce the time required by clinicians to find necessary information for treating the patient. Automatically updating the view as treatment progresses ensures that this efficiency is maintained throughout the treatment process. More significantly, automated and partially automated communications should provide significant reductions to workload compared to current manual generation of communications.

Interestingly, several of the clinicians interviewed felt that, while some aspects of the system may provide some decrease in workload, overall, the increased awareness of patient issues resulting from the proposal would *increase* workload since, in general, notifications and alerts would require action on the part of the recipient. At the very least, an alert or notification would require the recipient to make a decision regarding whether or not to take action. Those who expressed this view, however, universally agreed that if the proposal and functionality were implemented well the resulting improvements to patient care would compensate fully for any increases in workload. Evaluation of the proposal with regard to this requirement is discussed in detail in Section 7.3.6.

5.5 Support Versus Access Control

Section 5.2 introduced the concept of access control models and identified the VOICE model as an extension of RBAC in that they both create an association between Users, Roles, and the user's system view. However, the main purpose of access control models, including RBAC, is to *restrict* access to objects and data within the system, not to support teamwork. As a result, RBAC does not contain the components necessary to reflect associations between users undertaking different Roles, which means that RBAC is not useful for modelling teams and, therefore, not appropriate for supporting teamwork. Although proposals applying RBAC or extensions of RBAC to the healthcare domain do exist, each of these proposals, again, is aimed at restricting access rather than supporting collaboration. As a result, these models include features that are not necessary for meeting the requirements defined here, and include assumptions and restrictions which limit their applicability to collaboration support, such as requiring team structure to be pre-defined and static. This section introduces some of these models and discusses them with regard to the current proposal and the identified requirements. Because the aim of this work is not to provide access restrictions, a comprehensive discussion of the many access control models available would be inappropriate. Instead, discussion will focus on those access control

models which most closely resemble the conceptual model proposed here, specifically those models which incorporate a team component.

5.5.1 Other Access Control Models

This section introduces four access control models incorporating a team component, each of which constitutes an extension of RBAC. TeaM-based Access Control (TMAC) [103], Context-based Team Access Control (C-TMAC) [104], and Team-Based Access Control 2004 (TMAC04) [105] (different authors) are part of a family of models incorporating Teams as new entities in RBAC. In contrast, Team-and-Role-Based Organizational Context and Access Control (TR-BAC) [108] uses the concept of Team to extend the Role entity already present in RBAC.

5.5.1.1 The TMAC Family of Access Control Models

TMAC

As with this proposal, TMAC uses teams to provide a link between individual users and system objects by allocating certain object instances as ‘team resources.’ TMAC enforces access control restrictions by allowing only members of the team to access those resources (see Figure 5.8(b)). For example, in a healthcare application of TMAC, only users on the ‘team’ currently working with a patient would be allowed to see that patient’s record. In this case, ‘teams’ are pre-defined, static groups of individuals who routinely work together, while the patient record (and its associated components) are the system objects that the team is allowed to access. What subset of those objects each member is allowed to access is determined by the member’s team role. Associating permissions with team as well as role allows for finer-grained access definitions. Rather than every user in role R being able to see all objects of type O (as in RBAC), users with role R can only see objects of type O that are associated with team(s) to which they belong [103, 104].

C-TMAC

C-TMAC extends TMAC by incorporating an extra dimension to access permissions - context. ‘Context’ includes information about current tasks (and the objects required to complete those tasks) as well as situational information, such as location and time of access [104]. Thus, a team member’s access can change depending on what task is being undertaken, where the system is being accessed from, and how long it has been since the patient was last seen. C-TMAC uses the concept of Sessions to achieve a runtime binding between Users, Roles, and Teams. At

login C-TMAC requires the user to select in advance the roles and teams in which he wishes to participate for that session and his permissions for the session are defined based on these selections [104] (see Figure 5.8(d)).

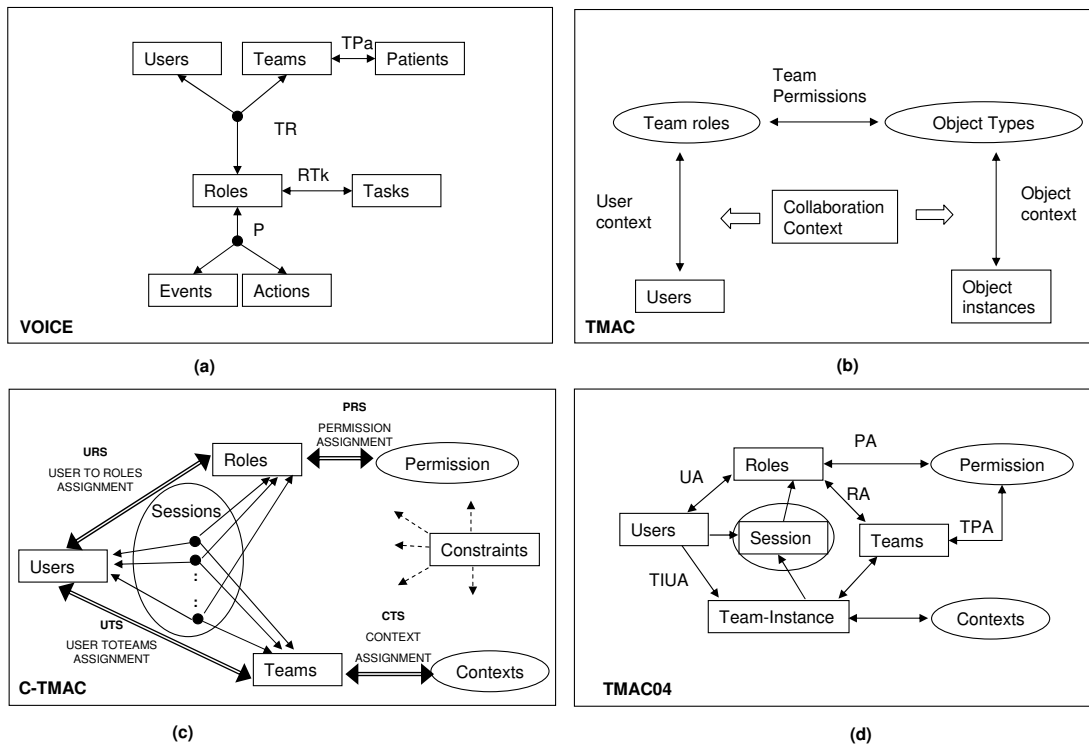


Figure 5.8: Access Control Models ((b) is based on [103],(c) appears in [104],(d) appears in [105]).

TMAC04

TMAC04 is an extension of C-TMAC. TMAC04 makes explicit the distinction between team *instances* and team *types*. In TMAC04, each ‘Team’ is a pre-defined set of Roles whereas a Team Instance is a set of Users working together. For example, in TMAC04 an Oncology Team may be defined as having certain Roles (i.e. consultant, radiologist, therapist, and chemotherapy nurse), whereas the set of people taking on those roles with patient X is an Instance of that team. Thus, a Team in TMAC04 represents a team type or structure, and a Team Instance in TMAC04 is actually a sub-team of the patient’s care team (as defined in this work). To avoid confusion, we refer to the TMAC04 Team as a team type. TMAC04 also introduces the concept of team

permissions which are associated with a particular team type. Team permissions are defined as part of the team type meta-data and can modify the permissions of team members. For example, a user taking role r on team t of type T and s of type S may have different access permissions within t and s as a result of differing team permissions over T and S . However, in order to accomplish this, TMAC04 retains the concept that team types are pre-defined and have static allowable roles and permissions. As with C-TMAC, TMAC04 also uses Sessions to achieve a runtime binding between Users, Roles, Team Types, and Team Instances [105](see Figure 5.8 (c)).

At first glance, TMAC and its extensions appear quite similar to the model proposed here. Each of the models includes some construct representing Users, Teams, Team Roles (here Members) and the user's view of or access to objects within the system. However, the underlying purpose of access control models and the VOICE model are quite different. Each of the access control approaches aims to *limit* users' access to information whereas the VOICE model proposed here aims to *increase* users' awareness of key patient information and changes to the patient's status. As a result, there are several substantial differences between this work and the TMAC family of access control models. The TMAC models are disease-centric whereas our model is patient-centric. The TMAC models require pre-defined team structures whereas our model allows for flexible, dynamic teams. Our model expects and is adapted for the evolution inherent in patient care, including evolution of teams, roles, and treatment, whereas the TMAC models assume stability. Finally, our model incorporates policies which allow the system to react pro-actively to changes to patients' status.

First we note that the TMAC family of models require that the structure, or allowable team roles of a team be defined in advance. Teams are defined as types, and a group of individuals working together is actually an instance of some type of team. That is, a team is defined as a set of roles. In an individual team instance, users are assigned to those roles. Teams consisting of different sets of team roles are different team types. This is important because the permissions of the team - what objects the team can access - is defined by the set of team roles. Therefore, teams of the same type will inherit the same set of permissions [103]. This approach is very limiting. Pre-defining teams as types implies that patient treatment can be defined in advance. It does not allow for cross-diagnosis team work or for unusual cases where an extra speciality may be required. In fact, the TMAC family of models take a very disease-centric view of teamwork in healthcare; each disease area has its own set of specialities which are incorporated into the team types for that area. The patient's other needs are not considered. Furthermore, TMAC allows only one team instance to have access to a patient's record at any given time [103], so when a patient is being treated by his cancer team, the surgical team and any other carers outside the cancer team cannot access his record. This view of healthcare is antithetical to the improved awareness and communication requirements which this research attempts to address.

In contrast, the model defined here is far more flexible. Because permissions are not defined or influenced by a team's roles, it is not necessary to define in advance what roles are allowed to participate on each team. This provides complete flexibility within teams - membership is not restricted in any way. Any user, playing any role, can join or leave the team at any time, either manually or as the result of a system policy. Because team structure is not limited in any way, our teams can accommodate patients with any set of diagnoses and can evolve dynamically as the patient's needs require. Our model takes a patient-centric approach, structuring teams to meet the patient's needs, rather than assuming that the patient needs what the pre-defined team has to offer. By incorporating *all* of the patient's healthcare providers, our approach allows for awareness, communication, and teamwork support not available through the TMAC family of models.

Second, because permissions in access control models represent organisational rules, they are expected to remain relatively static: the roles that a user is qualified to take-on may increase over time, but not rapidly and not for large numbers of users over a short period. Similarly, the responsibilities associated with each role (and therefore the permissions necessary to perform that role) may evolve over time, but it is unlikely that there will be regular, large-scale changes to multiple roles. However, this is not a valid assumption for healthcare in general or care teams (as defined here) in particular. Care teams and working practices in healthcare are expected to be highly dynamic (see Section 3.2.1); following a new diagnosis or completion of treatment a patient's care team may undergo significant change. As new technology and knowledge becomes available, the way that clinicians use technology will change. Similarly, as new knowledge is acquired about the efficacy of treatments, the way that patients are treated will change. As a result, policies and working practices are expected to evolve significantly and continually over time. The lack of restrictions within the model proposed here is specifically designed to make the proposal flexible enough to handle ongoing evolution at the individual care team and organisational levels, as well as with regard to future system usage. The inflexibility of TMAC and its extensions limits the ability of these models to evolve and adapt to changing needs.

Finally, the model proposed here incorporates Policy components which allow the system to *actively* support practitioner awareness and communication. Because awareness and communication are not part of access control, they are not considered in any of the TMAC access control models. As a result, although it is not unexpected, our model provides a different range of functionality and support than that provided by any of the TMAC access control models.

5.5.1.2 TRBAC

The structure and approach of TRBAC [108] is very different from both the TMAC family of models and the model presented here. While TRBAC uses the concept of teams to extend

RBAC, it uses very different mechanisms from TMAC, C-TMAC, and TMAC04. RBAC is founded on a subject-action-object permission model: a user can perform an action on an object if that user has permissions that allow the specified action to be performed on the specified object type. In RBAC, the 'subject' is defined over a set of roles, rather than users. TRBAC extends this by applying the same principle to the action and object components, providing 'categories' of objects and actions, as well as subjects. TRBAC also extends the categories of subjects, including *organisational roles* (RBAC roles), *teams*, and *personal roles*. TRBAC defines a Team as "a collection of participants (users) working in the same work unit or for the same project" [108], but views teams as a type of role within an RBAC framework along with Organisational roles and Personal roles. Personal roles are used to handle delegation. While a personal role is assigned to a single user (the person responsible for that role), she may delegate tasks (and associated permissions) to other users by naming them as members of her personal role. *Organisational roles* are Roles as defined above. Together, *Personal roles*, *Teams*, and *Organisational roles* provide multiple levels of abstraction of the role concept; *Personal roles* provide permission assignment on an individual user basis, *Organisational roles* provide permission assignment for groups of individuals sharing the same responsibilities within the organisation, and *Teams* combine the two, providing role-based permissions which are restricted to the user's domain (work group, project, etc).

In addition to incorporating different levels of abstraction within the subject component, TRBAC extends the subject-action-object model used in RBAC by incorporating Team (T) and object State (E) as attributes. Instead of defining access permissions as (Role, Action, Object) triples, TRBAC defines permissions as five dimensional (Role, Action, object Instance, Team, State) or (Role, Action, Object (type), Team, State) tuples. In this model, user u can perform action f on object instance i of type o if the user is assigned to a role which allows function f to be performed on objects of type o (as in RBAC), *and* u is playing an appropriate role on a team that has access to i , *and* i is in the correct state. Alternatively, permissions can be assigned on an object by object basis (rather than an object type basis). As a result, TRBAC provides a very high level of granularity options for assigning permissions. On the subject side, permissions may be assigned by user, role, or team, and on the object side, permissions may be assigned by object instance or object type. Including a state criteria allows for a temporal component as well; Objects may only be accessed at certain stages of the project - when the object has the correct state [108].

TRBAC was designed specifically for VOs in complex organisational settings. Specifically, TRBAC is aimed towards the common business VO model, where there is tension between the need to allow access to information for purposes of collaboration, and the desire to keep business assets private and secret. Each project and collaboration is unique and may require new procedures or processes which the team must create from scratch. Project objects are

often created collaboratively, with different team members contributing to and updating project objects. To add to the complexity of supporting access control in business VOs, these types of VO are often highly dynamic and ad-hoc with rapidly changing organisational aims and tasks and, therefore, access requirements.

In order to accommodate the complexity of inter-organisational VOs and the required granularity of access control, TRBAC adds substantial complexity to the RBAC model. Much of this complexity is not needed in the healthcare domain. For example, access to a system object in a care team (such as a piece of patient data or a summary letter) is not dependent on the ‘state’ of the object. If one team member requests a blood test, then other (qualified) team members may wish to have access to it whether it has just been ordered, has been completed, or has been signed off (viewed and acknowledged). In inter-organisational commercial VOs, project objects are created collaboratively with different members contributing to a single object (e.g. a product design document) over time. Although many people may contribute information to an EPR, a patient record is additive rather than collaborative. Decisions may be made collaboratively, but objects in the patient record are not collaboratively created and modified as in a commercial project. Objects and information entered into a patient record are final. This is necessary for patient safety - an incomplete or draft version of a treatment plan might be seen and acted on by other team members leading to incorrect treatment. Even when they are updated or an error is corrected, the original entry is maintained for medico-legal reasons. As a result, TRBAC incorporates complexity to support actions not required by care teams.

Although TRBAC is structurally very different from the model presented here, in some ways it is more closely related to our model than the TMAC family. TRBAC offers very flexible controls for highly dynamic, ad-hoc teams. Although the claim is not fully explained, TRBAC also purports to support awareness and notification features [108]. For our purposes, however, TRBAC fails to meet the requirements on two counts. First, TRBAC adds more complexity than is required. Extra complexity implies a greater level of overhead in terms of system maintenance. Second, as with all access control models, the purpose of TRBAC is primarily to *control* access to system objects. There is no indication of how or how effectively TRBAC will support awareness, provide pro-active support, or impact teamwork. Therefore, it introduces unnecessary complexity without providing any concrete evidence of benefit with regard to the requirements under consideration here.

5.5.2 Access Control Models Versus Collaboration Support

The TMAC family and TRBAC offer two very different approaches to extending RBAC to include a team component, and each of these approaches has similarities and differences to the

approach proposed here⁵. TMAC and its related models have an architecture similar to VOICE, but define system entities, such as teams, in a very different way. TMAC is disease, rather than patient-centric, and is not designed with flexibility in mind. In contrast, TRBAC is structurally very different from the VOICE model, but is more closely related conceptually. TRBAC is patient-centric and designed to be highly flexible (see Table 5.3). Despite these similarities, however, none of the access control models are appropriate for meeting the requirements considered here. First, each of these models, by definition, aims to control or restrict access to system objects, which is not the aim of this research. Second, each of the models includes complexity which is necessary to support access restrictions, but which is not necessary to support team work. Finally, none of the models presented here convincingly provide the level of pro-active support and ease of information access necessary to meet the defined requirements.

So, although certain aspects of the VOICE conceptual model appear similar to approaches employed in access control approaches, the objectives of our model are very different and, as a result, our model provides significantly different outcomes than the various access control models. Here, we use policies and teams to *increase* team members' awareness of organisational information and to support communication and coordination within collaborative teams. Because we are focused on improving awareness, the model presented here is simpler and more flexible and does not require the extra variables necessary to support access control. Additionally, the model presented here is able to support a range of functionality that goes beyond information access.

Model	Focus	Team Structure	Evolvability	Policies	Access Aims
VOICE	patient-centric	Flexible	High	yes	Organise
TMAC family	disease-centric	Pre-defined	Low	No	Restrict
TRBAC	patient-centric	Flexible	Very High	No	Control

Table 5.3: VOICE versus TMAC and TRBAC.

5.6 Conclusion

The move to a patient-centric approach in healthcare has led to a shift in working practices and, consequently, a change in the requirements for healthcare information systems. Traditional models of patient-centric work, however, emphasise only one aspect of this new way of working,

⁵It is worth noting that the authors of both TMAC and C-TMAC present their work as general models applicable across domains, but in both cases healthcare teams are used as an explicit example of an application for which their model would be suitable. TMAC04 and TRBAC, however, are presented as business oriented models, and their authors make no comment on suitability of these models to healthcare teams.

focusing either on clinicians as team members or on the interaction between clinicians and the patient record system. Here, a conceptual model is proposed that incorporates both aspects of patient-centric care teams- the care team as a distributed team that must work together and the information systems that support this distributed work. By considering both the human and technical aspects of the problem, a conceptual model has been developed that attempts to address the unique needs of patient-centric care teams. Specifically, this model supports efficient information access and exchange and pro-active, individualised access and support for care team members within the context of an integrated EPR.

At the highest level, the conceptual model proposed here incorporates two main ideas. First, the model identifies care teams as key objects within the system, and stores and tracks Team data as a means to provide appropriate support for care team members. Identifying and tracking care teams involves creating Teams as system objects and associating Users with patient care Teams. As in RBAC, Users are also associated with Roles. However, in contrast to RBAC, the association between Users, Teams, and Roles here is a compound one - each User is assigned one or more Roles *per* care Team and Users are associated with Roles *only* through care Teams, rather than having a direct association between Users and Roles which restricts the Roles to which a User can be assigned. Second, to provide pro-active support for team members, the model incorporates system actions in the form of Policies. Policies define automatic system actions by specifying *when* action should be taken, *what* action to take, and to *whom* (in terms of Role), the action should be applied. Combining Policies with care Teams allows for system actions to be carried out at the individual User level. By incorporating the concepts of providing support to users through the context of care teams and providing automated system actions through Policies, the model provides individualised patient record views to team members, supports information exchange, and provides individualised, automated communications pro-actively.

Because the model proposed here constitutes an extension of the RBAC access control model, it has similarities to other access control models, in particular the TMAC model and its extensions and the TRBAC model. However, the main aim of our model is not that of access control or restriction. As a result, the functionality provided by this model is very different from that provided by the access control models. Additionally, the access control models add complexity which is not needed to meet the requirements driving this research.

Implementation

Overview

Chapter 3 identifies several high and low level requirements for future healthcare information systems to support practitioners working in collaborative care teams and Chapter 5 presents a conceptual model aimed at meeting some of those requirements. As part of the evolutionary development approach adopted for this research and in order to consider the remaining requirements, a proof of concept prototype was also developed. This chapter discusses the prototype and its contribution to the research. Chapter 7 then covers the project evaluation, including the role of the prototype in the evaluation.

6.1 Introduction

As part of the evolutionary software development methodology selected for this project, a proof of concept prototype was developed. This prototype implements the conceptual model, demonstrating feasibility of the model and illustrating some of the functionality that can be achieved. As with the conceptual model, the prototype focuses on meeting the five selected requirements:

- The system should support efficient information access (across multiple sites)
- The system should provide efficient information exchange
- The system should provide pro-active support
- The system should provide individualised access and support for team members
- The system should reduce clinician workload

The prototype aims to implement the conceptual model as accurately as possible in order to highlight both the strengths and weaknesses of the model. Implementation also allows for consideration of technical requirements which are difficult to address within a purely conceptual context. Specifically, the prototype considers the following additional requirements:

- The system should be independent from the architecture of the underlying EPR
- Where possible and appropriate, support provided to clinicians should be automated and automatically updated
- The system should be able to adapt to changes in organisational policy and working practices without requiring specialist technical skill.

In addition to covering how the prototype relates to the stated requirements, this chapter discusses in detail the technical specifications of the prototype, its implementation, components, relationship to the conceptual model, and the functionality it provides.

6.2 Technical Specification

The prototype is implemented in the Java™ programming language. Java was chosen as the programming language because of the author's familiarity with the language and its platform independence. Because the prototype is proof of concept only and the author is not an experienced developer, efficiency of the chosen language was not considered. Similarly, because

the aim of the prototype is to prove feasibility and test ideas, it is not necessary for technical choices in the prototype, such as programming language, to be compatible with current or future information systems adopted within the NHS.

Necessary databases are implemented in Microsoft SQL Server 2008TM and OracleTM. A Microsoft SQL Server database stores data required by the conceptual model and additional, “sample” EPRs use both Microsoft SQL Server and Oracle to simulate integrated EPR components. One of the sample EPRs used in the prototype is an anonymised version of the CANISC database (discussed in Section 2.3.2.3). This database is in Microsoft SQL Server format, necessitating the use of this program for at least some of the database components of the prototype. However, MS SQL Server and Oracle are industry standards and relational databases are in common use worldwide [109], therefore these choices were deemed to adequately reflect current practice. To provide variation to system components, Oracle is used for some of the sample EPR components. However, in order to maintain architecture independence, a clear separation is maintained between the integrated EPR and the conceptual model components of the prototype.

Other than the CANISC dataset, the databases used in the sample integrated EPR are not representative of the complexity expected in a real patient record. However, they are fit for purpose. Because integrated, shared record projects are currently being undertaken by the NHS (see Section 2.3.2), the integrated EPR component of the prototype is out of scope for this project. It is necessary only to show that the conceptual model components of the project can make use of an integrated EPR, ideally, *any* integrated EPR. The EPR databases used in this project, while small, are sufficient to show that the conceptual model components of the prototype can make use of an underlying EPR and to demonstrate proof of concept.

6.3 Design

The VOICE model defined in chapter 5 proposes storing team information and using that information to provide tailored, pro-active support for team members, all within the context of an integrated EPR. In terms of implementation, this requires at least two components in addition to the integrated EPR: a database to store team and policy information, and a software component which is responsible for communicating with the database and integrated EPR, providing a user interface, and handling policy interpretation and execution. The prototype implements each of these components. However, structure and implementation of the integrated EPR is not considered in detail in either the design or evaluation of this project as details of the EPR are not relevant to the VOICE model and its aims (see Section 6.3.2).

Although the conceptual model only considers Users who are healthcare practitioners, it can

be assumed that healthcare practitioners will not be responsible for maintenance of the system. The implementation includes facilities for System administrators who do not act on any care teams. System administrators are assigned to a ‘no patient’ team with an ‘Administrator’ Role¹. As currently implemented, administrator tasks include creating and updating teams, user and patient details, roles, tasks, and policies, although a full implementation would include auditing and other functionality.

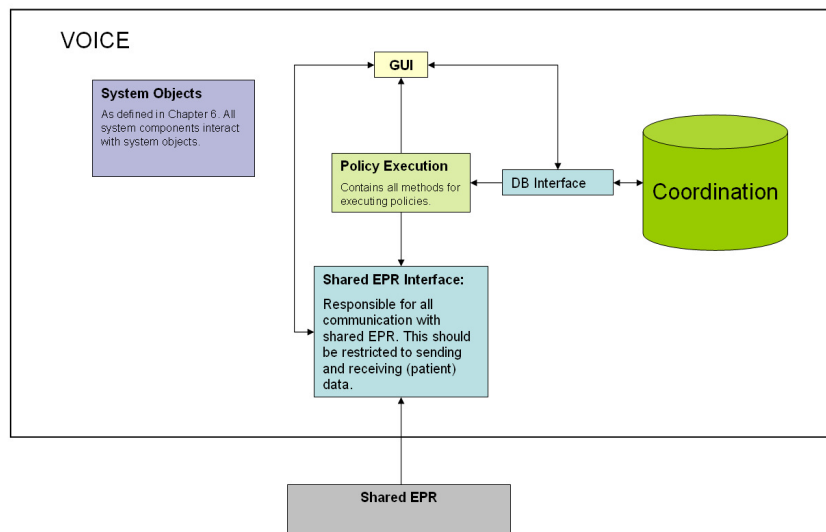


Figure 6.1: High Level VOICE Architecture.

6.3.1 Coordination Database

The conceptual model requires that the system should store and track team information including relationships between users, professional roles, teams, and patients, as well as Policies in the form of Event, Role, and Action. In the implementation, a **Coordination** database has been created to store data for each of these entities and the relationships between them. As discussed in Section 3.2.1, care team composition is expected to be highly dynamic. Therefore, team information will require regular updates. Use of a database to store team and associated data facilitates dynamic tracking of team information, and has the added benefit that manually altering or updating team data can be handled directly through the user interface and requires no technical expertise. Similarly, although the conceptual model does not specify that policies should be defined within a database, storing policies as relations allows significant flexibility in terms of

¹Because each team must be associated with exactly one patient, a Patient object named “no patient” is used for administrative roles.

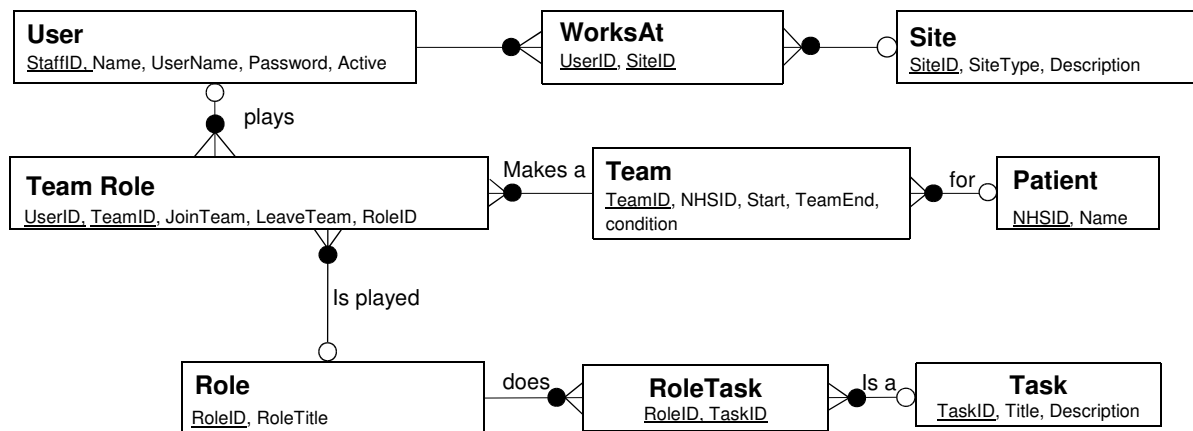


Figure 6.2: Team Components of Coordination Database.

modifying and updating policy specification. The **Coordination** database, therefore, performs these two functions: providing explicit linkages between users, patients, and care teams, and storing policy details.

6.3.1.1 Team Tracking

The team tracking component of the **Coordination** database consists of tables to store basic *User*, *Patient*, and *Team* data. To ensure that patient data is stored correctly in the underlying integrated EPR, a *Site* table is also included, linking users to care centres (see Figure 6.2). If a team member works with a patient in two different locations, the *site* attribute ensures that notes regarding a patient interaction are associated with the correct location within the EPR. Finally, *Role* and *Task* tables provide tailored information access by associating each professional *Role* with one or more *Tasks* performed by that *Role* (as described in Section 5.4.1) [106]. Where necessary, Bachman tables have been introduced to resolve many to many relationships.

As defined in the conceptual model, Teams are created for Patients and consist of Users (healthcare professionals) who have professional Roles. Team membership information, including professional Role, is recorded in the Member table which resolves the multiple many to many relationships between Users, Teams, and professional Roles. Including Role as part of the primary key in the Team Role table allows a single practitioner to play multiple Roles on a single team. This is beneficial in two ways. First, as discussed in Section 5.4.1, a practitioner's role on a team may change over time. Second, it allows for greater flexibility with regard to Role definition, which impacts both the User's standard view of the patient record and the support

provided, such as alerts and notifications. Each Role is defined by the set of Tasks it encompasses. To facilitate maintenance, free text (human readable) title/description attributes have been included in both the Role and Task tables.

It is important to note that the **Coordination** database does *not* store patient health information, nor does it store significant employment details. The **Coordination** database only contains the minimal data required to provide the necessary associations. Patient information in particular is limited to an identifier and, for increased efficiency, the patient's name.

For medico-legal reasons rows should never be deleted from the team components of the database. Instead, each new row is date-stamped at creation and again when it becomes inactive. This allows for a historical audit of both team membership and each team member's view of the record. As the result of an oversight, date-stamp attributes were not included in Role and Task related tables. However, for medico-legal reasons, it is desirable to include date-stamps in all aspects of the system. Future work includes incorporating date-stamp attributes into all tables of the **Coordination** database.

Because the **Coordination** database is relational, team inheritance has been implemented by creating different teams for each patient diagnosis, where a particular diagnosis merits a team. This allows teams to be viewed at a varying levels of granularity. Each diagnosis team is a subgroup of a care team, whereas a patient's care team is the aggregate of all currently active diagnosis teams for that patient; sub-teams can be identified individually, or as part of the larger care team.

6.3.1.2 Policies

The VOICE conceptual model uses *policies* to increase the range of pro-active support functionality. *Policies* tell the system what actions to perform and when. In particular, *policies* can be used to provide alerts and notifications and to allow the system to automatically update team related information in the **Coordination** database. Each policy consists of three components: an *Event* that fires the policy, an *Action* that the policy executes, and a professional *Role* to which the *Action* is applied.

Database triggers serve a very similar function within a database to that played by policies in the VOICE model. That is, "a trigger defines an action that the database should take when some event occurs in the application" [109]. As with Policies, each trigger is comprised of three components:

- "an *event*, which is the update statement that initiates the activity;

- a *condition*, which is the predicate that determines whether the trigger will fire;
- an *action*, which is what happens if the trigger does fire” [110, pg. 125]

Each trigger is associated with a particular table and may be invoked when an insert, update, or delete statement is executed on that table if the trigger’s condition is met. Triggers can be used to enforce constraints that cannot be enforced elsewhere in the DataBase Management System (DBMS), to automate critical actions, and to update or insert values and call other procedures. Triggers can also support auditing, automatic generation of derived values, enforcement of constraints, and creation of backup data [111, pg. 448].

Triggers are powerful tools within DBMSs. However, there are several potential drawbacks with regard to using triggers for this work. First, triggers operate entirely within the database and can only be invoked when a statement is executed. This means that triggers cannot be used to address concerns such as a user logging out of the system without saving changes. Because triggers are part of the database itself, they have limited ability to interact with other system components, such as system software or other databases used by the system. Given that this proposal incorporates at least two distinct databases, this becomes a multi-fold problem. First, triggers can only respond to changes within the database for which they are defined. This means that, in a federated integrated EPR, triggers could not take actions across multiple databases within the federation. It also means that triggers would have to be defined in *each* constituent database of the federation. If the integrated EPR utilises a data silo approach this is less of a problem, but triggers still cannot bridge the gap between the **Coordination** database and the integrated EPR’s silo. This means that triggers defined in the EPR cannot make use of the team information stored in the **Coordination** database and triggers defined in the **Coordination** database cannot impact the EPR. Additionally, triggers cannot make use of non-EPR databases providing technical medical information such as medication interactions or treatment advice. Finally, altering triggers requires technical database management skills. This severely limits the flexibility and evolvability of triggers and violates the stated requirement that system maintenance should require as little specialised technical skill as possible. Given the highly evolutionary nature of medicine and healthcare policies and requirements, this is a significant concern.

As a result of these concerns, it was decided that database triggers, in themselves, were not sufficient for enacting system policies as defined in the conceptual model. Instead, the **Coordination** database was extended to include the three attributes of a Policy (Event, Action, and Role) (see Figure 6.3). A single Bachman table (Policy) resolves the many to many relationships between the policy attribute tables, with the Role table providing the link into the team portion of the database. The Role component of a Policy identifies the professional roles to which the policy

applies, while the Action attribute determines what action(s) the system should take when the policy is fired. The *Event* table represents real world events that can occur during system use which fire a *Policy*, such as a new patient diagnosis being recorded.

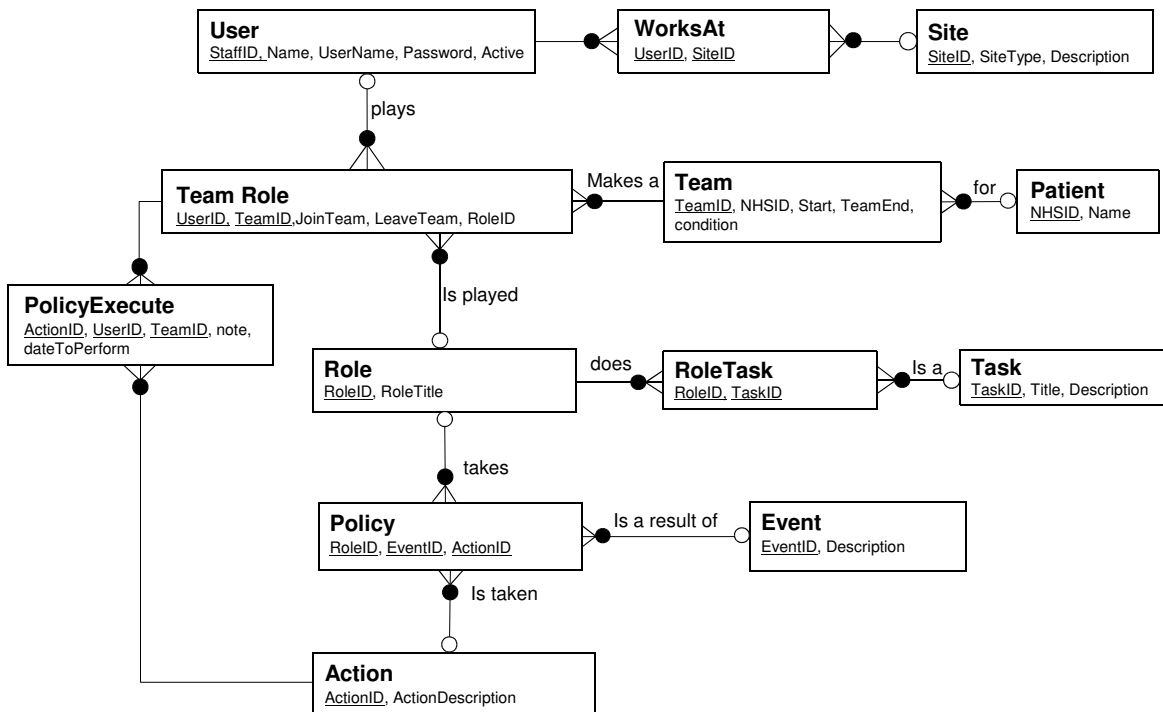


Figure 6.3: Coordination Database Entity-Attribute-Relation Diagram Including Policy Tables.

Event IDs are hard-coded into the Java component of the system wherever a given event may be detected, and a method is called which searches the database for all Policies containing the given Event. The system then uses patient and membership data for the current team along with the professional Role attributes of both team Members and triggered Policies to identify individuals to whom the Policies should be applied.

To illustrate how Policy execution works, consider the Policy example introduced in Chapter 5, “When a new diagnosis is entered, the patient’s GP should receive a summary.” Here, the Event is “new diagnosis entered,” the Action is “send summary,” and the Role is “GP.” In the software component of the system there is a method which sends new diagnoses to the integrated EPR to be saved. The Event ID for “new diagnosis” is hard coded within this method in a line command that starts the policy execution process. Whenever this method is executed, the system searches for all Policies with the “new diagnosis” Event ID. Once a list of Policies with the “new diagnosis” Event have been identified, the system must then map the associated Actions

to system Users. For the current example, the system then uses ‘current patient’ and ‘current team’ data to identify which User is this patient’s GP, and a summary notice is added to that GP’s view of the given patient record. If multiple Policies exist for the “new diagnosis” Event then the system completes the User identification and Action processes for each (see Figure 6.4)

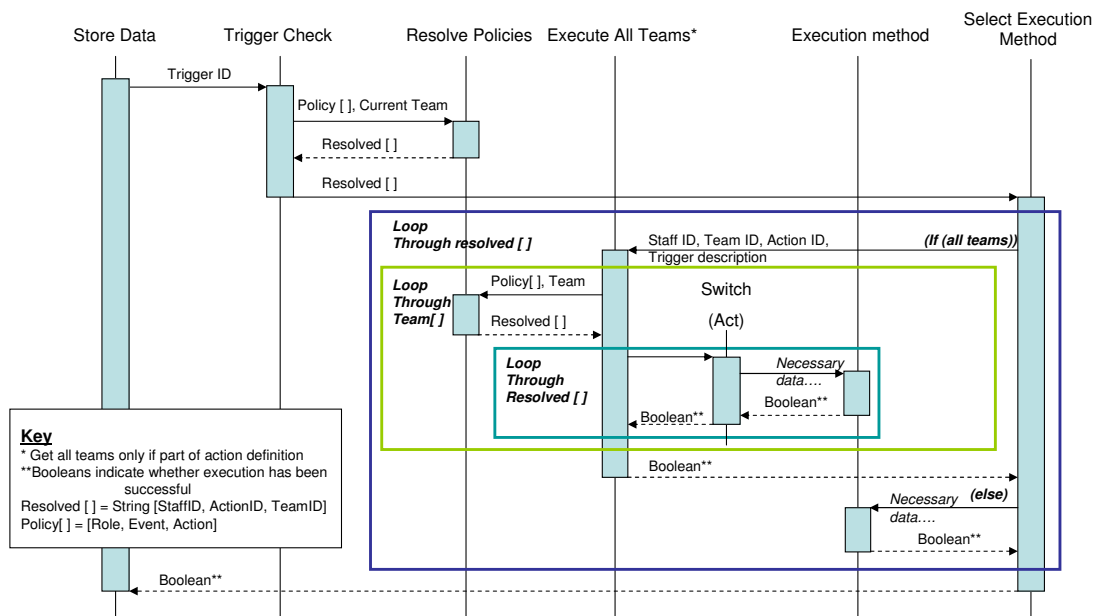


Figure 6.4: Sequence Diagram for Policy Execution.

Although the system requires only unique IDs for Policy interpretation and execution, humans will be creating and updating Policies. To facilitate Policy maintenance a human-readable free text description is included for each *Role*, *Event*, and *Action*.

Incorporating system policies into the **Coordination** database has the benefit of providing a direct link between system policies and team information. Additionally, storing Policies as relations adds flexibility and usability to the system. Rather than requiring technical expertise, updating, adding, or removing a policy requires only a database update which can be executed through the user interface. As with team membership, system policies can be altered by anyone with the correct access. This is particularly important since the lack of clearly defined system requirements suggests that system policies will, initially, be similarly poorly defined and, as a result, system policies are expected to change significantly over time. It is worth noting, however, that this flexibility applies only to Policies using existing *Actions* and *Events* and does not address situations where a new *Event* or *Action* is required. In the case of a new *Event*, a new line of code (stating the event ID and calling an appropriate method to determine whether

any policies have been fired) is required at each point where the event may be detected. In the case of a new Action, a method executing that Action must be implemented. This may require a significant amount of new code, depending on the complexity of the required system action(s).

6.3.2 Integrated Electronic Patient Record

In Chapter 2 it was proposed that current integrated EPR proposals within the NHS would not fully meet the needs of collaborative care teams. The research hypothesis implies that the conceptual model described in Chapter 5 will improve the usability of such proposals. In order to demonstrate this, the prototype must include an integrated EPR. However, because it is currently unclear what form an integrated EPR will take- whether it will follow a federation or silo model, what language(s) and DBMS(s) will be used- the conceptual model should not be affected by the EPR, its design, or implementation. In order for the prototype to effectively implement the model, then, it is necessary to ensure that the prototype components implementing the conceptual model are not impacted by the structure or implementation of the integrated EPR. The implementation *does* assume that the integrated EPR follows a three-level ANSI-SPARC model - that the data is independent of the user interface - and that data from multiple sources can be accessed through a single interface. In particular it is assumed that, given a patient and team member or point of care, the integrated EPR will handle all of the *where* questions relating to patient data- where to save new data and where to look for existing data. The integrated EPR itself is out of scope for this project. Keeping it separate in the implementation ensures that it remains out of scope. A complete discussion of how separation of the two parts of the prototype is achieved is included in Section 6.3.3 and, for completeness, a brief explanation of the implementation of the integrated EPR is included here.

In this prototype, the integrated EPR is solely responsible for retrieving and saving patient data. The integrated EPR uses a federated architecture incorporating three sample GP databases created by the author, and an anonymised subset of the CANISC database as well as a Java program responsible for ensuring that the correct component database is accessed for each query. Each constituent database has a single Java class to translate information from the internal database schema to an appropriate conceptual schema. Attribute information, such as database type, associations between users, the current patient, and care sites allows the system to identify which component database to access at any given time (see [112])

6.3.3 Classes

Because it is unclear what architecture will ultimately be employed in an integrated EPR and to increase generalizability of the project, it has been decided that the prototype should be independent of the integrated EPR architecture. This means that a clear separation must be maintained between the integrated EPR and the rest of the prototype. Additionally, best practice dictates use of the three level ANSI-SPARC model, maintaining separation between the internal schema, conceptual schema, and user view(s). As a result of these requirements, the prototype includes six groups of classes: user interface/view classes, a single conceptual schema class for communication with the **Coordination** database, policy interpretation/execution classes, a single class for communication between the prototype and the shared EPR, system object classes, and the shared EPR itself (out of scope for this project).

User Interface Classes

User interface classes are responsible solely for organising and presenting information. The interface displays each Task on an individual tab, allowing the User to switch easily between Tasks. Because the list of tabs to be displayed is determined at runtime, the system is able to dynamically generate the patient record view for each patient both over time and within a single session. For example, if a clinician's role changes with a particular patient as the patient progresses through treatment, this will automatically cause a different Task list to be defined when the patient is next selected, and an appropriate tab set will be generated accordingly. Similarly, where a clinician undertakes different roles with different patients, the set of Tasks displayed for each patient will reflect the clinician's role with that patient. Each Task is defined in its own class and a single MasterFrame class is responsible for determining which components to display and where. The MasterFrame class uses team Membership, Role, and Task information from the Coordination database to dynamically generate the user's view. Interface screen-shots are provided in Section 6.4.

Coordination Database Interface

All access to the Coordination database is accomplished through a single class and, to avoid creating multiple database connections in a single session, this class is defined as a singleton. The Coordination database interface class contains all methods for saving, updating, and retrieving data related to the conceptual model including team, role, and policy data. This class does *not* handle patient health data of any kind. Because Policy information is stored in the **Coordination** database, this class contains methods for updating the Policy table and one method for

extracting a list of Policies from the database when a policy Event has been triggered. All other methods relating to policy execution are contained in the Policy Classes.

Policy Execution Classes

Policy execution is the most complex algorithm implemented in the prototype. As a result, a decision was taken to separate, as far as possible, methods relating to Policies into a few self-contained classes. From a design perspective, Events exist independently of Policies. For example, a practitioner should be able to save a diagnosis (Role permitting) whether or not this Action fires any Policies. Similarly, Roles exist independently of Policies, so Role and Event methods are not stored in the Policy classes. Policy *Actions*, however, exist only as Policy components. Therefore, methods for executing Actions are contained in a single class.

Integrated EPR Interface

As with the Coordination Database, the integrated EPR is accessed through a single interface class which is defined as a singleton. This class is responsible for handling all exchange between the underlying EPR and the rest of the prototype, acting as a middle layer between the main prototype and the shared EPR and translating between the two. Specifically, if the main prototype needs to interact with patient health data (read or write), it does so by calling an appropriate method in the EPR interface. The interface then translates this request into a form understandable to the integrated EPR. When a response is received, it is translated into the form expected by the main prototype. In this way, the main prototype is kept as separate as possible from the architecture and implementation of the integrated EPR. If the EPR is updated or changed, the interface is the only class of the prototype that requires updating. The exception to this, of course, is when method arguments change as the result of an update. For example, if a method for accessing a patient's weight required only the patient ID before an update and requires both patient ID *and* point of care ID (where the weight was taken) following the update, then all calls to that method would also need to be updated². However, the interface approach does minimise dependence on a particular structure or implementation of the integrated EPR. The prototype will work equally well with a federated, data silo, or even web-services style EPR architecture, or any combination thereof. Similarly, the software or data structures of the database components of the integrated EPR do not affect the main prototype. Nor is it even necessary for the two components to be written using the same programming language.

²If the change were to happen in reverse, alterations to classes other than the interface could, of course, be omitted.

Object Classes

Finally, because Java is an object oriented language, each of the system objects in the **Coordination** database also exists as an object class in the software component of the prototype. Representing system entities as objects has the advantage of maintaining relationships between entities in the software as well as within the database. For example, in the software component of the prototype, a Team object has as attributes both a patient object and a list of team member objects. Each team member object consists of a user object and a role object. Each role object, in turn, contains a list of task objects associated with that role (see Figure 6.5). Although this is not the most efficient use of runtime memory (if two team members have the same role, for example, then the task list associated with that role is duplicated in the two member objects), it maintains the relationships between objects and reflects the real-world structure that the system is attempting to represent.

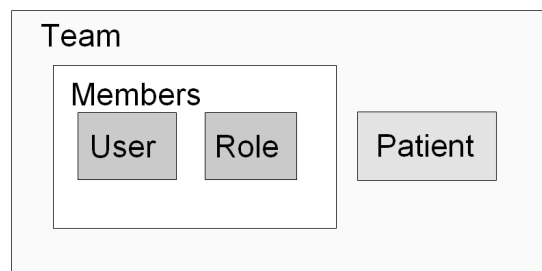


Figure 6.5: Nested Team Object Model.

6.4 Functionality

Although the prototype serves multiple purposes in this project, its original aim was to demonstrate the technical feasibility of the conceptual model. This aim breaks down into two distinct components: 1) that the conceptual model can be implemented and 2) that it can provide the functionality/meet the requirements specified in Chapter 5 and at the beginning of this chapter. Section 6.3 discusses how the model is implemented in the prototype, demonstrating feasibility. This section covers specific functionality that was implemented to support the stated requirements. For ease of analysis, functionality is grouped into four categories based on the identified requirements: system maintenance/management, tailored views, pro-active support, and team management. How effectively the implemented functionality actually supports the requirements is addressed as part of the evaluation and is discussed in detail in Section 7.3.6. It should be noted that, where possible, functionality which is currently available or is expected to be available

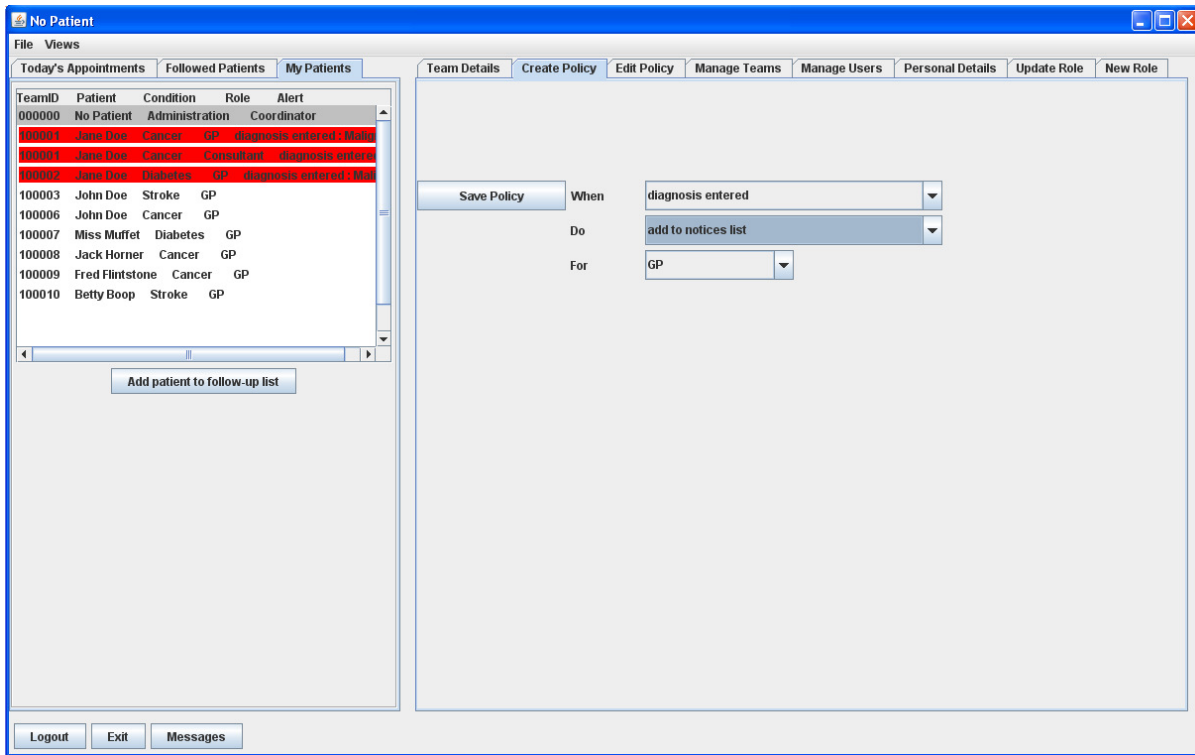


Figure 6.6: Policy Creation Interface.

through other systems is not duplicated in this prototype. Because the model proposed here is intended to extend a shared EPR, it is assumed that all functionality available as part of the shared EPR will remain in place and, therefore, does not need to be duplicated in this prototype.

6.4.1 Management and Maintenance

System management and maintenance functionality relates to work done by a system administrator and covers such items as adding and removing team members manually and updating policies, roles, and user information. As has been previously stated, because this project is forward looking and the requirements are not currently well understood, as well as the evolutionary nature of healthcare, system requirements are expected to evolve continually and significantly over time. As a result, it was decided that the system should be as flexible as possible and, wherever possible, alterations to the system should not require expert knowledge. In the prototype, this was accomplished by storing policies and role information as relations in the database and allowing administrative users to update these tables through the user interface.

The reasoning behind this decision is exemplified by the case where a new policy is required. If the policy Event or Action does not already exist within the system, then new code is required to implement the new Event or Action (as discussed in Section 6.3.1.2). However, if the Event, Action, and Role already exist in the system then the user is provided with an interface which allows the selection of policy components from drop-down menus populated with the free text description of each component (see Figure 6.6). The resulting policy is saved as a new row in the Policy table of the Coordination database. Editing or removing a policy, as well as adding, editing, or removing a role are implemented similarly. In this way, anyone with appropriate authority can make changes to system policies without the need for specialist technical knowledge.

6.4.2 Tailored Views

Providing tailored views to users is aimed at making the right information available to the right person at the right time. For the purposes of this project, this involves ensuring that users have access to information when required and organising that information in a sensible and useful way for each user. Currently, the prototype provides each user a view based on role, patient, and team. Each patient's care team is divided into diagnosis-based sub-teams. When a user is assigned to a patient he joins one or more of that patient's diagnosis sub-teams and is assigned a Role on each sub-team, as appropriate. These roles may be the same for all sub-teams of a given patient, or they may be different for different sub-teams. At times, a user may simultaneously play multiple roles on the same sub-team. Because Role is part of the primary key for team membership, the user has one Member instance for each distinct Role on a given Team. Additionally, a team member's role may change over time. When a user logs into the system, all of his current team-roles are identified and a patient list ("My Patients") is generated and displayed (See Figure 6.7). When the user selects a patient, the system identifies the tasks associated with the user's role for that patient to define the user's view of that patient's record. When the user selects a new patient, the view of that patient's record is again dynamically generated based on the user's team role for the selected patient.

In addition to the "My patients" list, the prototype also automatically generates a list of "Today's patients." A user managed "Follow-up" list is also provided. A button is provided on each of the patient lists which allows the user to add or remove a patient from the "Follow-up" list (see Figure 6.8). The "Follow-up" list can then serve as a reminder to the user of which patients still require action or attention. During evaluation the patient lists were greeted very enthusiastically. Although not implemented in the current version of the prototype, clinicians suggested providing different types of lists for different roles. This is well within the range of what the prototype could provide if time allowed.

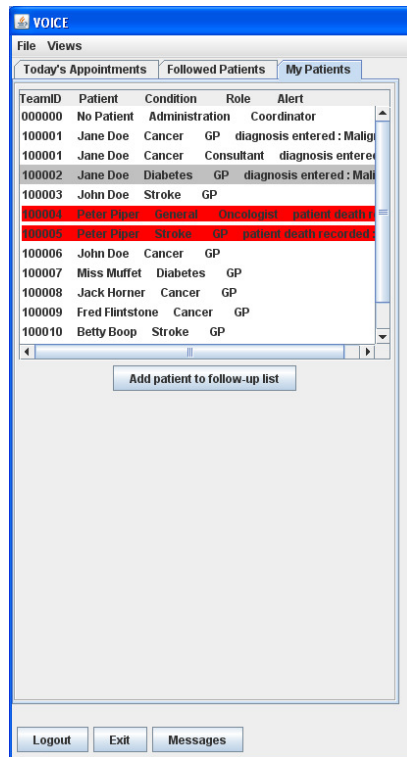


Figure 6.7: “My Patients” List.

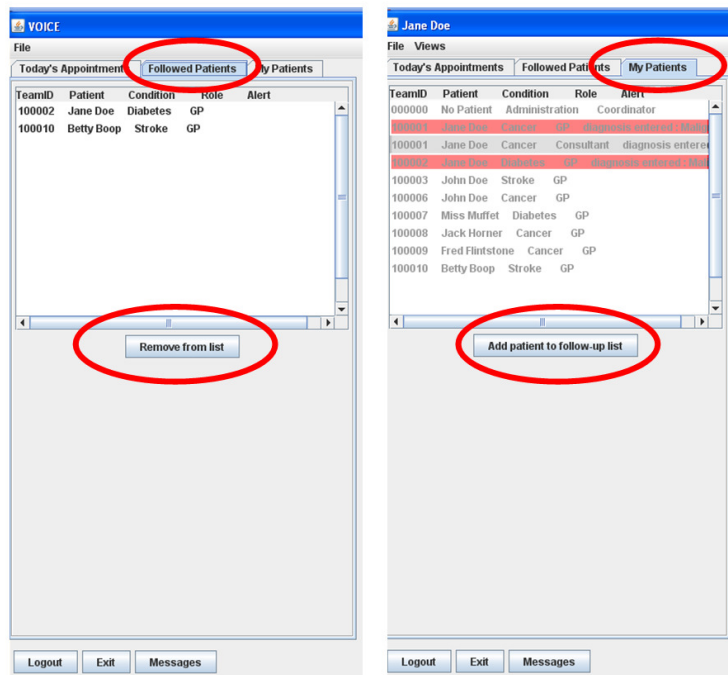


Figure 6.8: Follow-Up List.

As discussed in Section 8.2, user-interface design was deemed out of scope for this project. Currently, if the user is working with a patient for multiple sub-teams the prototype displays each sub-team separately. Similarly, if a user plays multiple roles on the same team concurrently, each is displayed separately. However, this may or may not be appropriate and, for some roles, is clearly inappropriate (such as a GP who will, by default, become a member of *every* sub-team for each of his patients). It is possible to display only one instance of each patient if the user is working with the same patient on multiple sub-teams. However, it is not clear that this is an ideal case for all Roles. This is particularly true if the user plays multiple roles. As a result, more investigation into optimal design for displaying patient lists is required. This has been left for future work.

During requirements gathering, two main concerns were identified relating to tailored patient record views³: not having access to information when required and having inappropriate (too much) access to information. To partially address the first concern, a menu bar was added to the user interface for clinical roles allowing the user to easily switch between views (see Figure 6.9). To accommodate legal requirements, the menu bar is also role-based; only certain roles have access to the view menu. These concerns also related to population of patient lists (“What if I am seeing a patient and they are not on my list?” and the converse). The CANISC system currently includes a patient search function. It is proposed that this function should remain in place for clinical roles. As with other existing functionality it has not been duplicated within the prototype.

The second concern, having inappropriate access, is partially addressed in three ways. First, tailored access can be used to restrict access to data items within a particular patient’s record, if desired. This may be appropriate for some roles, such as pharmacist, but is not appropriate for all roles. As discussed in Chapter 5, restricting access for clinical team members especially could result in lower quality of care. Auditing is suggested for ensuring appropriate access among users taking on clinical roles. This includes logging all access to patient data. Because logging and auditing functionality already exists within many healthcare information systems, it has not been duplicated in the prototype. Finally, automation of team management has been considered. If the system automatically updates team membership through Policies, then the system is more likely to be accurate and up-to-date and will be easier to maintain. Automation of team updating is discussed in more detail in Section 6.4.3.

³These concerns were confirmed during evaluation.

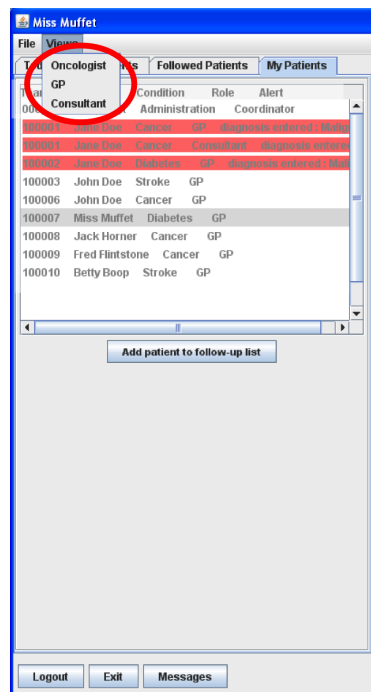


Figure 6.9: Change View Menu.

6.4.3 Team Management

Team management functionality relates to maintaining an accurate and up-to-date list of care team members, including team members' roles. Although teams and team member details, as well as user details, can be updated manually by a system administrator (see Figure 6.10), this is time consuming. Expecting teams to be maintained entirely by manual updates is impractical in a highly evolutionary team. As a result, effort has been made to include functionality capable of reducing the system administration workload associated with team management. Due to time constraints, only one team management policy is included in the current version of the prototype (When a patient dies, remove all team members from the patient care team). While interviewees pointed out the inappropriateness of the content of this policy during evaluation⁴, it does illustrate the ability of the system to execute automated team updates through the policy mechanisms. Other potential team update policies include, for example, 'When a referral is made, add the recipient to the patient's care team' or 'When a patient changes GP, make the previous GP an inactive team member⁵.' As part of future work, it is expected that policies

⁴Because a clinician may legitimately require access to a patient record post mortem or after treatment is completed, policies that remove a team member from a team must be considered very carefully. In particular, removing a team member or deactivating a team immediately upon completion of treatment or death is inadvisable.

⁵In the current prototype, members have an 'active' status which may take as values 'active' or 'inactive.' However, during evaluation it became clear that multiple levels may be required for this attribute. Certainly 'active,' 'inactive,' and 'no longer on team' would be appropriate as, for medico-legal reasons team member history must

involving the patient's care pathway will also be introduced, whereby a member's 'active' status and/or role is updated automatically as the patient progresses along the care pathway.

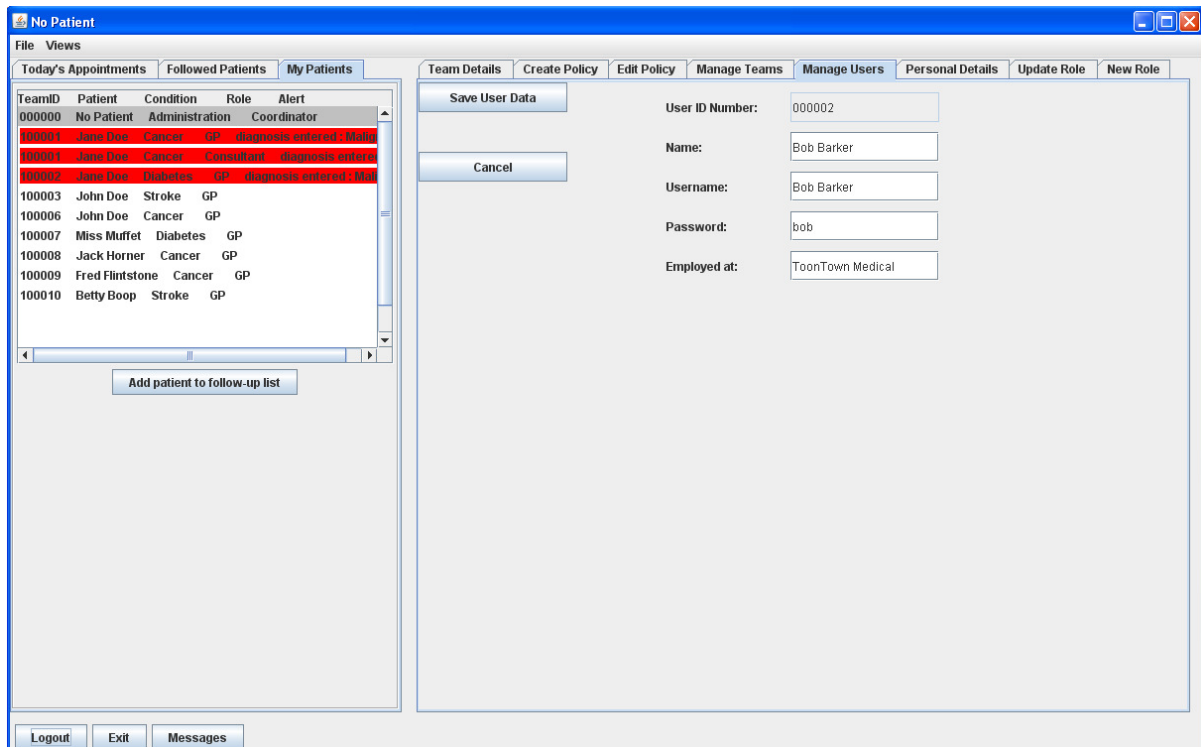


Figure 6.10: Update User Details Interface.

The concerns discussed with regard to tailored views also apply to team management. It cannot be expected that any set of policies will be perfect or will be able to anticipate every circumstance that may arise with regard to treatment. Therefore, it must be assumed that, at least in some cases, users may be left off of a team or left on the team list after they have completed working with a patient. To address these concerns, methods for coping with such situations were considered. One mechanism for ensuring access even if a patient is not in the user's list is to include a patient search function. Although a search function was not implemented in this prototype, CANISC has a patient search function which could be included in a full implementation of the VOICE conceptual model. However, there are additional concerns which must be considered with regard to such an option. Currently, access in CANISC is restricted by organisation and system group; each user's view is determined by her home organisation (i.e. be maintained.

Velindre, Princess of Wales, etc.) and the system group to which she belongs (e.g. colposcopy, palliative care, etc.) [3]. Although it is unlikely that this policy will remain unchanged when a national shared patient record is put in place, what shape future organisational policies regarding information access in a national shared patient record may take is not yet clear. Any future search or related functionality must implement these organisational policies.

The other concern, that some users may retain access beyond what is required, is a more difficult problem to address. As has been previously discussed, restricting access is problematic. Throughout this project, logging and auditing user access of patient data has been suggested as a means for addressing inappropriate access (see Section 7.3.5). It is possible to remove a member from a team using policies, but this would not stop a user from accessing the patient record using the search functionality proposed above. The tension between the two access-related concerns makes finding a perfect solution unlikely. A decision must be made in the design of any healthcare information system whether to err on the side of too much access or too little. Given the potentially life-critical nature of health record access, the views expressed by clinicians, and the current state of data protection rights within the European Union, it was decided that, for this project, the system should, for most users, err on the side of allowing, rather than restricting, access. However, for a subset of users, the conceptual model does allow for access restriction simply by not providing the extra access tools (such as view menu or search function) as part of the user interface for those roles.

6.4.4 Pro-Active Support of Awareness

In some ways, each of the user functionalities discussed could fall under the heading of supporting awareness; every user function implemented aims to allow the user to efficiently identify relevant patient information. However, this section will focus primarily on the most pro-active of those functionalities: notifications and alerts. Less active support for team members is covered briefly at the end of the section.

Notifications are defined as non-urgent updates to patient status. Notifications may include, for example, return of blood results, notice of completion of treatment, summaries, or communications from other team members. Because notifications are non-urgent, they might only be displayed when the patient's record is opened. In contrast, alerts are urgent or unexpected. Alerts may include, for example, notice that a patient has been admitted to hospital unexpectedly or that complications relating to surgical recovery have occurred. Because they are urgent and/or unexpected, alerts are available *outside* the patient's individual record. For reasons of scope and the author's area of expertise, implementation of notifications and alerts focused on the general ability to send a notice or alert rather than the specific detail of when to send an alert

and what it should contain. Additionally, because notifications and alerts are so closely related, the important distinction is that of receipt - whether the communication is viewable only as part of the patient record or if it is available outside of the individual patient's record. Notifications and alerts together will be referred to as *communications*.

System Policies support both automated and manual communications⁶. Automated communications are generated entirely by the system as Policy Actions, generally as the result of alterations to a patient's status or team and changes to the patient record. Currently, this includes updates to the patient record or the Coordination database. Automated communications are generated by policies and may be sent to one or more team members as appropriate (see Section 6.3.1.2). Manual communications are generated through a "Send Notice" task tab (see Figure 6.11). The user sending the communication selects the recipients based on role and team and enters the message as free-text. Manual communications are currently stored and displayed as part of the communications list discussed below (see Figure 6.12). However, in a full implementation it is expected that such communications would be stored as separate documents (similarly to summary letters) within the patient record.

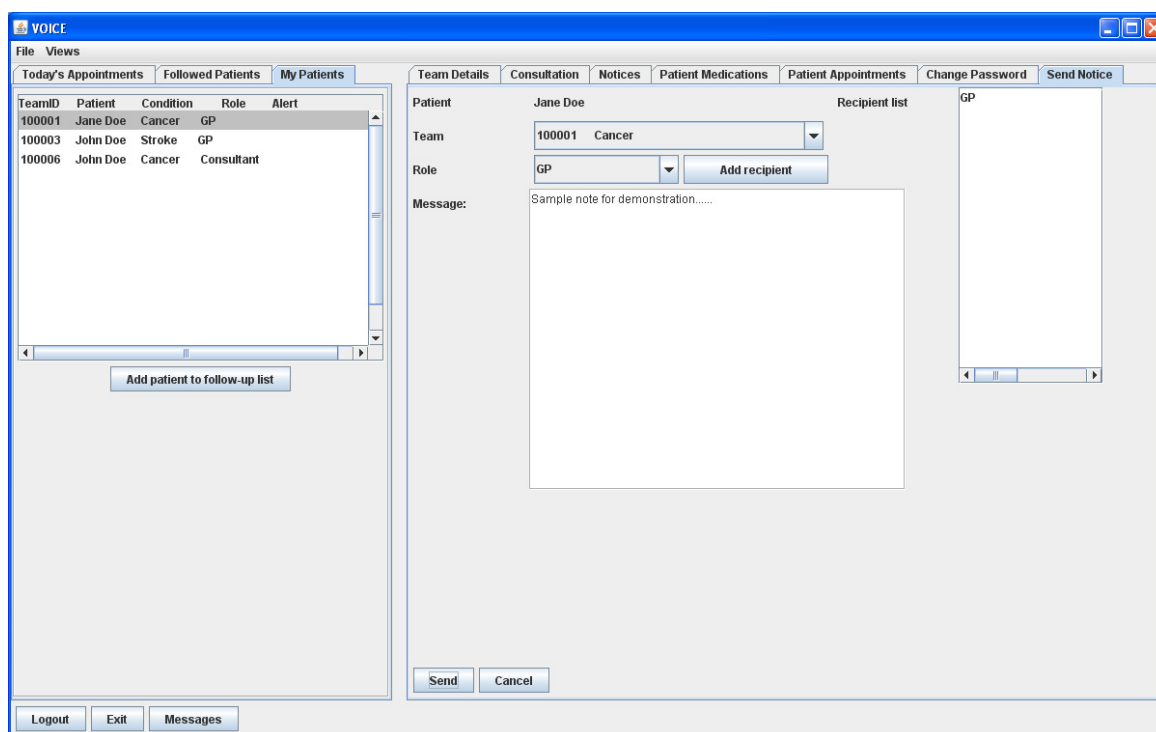


Figure 6.11: Send Manual Communication Interface.

⁶Partially automated communications, such as partially pre-populated referral forms, are expected to be available through the WCP so were not implemented here. However, such functionality could be provided by the system as currently designed.

Because user interface is not considered in detail as part of this project, a variety of communication display and receipt options have been implemented in the prototype. A “Notifications” task tab is included in the clinicians’ patient record view which displays a chronological list of short patient updates (see Figure 6.12). This list includes both alerts and notifications. Second, patients with an alert are highlighted in the patient lists, along with a short statement for the reason for the alert. When a highlighted patient is selected, the user is offered the option to remove or retain the highlighting (‘Mark as viewed’ or not). Finally, a ‘Messages’ button is included which provides the user with a list of ‘active’ alerts; Alerts that are currently marked as ‘not viewed.’ Again, because interface design was not a priority in this project, none of these options are optimised. Identifying appropriate display mechanisms for communications is a matter for further research.

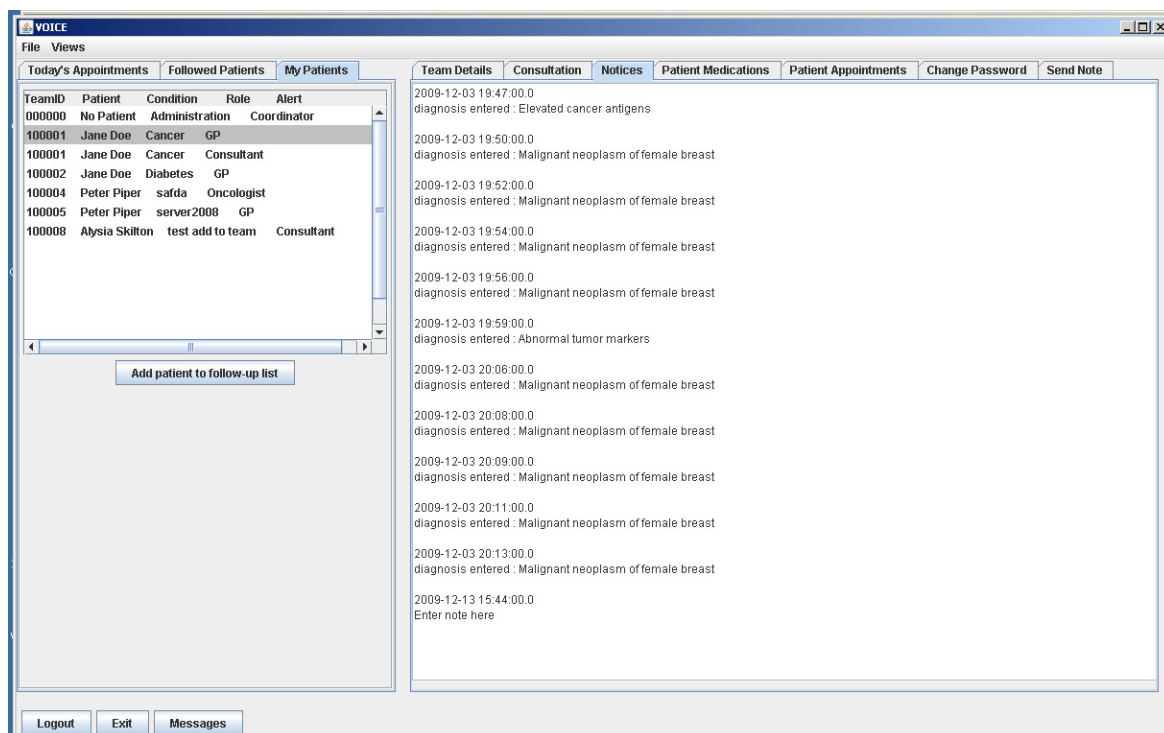


Figure 6.12: Notifications List.

Although including communications within the system may be useful, there may still be times when team members wish to communicate synchronously or externally to the system. To support this, a list of team members and their details (as available) is also provided (see Figure 6.13).

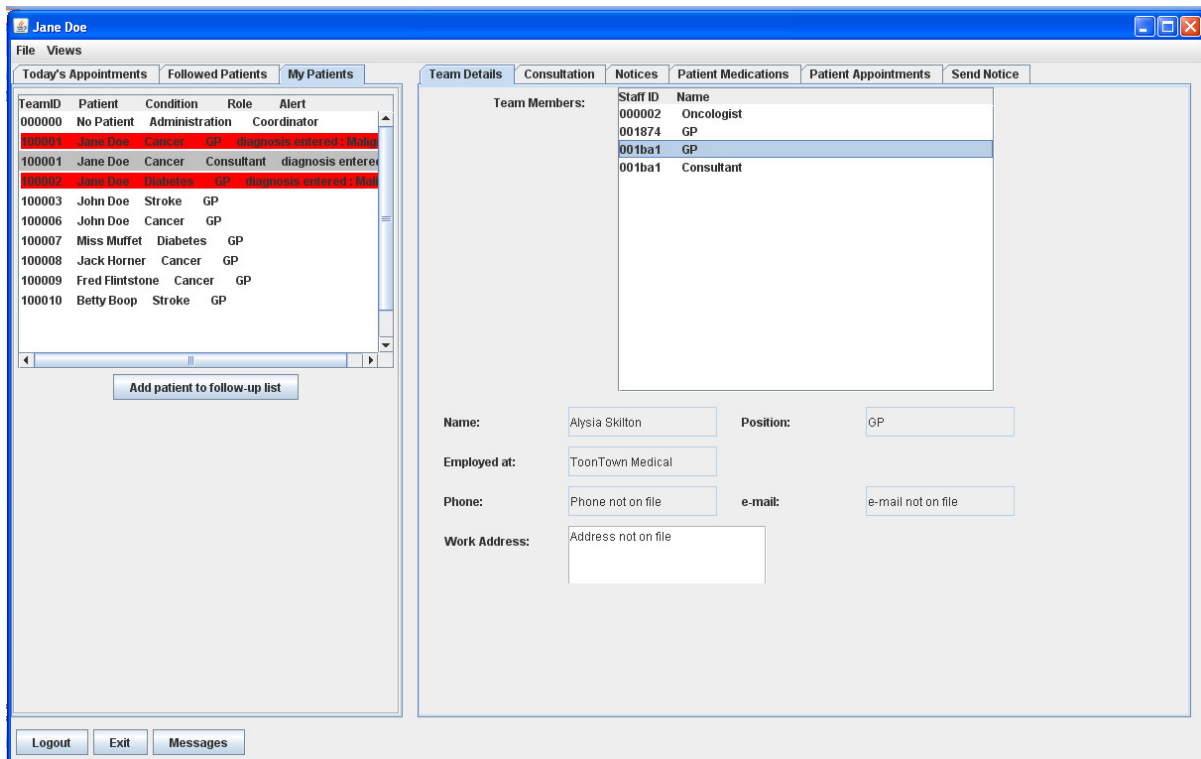


Figure 6.13: Team Details Display.

6.5 Conclusion

As discussed in Chapter 4, an evolutionary approach using one or more prototypes was selected for this research to compensate for vague and poorly understood initial requirements. Although the prototype was initially considered as a means to help refine requirements and to elicit feedback from clinicians and developers, in the end it served multiple purposes in the project, enhancing discussion in developmental stages of the project, demonstrating feasibility of the model and design, and providing illustration and a starting point for discussion in the evaluation stages. Design and implementation of the prototype provided useful insight into requirements specification, clarifying some requirements, highlighting potential problems with others and, in some cases, suggesting new requirements.

The prototype successfully implements the conceptual model and illustrates some of the range of functionality which the model is able to provide. This includes tailoring a user's view of the patient record to her professional Role with each patient, automatically taking system actions, such as sending alerts to specific team members, and creating, sending, and storing communi-

cations within the patient record.

Although the prototype was not demonstrated to collaborators until the latter stages of the project, design aspects of the prototype were discussed throughout. As a result, the prototype met the aim of improving communication and discussion. Additionally, the prototype allowed the research to consider requirements not explicitly covered by the conceptual model, such as architecture independence. The prototype also provided explicit examples of functionality provided by the conceptual model. In the evaluation of the project, clinicians were asked to evaluate the functionality provided by the prototype against the high-level requirements which the conceptual model attempts to address. In this way it was possible to more fully engage clinicians in the evaluation process and to elicit more meaningful feedback from them than would otherwise have been possible. Finally, although proving feasibility is not usually considered an aim of the prototype(s) in evolutionary development, because of the exploratory nature of this project proving feasibility of the proposed model was necessary. The prototype served this purpose by demonstrating that the VOICE model is implementable. Chapter 7 provides a detailed discussion of how the prototype was used in project evaluation.

Evaluation

Overview

Chapters 2 and 3 identified a list of information systems requirements for healthcare practitioners working as members of patient-centric care teams. Chapters 5 and 6 then presented one possible approach for meeting these requirements. This chapter evaluates the requirements and the proposed approach. The evaluation considers relevance of the requirements, value of the proposal both within the domain and its potential application to other domains, and whether the proposed solution supports the research hypothesis. Chapter 8 then goes on to identify some ways in which the work could be taken forward.

7.1 Introduction

Evaluation in a project of this type is necessarily complex and subjective. Because the hypothesis posits that recording and using team information will provide improved support for care team members, the evaluation must measure improvement, which is an inherently subjective undertaking. From the user's perspective, improved support is determined by functionality. Does this system provide functionality that is useful to me that is not currently available or is currently imperfect in some way (i.e. I have to change systems for some functionality or an option is hard to find or inefficient to use)? However, because the novelty of this work is in the conceptual model, rather than the functionality, the evaluation strategy must evaluate the model. In order to address this mismatch, the evaluation strategy was broken into three main components: evaluation of and through the prototype, user evaluation, and developer evaluation. Together, these evaluation components provide a link between the current reality of healthcare information systems, the VOICE conceptual model, and the functionality that can be achieved using the VOICE conceptual model. These three components are supplemented by an analysis and discussion of issues that were identified over the course of the project, but which were not raised in the formal evaluation (Section 7.5).

Evaluation Structure

The hypothesis states that improved, pro-active support for collaboration can be provided through context-based, targeted, tailored, and automated access and communication. In order to evaluate the proposal against this statement two criteria must be tested, that:

- the model can provide the stated context-based, targeted, tailored, and automated access and communication
- context-based, targeted, tailored, and automated access and communication, along with associated functionality, constitutes an improvement over existing proposals

In order for the proposal to be worthwhile, the evaluation must also test whether it meets two additional criteria:

- the model can be implemented
- the proposal is suitable for the domain

The first evaluation component, clinician interviews, primarily considered the first two evaluation criteria: whether the model can provide context-based, targeted, tailored, and automated access and communication, and whether this constitutes an improvement over existing proposals. For the first criteria, clinicians were shown examples of functionality that the conceptual model can provide and were then asked whether they felt this functionality met the stated requirements. For the second criteria, they were simply asked whether they felt that the proposal constituted an improvement over existing proposals. The clinician evaluation component is discussed in more detail in Section 7.3

As mentioned in Chapter 6, the prototype was used to demonstrate feasibility of the approach, covering the third evaluation criterion. For developers, a single interview was conducted which included three Principal Software Developers involved in developing and maintaining the CANISC system¹. This interview aimed to address the final evaluation criteria, is the proposal appropriate for the domain - can it reasonably be integrated into existing systems or proposals and how maintainable is it? The prototype and developer components of the evaluation are discussed in detail in Sections 7.2 and 7.4, respectively

7.2 Prototype Evaluation

As has been previously stated, because the proof of concept prototype is an implementation of the conceptual model, it can be used to verify feasibility of the approach; the prototype demonstrates that the conceptual model can be implemented, showing that the conceptual model is technically feasible. Because the prototype is proof of concept only, however, the scope of what can be derived from it in terms of direct evaluation is limited. For example, the prototype is not suitable for evaluating performance issues such as scalability or speed/response time.

In addition to demonstrating that the model can be implemented, the prototype also incorporates a range of functionality which can be achieved using the conceptual model. The first of the four evaluation criteria states that in order for the hypothesis to be met the model should be able to provide context-based, targeted, tailored, and automated access and communication. Because the prototype implements the model, it is enough to show that the functionality in the prototype provides context-based, targeted, tailored, and automated access and communication. Verifying this was achieved through interviews with clinicians, discussed in Section 7.3.6.

¹For information on CANISC, see Section 2.3.2.3

7.3 Clinician Evaluation

As end users, practitioners are, in general, interested in *what* the system does - what functionality it can provide - rather than the underlying architecture or model. Therefore, it was decided that the practitioner interviews should focus on requirements and functionality. Clinicians, as end users, are the most suitable people to evaluate the first aspect of the hypothesis - does the proposal provide *improvement* over existing systems. Improvement was evaluated on quality as well as quantity. If the system provides functionality not currently available, but the new functionality is not considered valuable, then the system cannot be said to provide a meaningful improvement. Similarly, if the system provides functionality similar to what is already available, but provides it in a way that is seen as being better than existing systems, then the proposal can be said to provide meaningful improvement. The clinician interview component of the evaluation focused on answering three questions:

1. Does the proposal address an area of need? (Are the chosen requirements important?)
2. Does the proposal meet the aims it intends to meet? (Does the proposal meet the chosen requirements?)
3. If the proposal were fully implemented, would it constitute an improvement over existing systems?

7.3.1 Structure

Clinician evaluation meetings were conducted as six structured interviews including a brief presentation on the proposal as well as a demonstration of the prototype. Interviewees consisted of clinicians working in various positions at or for Velindre NHS Trust who had experience of cross-boundary collaboration as part of patient care teams². Interviewees included practitioners in a variety of roles³. At various points throughout the presentation, interviewees were asked for feedback. Interviewees were also encouraged to comment or ask questions at any time during the meeting. The presentation was organised as follows:

- A brief introduction to the work
- High level requirements (see Section 7.3.3)
- *Feedback* - importance of high level requirements

²Some, but not all, interviewees also had experience working in MDTs

³Clinical Senior Lecturer, Clinical Director, Chemotherapy Modernisation Manager, Therapy Services Manager, Medical Director, and Consultant in Palliative Medicine.

- A brief overview of the proposal and high level architecture
- Sample patient scenario (see Section A.1.1)
- Prototype demonstration
- *Feedback* - usefulness of functionality
- *Feedback* - does the proposal meet the requirements

The sample patient scenario covered some events that may happen in the care pathway of a hypothetical cancer patient and the actions that the proposed system could take for each event or stage of treatment. The sample patient scenario was not intended to comprehensively cover a complete patient journey, but to highlight some of the ways the proposal might directly impact working practices. The scenario also illustrated how the same functionality might be applied differently in different situations. A demonstration of the prototype was provided after the scenarios to illustrate in more detail how some of the functionality could work in practice. It should be noted that not all functionality illustrated in the scenarios was implemented in the prototype. In particular, functionality that is expected to be available through other systems, such as CANISC or the WCP, and timing and care pathway functionality, which is planned as part of future work, were included in the scenario but have not been implemented in the prototype. A table showing the complete scenario is included in Appendix A (Table A.1.1).

7.3.1.1 Feedback

The interview questions covered three distinct, but related areas. First, are the chosen requirements appropriate? Are they important and have any requirements of greater importance been missed? Next, clinicians were asked to comment on the functionality. To facilitate feedback, functionality was divided into three groupings: notifications, alerts, and team access. For completeness, future work functionality that was presented in the scenario but which was not implemented in the prototype was also included as a functionality group for clinicians to comment on, but the feedback questions were not asked for this group. Finally, clinicians were asked whether they felt that the proposed functionality met the listed requirements.

The first set of questions served as requirements validation. If the clinicians felt that the requirements were not meaningful, then the proposal would be likely to have little value as it would be addressing unimportant requirements. The final set of questions, asking whether the functionality met the stated requirements, provided the link between the requirements and the conceptual model. If the functionality provided by the model meets the stated requirements, then it can be said that the conceptual model meets the requirements. Finally, questions about usefulness of the functionality address the second evaluation criterion - does the proposal provide *benefit*?

7.3.1.2 CaNISC

As noted in Chapter 5, the proposal is intended to work with any underlying shared EPR. Although it is not as ambitious in scale as some of the other shared patient record proposals which have been discussed (see Section 2.3.2), CANISC is a shared EPR and is one of the systems currently in use at Velindre. CANISC is well thought of⁴ and is familiar to all of the interviewees, most of whom use the CANISC system as their primary patient record system. In contrast, some interviewees had not heard of other shared EPR proposals, such as the WCP. So, while the WCP was introduced as a possible future shared EPR, of which CANISC would be a part, the majority of the interviewees emphasised the proposal as an extension to CANISC in order to give interviewees a familiar frame of reference for considering the proposed functionality. This is reflected in the phrasing of some of the interview questions as well as in some of the clinicians' comments.

The biggest drawback to using CANISC as a reference for the clinician interviews was that, while CANISC covers more than one care site [56], it does not provide as much cross boundary information sharing as is expected in future shared EPRs. In particular, CANISC does not include GP data, nor do GPs have access to information stored in CANISC. Additionally, many interviewees expressed frustration about NHS policies which restrict users' access to some patient information within CANISC. As a result, it was sometimes necessary to re-emphasise that this proposal assumes a high degree of cross boundary information access.

Describing the proposal as a potential future extension to CANISC (or the WCP if the interviewee was familiar with it) had a few other unintended consequences with regard to the interviews. For example,

- Several interviewees commented on the CANISC system, both on aspects that they particularly liked about the system and aspects that they would like to see improved (see Table A.7).
- Many interviewees also raised issues regarding current challenges to cross-boundary information access.
- One interviewee was concerned about potential changes to the CANISC interface since the user interface on the prototype did not completely match the current CANISC interface.

However, none of these side-effects compromised the evaluation. Comments directly relating to CANISC and information exchange often served to reinforce information gained during the

⁴as evidenced by clinician comments during interviews and the fact that it has been accepted as the all Wales cancer information system.

background phase of the project, such as the high emphasis placed by clinicians on the need for better information sharing. At the same time, the presentation component of the interview provided opportunities for extra explanation of aspects and scope of the proposal, when necessary. A complete copy of the interview questions is included in Appendix A (Section A.1.2). A complete copy of interview questions is also included in Appendix A.

7.3.2 Results Analysis Process

Although the clinician evaluations were conducted as structured interviews with the same pre-determined set of questions asked at each meeting, respondents were encouraged to comment and ask questions throughout the presentation. As a result, while all of the clinicians answered the pre-defined list of questions, most answered at least some of them out of order or at an unexpected time. Some clinicians thought of a comment or concern about a particular functionality long after the questions about that functionality group had been asked, while others answered questions before they had been asked. For this reason, the chronological structure of the interviews has been ignored, and clinician responses grouped by topic⁵. Clinician comments will be considered according to the structure of the interviews. First, the importance of the identified requirements will be discussed, then comments on functionality, whether the functionality meets the requirements, and finally general comments relating to the proposal as a whole.

Because the order of clinician comments was not considered, analysis of the interviews was completed over several stages. Five of the six interviews were initially stored as voice recordings which were directly transcribed. The sixth evaluation was not recorded, so the initial transcript consisted of notes taken during the meeting. Each transcript was then summarised as a list of “points raised.” Each distinct idea expressed by the interviewee was recorded as a separate point. Questions raised by interviewees were classified as either clarifications or issues. Questions of the type “Is this how the system works?” or “Does the system provide this functionality?” were classified as clarifications. If the answer to the clarification was yes, the question was omitted from the points raised summary. Otherwise, the question was included. Other questions, such as “How are you going to ensure patient privacy?” were included as issues/points raised whether or not the question was answered at the interview. Depending on context, included questions of both types were either treated as areas of concern or suggestions.

In general, comments or suggestions that were deemed to be either out of scope or the result of a misunderstanding have been removed from this discussion but are included in Appendix

⁵For completeness, Appendix A contains a complete list of the questions asked, and a summary of clinicians’ immediate responses (Sections A.1.2 and A.2, respectively). An abbreviated version of Tables A.1 to A.5 is included here as Table 7.1

A⁶. For example, if a clinician suggested an ‘improvement’ that is already part of the current proposal, this was considered a miscommunication and has been included only in Appendix A. However, if a miscommunication or out of scope comment was deemed relevant or important⁷ it has been included in the discussion here. Once the summaries were created, it was possible to review the interviews as a collection to distinguish topics common to more than one interview, regardless of when a particular issue or concern was discussed within each interview. Where a comment concerns more than one topic, it has been included in both. Where a single clinician repeated the same comment more than once, the duplication has been removed. Where two or more clinicians made similar comments, this has been noted.

The nature of qualitative analysis makes it inherently subjective. Here, the multiple stages of analysis - translating from a direct quote to a summary statement to a grouping of summary statements - make the evaluation particularly subjective. To reduce this problem, direct quotes have been used wherever possible and any points raised which were not included here are included in Appendix A. Additionally, although different interviewees had different views about the correct approach to take, the consistency of themes across interviews is striking. For each topic, a table has been included showing the relationship between respondents and points raised.

7.3.3 Main Requirements

The first aspect of feedback requested from clinicians related to the proposed requirements:

- Improve efficiency of information access
 - Provide context-based access
 - * Targeted, tailored, automated
 - * Reduce information overload
 - * Support tasks seamlessly
- Improve efficiency of information exchange
 - Targeted, tailored, automated communication
- Provide pro-active support
 - System automatically takes specific, pre-defined actions

⁶Tables A.6 through A.9

⁷For example, concerns that the proposal would restrict information access, despite being the result of miscommunication, were raised by all six clinicians and have been included in Section 6.4.3.

Question	Resp 1	Resp 2	Resp 3	Resp 4	Resp 5	Resp 6
Would you consider the main requirements to be useful? Important?	Yes	Yes	Yes	Yes	Yes	Some
Do you feel that there are any requirements of higher priority? If so, please elaborate	No	Yes	No	No	Yes	Yes
Would you consider the notification functionality to be a beneficial addition to CANISC?	Yes	Yes	Yes	Yes	Yes	Perhaps
Do you have any concerns relating to the notification functionality? If so, please elaborate.	Yes	Yes	Yes	No	Yes	Yes
Do you have any suggestions on how to improve the proposed notification functionality?	Yes	Yes	Yes	Yes	Yes	Yes
Would you consider the alert functionality to be a beneficial addition to CANISC?	Yes	Yes	Yes	Yes	Maybe	Yes
Do you have any concerns relating to the alert functionality? If so, please elaborate.	Yes	Yes	No	Yes	Yes	Yes
Do you have any suggestions on how to improve the proposed alert functionality?	Yes	Yes	No	No	No	Yes
Would you consider the team management functionality to be a beneficial addition to CANISC?	Yes	Yes	Parts	Yes	Yes	Yes
Do you have any concerns relating to the team management functionality? If so, please elaborate.	Yes	Yes	Yes	Yes	Yes	Yes
Do you have any suggestions on how to improve the proposed team management functionality?	No	No	Yes	No	Yes	No
Does the proposed functionality meet the original requirements?	Yes	Yes	Yes	Yes	Yes	Yes

Table 7.1: Clinician Responses to Interview Questions.

- Reduce workload
 - Require minimal maintenance
 - Improve efficiency

Clinicians were asked

1. Would you consider these requirements to be useful? Important?
2. Do you feel that there are other requirements of higher priority? (Is there anything we have missed?) If so, please elaborate.

While responses to the first question were minimal, they were largely positive (see Table 7.1). As one clinician put it, “It resonates with a lot of what we’re trying to achieve ” [113]. One clinician did object to the question, saying, “I guess, the way you’ve got them there... you can’t *not* want to improve efficiency of information access ” [68]. This clinician felt that cross boundary information access as provided by a standard shared EPR would be sufficient to meet his needs and that this access rated as a much higher priority than the requirement proposed for this project. This statement reinforces the domain requirements analysis discussed in Chapter 2, but since this project focuses on extending cross-boundary, shared EPR proposals, the requirement for improved cross-boundary patient information access is not a concern for this research. When asked “Is there anything we have missed?” some clinicians suggested additional requirements, mainly pertaining to particular areas of interest or responsibility, such as more explicit support for MDTs and functionality to support clinical trials. One interviewee pointed out that the proposal does not currently include patient access to the system. Providing patient access could easily be accomplished by adding ‘Patient’ as a Role within the system. However, there are medico-legal, psychological, and patient privacy issues associated with allowing patients to access their records. The possibility of providing patient access through the proposal and the concerns surrounding this are discussed in Section 8.3. Other clinician suggestions for extensions to the proposal focused mainly on specific functionality and are discussed in the relevant sections below.

7.3.4 Communication Functionality

In order to cover all aspects of communication functionality, it was initially broken into three subgroups: alerts, notifications, and user generated communication. Because user generated communication as currently implemented in the prototype covers only one function - sending a note to one or more team members - it was included with notifications in the presentation and two communication functionality groups were presented to clinicians - alerts and notifications. For each of these groups, interviewees were asked three questions:

- Would you consider this functionality to be a beneficial addition to CANISC?
- Do you have any concerns relating to this functionality? If so, please elaborate.
- Do you have any suggestions on how to improve this functionality?

Most of the comments apply to both automated alerts and notifications as well as user generated communications, so they will generally be considered together. A few of the comments applied specifically to the user’s ability to generate and send a communication. Where this is the case,

	R1	R2	R3	R4	R5	R6
General			✓	✓	✓	✓
This resonates with what we want to achieve			✓			
This would be useful				✓	✓	
It sounds impossible			✓			
You can't <i>not</i> want to improve efficiency						✓
Priorities and current challenges	✓	✓	✓	✓	✓	✓
Information exchange is currently a big problem	✓					
Cross boundary information is the highest priority				✓		
Information from others is important				✓		
Even if the system is massive, that's better than not having information at all			✓		✓	
Information access is more important than information exchange						✓
Letters are sufficient for information exchange						✓
Information access is what's frustrating						✓
Speed of exchange is more important than efficiency of exchange						✓
The most important thing is to break down the barriers to access						✓
The proposed functionality is less important than getting access across boundaries						✓
Linking in with other systems is important	✓	✓				✓
Suggestions for improvement	✓	✓				✓
More clinical trials functionality	✓					
More functionality for MDTs	✓					
Include patients		✓				
This doesn't cover speed of delivery						✓
Make it easier to collect information						✓
Other			✓	✓		✓
How we use the system evolves				✓		
What people want will vary from person to person			✓			
What people want will vary from situation to situation			✓			
If you can reduce workload, that would be good						✓

Table 7.2: Clinician Responses to Requirements.

it has been noted. Table 7.3 contains a summary of user comments regarding communication functionality and an indication of which respondent(s) expressed each point of view.

Table 7.1 shows that all six interviewees indicated that at least one type of communication functionality would be a beneficial addition to CANISC with only two clinicians indicating uncertainty about one form of communication. This result is reinforced by statements made by several interviewees that alerts are “quite important” [113] and that “probably, even if you only ever did this, that would make a major difference” [114]. Multiple interviewees also highlighted communication as a current challenge; “The lack of communication to GPs, both about

	R1	R2	R3	R4	R5	R6
Current challenges and requirements	✓	✓	✓		✓	✓
Alerts are a high priority			✓			
Now, it is a lot of work to generate and send a communication			✓			
Currently, we only get notices by phone, if at all	✓					
Currently we use outlook, but this is problematic	✓					
There can be communication issues with GPs					✓	
Currently, we have a lag in notifications (from GPs)		✓			✓	
Lack of formal, agreed communication is a problem						✓
We don't know where the patient is	✓					
Quantity of communications		✓	✓	✓	✓	✓
There is potential for information overload	✓	✓				
Incorrect, inappropriate, or over-alerting is a concern			✓			
If people get too many notices they will ignore them			✓		✓	
People should be able to personalise what they see/receive						✓
If 90% of things are alerted, then the rest will be forgotten						✓
Different things are important for different people			✓	✓		
Give a brief note, then let people opt for more			✓			
Need to ensure that nothing is missed	✓					
Things are missed now. It's never going to be perfect	✓					
Filtering 'appropriate' information is a major challenge						✓
Actioning communications	✓	✓	✓		✓	✓
Needs to show if it has been acted on/handled/viewed	✓	✓	✓		✓	✓
I don't want to be required to 'sign off'						✓
I would like to be able to reply to a communication	✓					
How do you ensure that an alert is received?		✓			✓	✓
If alerts are not picked up in a timely manner, they lose value					✓	
Can I let someone else know 'you need to act on this'?					✓	
Learning how to act/react will take time	✓				✓	
Need institutional policies about how to handle alerts	✓				✓	
Would cause/require cultural change	✓					
Workload and and duplication of effort	✓			✓	✓	✓
Could increase workload but also improve patient care	✓					
I don't want to have to do the same thing in two places	✓					
I don't want to have to look in two places for information	✓					
Could increase stress levels.				✓		
I would like a way to prioritise work based on alerts					✓	✓
Other	✓	✓	✓	✓	✓	
This would make a big difference/ would be helpful	✓	✓	✓			
It's good that it's stored in the record	✓	✓	✓			
Even if someone can't act now, it's available when needed	✓		✓	✓		
I can act without having to actively go and search for alerts				✓		
Can users create an automated communication?					✓	
Can users alter or edit automated communications?					✓	
Communications would become secure and recorded in system	✓					
Flexibility of addressee is important				✓		
I should be able to grammar/spell check within the system		✓				
It should be linked to the pager/triage system					✓	
Storing everything in the record means you can keep an audit trail		✓				
Storing everything in the record is good if there is a complaint		✓				
Manual notices would be useful for things that you want to share but which don't warrant a letter		✓				

Table 7.3: Clinician Responses to Communication Functionality.

diagnoses and discharges is one of the main problems we have” [113]; “Currently, we get notices by phone, if at all” [67]; “One of the problems at the moment is the lack of formal, agreed communication” [68]. However, Table 7.1 also shows that every clinician had some concerns about, and suggestions for improving, at least one form of communication functionality⁸. The majority of these concerns fell into three categories: quantity and quality of alerts/information overload resulting from alerts, receipt/actioning of a communication, and duplication of effort. Table 7.3 contains a complete summary of clinician feedback relating to communication within the proposal, both automated and user generated, grouped by topic and indicating which clinician(s) raised each point.

If alerts and notifications are over-used, then the potential for information overload is clear. As one clinician put it, “Some people may be inundated with stuff they don’t want” [67], while two other clinicians explicitly pointed out that the more alerts people receive, the more likely they are to ignore them. “...the more information the GP receives, the more they will click it off... and therefore the less they will actually take note of, but that’s just balance. You can’t have it both ways, particularly around cancer” [113]. One clinician, however, also raised the concern of inappropriate alerts.

“... the concern is that what’s important to alert [for] somebody is not important for another. Or, they may get the alert at the wrong time. So, if you get an alert for a very serious allergy, but it came up, you know, on half the patients all the time, then you’d click it off and it would just be irritating and slowing down the system. So it needs to be available at the time relevant to that alert” [113].

It is worth noting that this problem is slightly different for automated versus user generated communications. Automated communications can be controlled simply by limiting the number of alert and notification policies. User generated communications are much harder to control. As one interviewee pointed out, “it’s very time consuming when it’s not appropriate” [115]. She went on to say, however, that

“It’s trying to get that... appropriate balance for the consultant who’s hideously busy and he needs to know about the dire emergency, but he doesn’t need to know about the little things. And the junior nurse or junior doctor thinking, ‘Well, I don’t know what I need to tell them so I’m going to tell them everything,’ which is what happens within the normal working day.... But that’s a training thing, medically or clinically, rather than, necessarily, use of the system” [115].

⁸An extended version of Table 7.1 showing what concerns each interviewee had is included in Appendix A as Tables A.1 through A.5

At the same time, two clinicians pointed out that there are concerns about comprehensiveness. The first felt that “if you [automate] 95% [of important alerts] and leave 5%, the 5% gets forgotten” [68], while the second pointed out the medico-legal issues of an alert being missed; if a patient suffers harm because an alert which should have been sent is missed or not sent, then the system could be held to blame. He went on to point out, however, that important communications are sometimes missed in the current system, and that no system will be perfect [67]. Interestingly, the developers interviewed for the domain appropriateness component of the evaluation agreed with the second point of view. They felt that trying to cover every possible case would provide a poor cost/benefit ratio and that it would be more pragmatic to focus on alerts of the highest priority.

The first and third of the communications concerns, that there is the potential for information overload and that alerts may be incorrectly sent, are closely tied to policy definition, while the second concern - that people may ignore the alerts - could occur as a result of either of the other two. If too many policies are created that generate alerts, or if policies and/or recipients are not well defined, then there is the very real possibility that automated communications could become a hindrance to clinical work rather than being helpful. Similarly, if clear policies are not put in place regarding sending of user-generated communications, these could also become overwhelming. In the first scenario, almost everything could be highlighted as an alert, in which case items requiring immediate attention would not be more obvious than in a system with no alerts. In the second scenario some alerts would pop-up too often, at an incorrect time, or for the wrong or too many people, meaning that users could not rely on an alert to provide meaningful information. In either case it is realistic to believe that many, if not all, users would ignore the alerts altogether. The fact that every clinician raised some concern relating to information overload and the level of alerting highlights the extreme importance of this concern, while the fact that every clinician also indicated that some form of automated alerting could be useful indicates that the clinicians feel that an appropriate balance can be achieved and that the potential benefits make the functionality worth pursuing, despite the potential drawbacks. In fact, more than one clinician highlighted the importance of balance:

“...you could do all kinds of frills. You could do letters [and] you’d get them much more quickly- balanced against [the fact that] it’s so easy to tell someone something that’s going on... [that] you tell too many people something that they aren’t really interested in” [68].

With regard to communication, this research focused on demonstrating that such communications between team members could be achieved, rather than considering when they should be sent and what information they should contain. This decision was taken for two reasons. First, it was felt that healthcare professionals are best suited to make these types of policy decisions.

Second, time restrictions did not allow for an in-depth examination of potential policies as this would have required a complete definition of professional roles along with a detailed study of the working practices of various healthcare professionals. However, it is clear that determining a range of initial alerts and communication policies is a key area if this research is to be taken forward, and this has been identified as an area of future work (see Section 8.2).

The second major area of concern relates to receipt of communications and acting on them appropriately. This category can be further broken down as three closely related, but distinct questions - how does the system ensure that a communication has been received/read, how do team members know whether a communication has been acted on, and what action, if any, should a recipient take in response to a communication?

The first of these concerns⁹ is tied to timeliness of an urgent alert. If, for example, an alert is generated over a long weekend, it may be several days before the recipient is able to view it and, by that time, it may be too late to take appropriate action [115]. To address this concern, forwarding urgent alerts to a 'triage' person was suggested by one interviewee, as this mirrors current working practices for telephone calls from patients undergoing chemotherapy treatment. If an urgent alert is generated outside of normal working hours, it can be forwarded to the triage person currently on duty who would determine the urgency of the case and either handle the alert or forward it to an appropriate person, such as an on-call physician. For the case where a clinician is on longer-term leave, there are multiple potential options. One solution would be to allow users to manually set up forwarding of alerts, similar to e-mail forwarding. In this case, the clinician would nominate a person or persons to receive alerts during the period of leave. Automatically setting up alert forwarding, while more convenient and fool-proof than asking users to remember to set up forwarding manually, is also more problematic from a technical standpoint. This would require the system to have access to each clinician's leave days as well planned coverage information (who is covering for whom, and when). Additionally, this approach would not be able to handle unplanned leave. Attaching a time component to urgent alerts which automatically forwards the alert to other team member(s) if it is not viewed within a specified time-frame would be a more fail-safe approach, but could contribute to information overload if the alert is not truly urgent or is only of interest to the specified addressee. Forwarding policies and time-frames would have to be carefully considered if this option were undertaken. How best to address this concern requires further research (see Section 8.2).

The second question, how do team members know whether a communication has been acted on, was raised by five of the six interviewees. To resolve this issue clinicians suggested that there should be a way to 'sign off' on a communication to indicate to other team members that it has been handled and they do not need to take further action. However, two interviewees also

⁹Raised by three of the six interviewees.

pointed out that, for some communications and for some team members, the member might want to be aware of the communication but would not be responsible for, or perhaps qualified to, sign off on that communication. Therefore, it would not be appropriate to force a user to sign off on a particular communication. This leads to a potential conflict. On one hand, if one team member handles a situation but does not sign it off, then other team members may spend extra time either duplicating the work or trying to find out if the communication has been handled. On the other hand, requiring users to sign off on every communication they view may result in some communications being marked as handled when, in fact, they have not been resolved. This approach could also interfere with a user's ability to quickly access the patient record in case of an emergency. Given the potential clinical implications of the latter two possibilities, an approach that allows team members to sign off on a communication but does not require them to do so, is suggested. This suggestion also opens the possibility of interesting further research. Some situations may require multiple team members to take action; allowing multiple team members to sign off on a communication, allowing team members to sign off on different parts of a communication, or allowing team members to comment on or attach a report to a communication could potentially enhance the usefulness of the proposed communication functionality.

One clinician also specifically requested the ability to reply to a communication. For example, if a patient is unexpectedly admitted to hospital, the patient's Oncologist may wish to send a notice to the hospital consultant to say 'Please let me know if you need anything from me, or if I can be of help.' Although sending a note of this type could be accomplished in the current prototype through the user generated communication functionality, it would require the user to create a new communication. Incorporating a 'reply' option would improve efficiency (the user would not have to go to a new screen and/or generate an entirely new communication), ease of use (the functionality would more closely mimic e-mail, which is already familiar to most users), and clarity (the original alert could be included in the reply, adding context to the reply, and the relationship between the communications could be maintained; a user reviewing the communications at a later date would more easily be able to reconstruct the 'conversation' if the relationship between communications can be identified).

The third concern relates to knowing how to respond to communications - do I need to act on this, or is knowing about it enough? If I do need to act, what action should I take? Do I need to act on it now, or can it wait until the patient's next visit? Although this issue was only raised by two clinicians with regard to communications, it is a topic that came up in several different areas of the interviews. Interviewees indicated that learning how to incorporate new functionality into the work routine takes time and would initially increase one's workload, but that this is the case with any new functionality. Interviewees also indicated that the potential benefits to patient care would offset the increased workload. Clinician views on the balance between clinical usefulness

I would like an alert for:	Respondent
Hospital admission	R1
Hospital discharge	R1/3
Major new investigation	R1
Patient death	R1/3
Out of hours service has added to the record	R2
Appointment cancellation	R3
Potential adverse reactions	R3
Patient may qualify for a clinical trial	R1/R3
Patient is nearing waiting time	R3
Unexpected changes to patient status	R3
There should be a policy that:	
Cancels a patient's upcoming appointments when a patient dies	R5
Cancels a patient's upcoming appointments upon hospital admission	R1
There should <i>not</i> be a policy that:	
Automatically closes a patient team when the patient dies	R3/R5

Table 7.4: Suggestions for Specific Alerts and Policies.

and workload are discussed in detail in Section 7.3.6.

The final area of concern for general communications relates to duplication of effort. Although this issue was raised by only one clinician, it is worth considering as it has potential implications for system adoption. Currently, communications happen via telephone, post, or e-mail, since messaging is not available within the record. While saving communications within the record could improve patient care by keeping all patient data together and making it persistently available to relevant team members, and would have positive medico-legal and patient privacy implications, it could increase workload if it becomes *another* option, rather than replacing current methods. “You don’t want to have to do messaging twice. You come in in the morning, check Outlook, then have to go and do messaging again in CaNISC” [67]. In such a case it is likely that one method would win out over the other. Since e-mail is multi-purpose and more familiar to users there is the very real possibility that, at least for user generated communications, e-mail would be used over in-system communications. The clinician who raised this point, however, also pointed out the proposed system would both cause and require substantial cultural changes and that organisational policies would need to be introduced to formalise and reinforce these cultural changes. Organisational policies about communications could potentially overcome or reduce this concern. Additionally, providing a link between e-mail and the patient record system is potentially possible, but requires further research, particularly with regard to data security and patient privacy.

7.3.5 Team Functionality

The third functionality group reviewed by clinicians related to team management and providing a tailored view of the patient record. For this range of functions, interviewees were asked the three questions listed in Section 7.3.4: whether the functionality in question would be beneficial, if there are concerns about the functionality, and are there any additional comments? Although Table 7.1 shows that all six respondents felt that at least some part of this functionality would be beneficial, the team aspects of the proposal were the least interesting to the clinicians overall. Some felt that information access is such a high priority that it outweighs potential concerns of information overload; “even if it’s massive... then it’s better than not being able to access it...” [115] and at least one clinician simply did not see the point of establishing teams, asking “What are the advantages... of being on a care team [versus] not being on a care team” (if I have access to all of the information anyway) [68]?

Team functionality falls into two categories, managing team membership and providing a view of the patient record that is appropriate to the user’s current role with the current patient. Because these categories elicited very different types of comments from interviewees, they will be discussed separately here.

7.3.5.1 Managing Team Membership

Despite the fact that this proposal is specifically not intended to restrict access to patient information, every interviewee expressed some concern that it would do so, and this was by far their biggest concern regarding team functionality. Although the context was expressed differently by different clinicians, all six made some comment relating to the fact that situations may arise where a user requires access to a patient record but where the user is not listed as a team member. Scenarios giving rise to this situation included unexpected absence, being on call, roles (such as physiotherapy) where the patient may see a different therapist on each visit, and administrative delays causing team membership to be out of date (see Table 7.5). It is clear that, at least in part, this concern is caused by current policies which restrict access to information “The systems we have at the moment are black and white - they just tell me I cannot [access certain information]” [113]. However, when asked, clinicians did state that having a patient search option, would fully alleviate this concern.

Concerns regarding restriction of access to patient records is particularly interesting since the non-restrictive nature of the proposal was mentioned several times throughout each interview. The fact that every one of the interviewees still expressed concerns relating to being denied access shows how substantial and important this worry is for users. This validates the decision, taken early on in the project, to focus on organisation and presentation of information,

	R1	R2	R3	R4	R5	R6
Tailoring the View	✓		✓			✓
Different users will want/need different things	✓		✓			✓
View for each role is very important	✓					
What is needed will vary between situations			✓			
Needs to consider treatments as well						✓
It might need to let people personalise their view						✓
Let people set their level of notification						✓
Ensuring Appropriate Access	✓	✓	✓	✓	✓	✓
I need access to patients whose team I am not on		✓	✓		✓	✓
Membership information could be out of date or have errors	✓				✓	
Current system just denies access			✓			
Accidentally blocking access is a problem			✓			
Patient may see unexpected person (for some roles the person changes regularly)				✓	✓	✓
Some roles are taken by one person at a time and pass around					✓	
Some practitioners move often						✓
Someone might be on call for an entire hospital						✓
Multiple consultants may be cross-covering each other						✓
People may be left off of a team and not know						✓
How often do you update the team? In clinic, am I on those teams for the day?						✓
Ensuring Patient Privacy	✓	✓	✓	✓		✓
You must get informed consent		✓				
Be sure to remove members no longer on the team	✓	✓		✓		
Make information available, then audit access			✓			
Warn me when I am accessing information out of 'normal bounds'			✓			
You need to check if a person is authorised to have access		✓				✓
Patient security is an issue						✓
How do you make sure people don't abuse access?						✓
Other Comments	✓		✓		✓	✓
Not as beneficial as 'multi-patient' mode	✓					
This is important because it determines who gets notified	✓					
I would get better patient management	✓					
Some of our systems do this too well - provide too much information			✓		✓	
Updating members and referring would be new and useful			✓			
If I have access anyway, what's the advantage of being on the team?						✓
There are many sub-teams						✓
Teams usually very structured - staff change but roles don't						✓

Table 7.5: Clinician Comments Regarding Team Functionality.

rather than access restriction. Although users would primarily access patient information as team members, it is recommended that a patient search (such as the one currently included in CANISC) or similar function be included in any final shared patient record system to allow for instances where clinicians require unexpected access to a patient record.

Closely related to concerns about not having enough access are concerns about users potentially having too much access. These included ensuring that patients give informed consent before their information is made available, ensuring that users do not remain on a patient's team longer than necessary, checking that access is authorised, and ensuring that users do not abuse the ability to access patient records.

The issue of obtaining informed consent was deemed to be out of scope for this project on the premise that this proposal builds on a shared EPR. In order for patient information to be shared through the EPR, the issue of informed consent would need to be addressed. Since this proposal neither extends nor limits information available through a shared EPR, the proposal should not require additional consent from patients.

The other concerns relating to having too much access all centre on the idea of users accessing a patient record without reason, either intentionally or accidentally. There are two main solutions to this problem: restricting access or logging and auditing access. Given the emphatic opposition of interviewees to access restriction discussed above, logging and auditing record access is suggested as a means of addressing this concern. This approach was suggested by one clinician who suggested that warnings be put in place so that users are made aware that they are leaving 'usual' access areas and that their use of the patient record may be audited, particularly if they regularly access unusual or unexpected areas of the system.

“My feeling about access to information like this is always to err much more on the side of responsibility to reasonable use rather than declining people access because, you know, for all the times I hear of inappropriate [accessing of] clinical records I hear ten times - all the time - ‘I didn't have access to somebody's very important clinical information when we were trying to help them.’ So, given [that] it's auditable... you can have certain warnings... little doors you have to go through to get the access.... If I'm looking at another organisation's notes [have a pop-up that says] ‘You're not from this organisation. Are you sure you [want to access this information]?’ and within it a little note (which I'm sure we would ignore after a while) that says ‘A proportion of these accesses will be audited for appropriate use’” [113].

7.3.5.2 Providing a Tailored View

Again, two main points were raised with regard to providing a view of the patient record that is tailored to the user's professional role: that there is a great deal of variation to be catered for and that it may be necessary to allow individuals to personalise their view. The concern about variation has multiple facets. First, clinicians expressed general concerns about the sheer numbers of professional roles that would need to be catered for; "You're talking about having a system for the whole of the NHS. That's a lot of people, even in Wales, to have a system that is functional for everybody" [68]; "It sounds an impossible task" [113]. This is an issue that has been identified as a necessary next step if the work is to be taken forward (see Section 8.2). However, since this proposal aims to extend a shared EPR, it is suggested that the standard view provided by the EPR can be used initially, and differentiated views can be phased in over time as differences are identified. Initially, a set of standard information and functionality can be made available to all users. As the requirements of each professional role become more clearly defined and new functionality identified and developed, the view for each role can be evolved. The ability to easily manage and update the view associated with each professional role is one benefit of recording role and task associations within the Coordination database (see Section 6.4.1).

Variation which needs to be tailored for also includes situational and contextual variation. As currently presented, the proposal provides tailored access based on the user's current role. However, other factors, such as concurrent diagnoses or location of access, may impact the user's information requirements. Georgiadis et al. suggest using location of access to enhance patient security by limiting access to patient information outside of the organisation's network [104], but location of access also has potential clinical implications. For example, in an Accident and Emergency ward patient allergies should be very prominently placed, whereas in a normal consultation setting, where the patient's allergies will only need to be checked in case of changes to his medication, this may not be as important. Context-based access could also include factors pertaining to the patient himself or the stage of treatment. For example, for a patient with diabetes, it may be desirable to include a blood sugar graph in the view for all team members, whether or not the team member's role is related to the diabetes diagnosis. Extending the current proposal to include additional contextual factors in the tailored view is discussed in Section 8.3.

The second point raised with regard to tailoring a user's view of the patient record - allowing a user to personalise their view - is one that has been discussed periodically throughout the project. Although there are potential advantages to allowing users to individualise their access, there are also significant potential issues [116]. In particular, there are medico-legal concerns about allowing a user to decline set levels for what alerts are received. Increasing alert levels

	R1	R2	R3	R4	R5	R6
Lists would be very useful	✓	✓		✓	✓	
Have different lists for different roles	✓			✓	✓	
Currently, nurses keep lists on paper. Having access to that information would be beneficial	✓					
Lists combined with the integrated care pathway could help to manage groups of patients	✓					
You could have a list of patients to be discussed at the next MDT meeting		✓				
You could automatically adjust the priority of items in the to-do list according to deadlines						✓
For some roles (i.e. pager) one person at a time has that role, but that person changes regularly					✓	
Electronic referral would be useful	✓					
Some MDT Modules tell you who's 'in'	✓					
Referrals between MDT members as a result of MDT meeting would be good			✓			
Nurse specialists would love to have details for other team members		✓				
Integration of MDT discussions and immediate actioning of MDT decisions through system would be beneficial			✓			
Don't close the team for patient deceased			✓			
Being able to change Roles through the menu is beneficial					✓	

Table 7.6: Suggestions for Specific Tailored Access Functionality.

(so that the user receives a greater number of alerts than her role would normally suggest) has implications for patient privacy, and decreasing alert levels (so that the user receives fewer alerts) could compromise patient care. This was also the view taken by developers during the domain appropriateness stage of the evaluation. Although the idea of allowing personalisation is an interesting one, there are both technical and legal concerns that need to be investigated before it can be undertaken (see Section 8.3).

7.3.6 Functionality Meeting Requirements

Table 7.1 shows that all six interviewees felt that, overall, the suggested functionality meets the identified requirements, but Table 7.7 shows that they did not feel that the proposal meets the final requirement - that the system should reduce clinician workload. Originally, this requirement was stated differently - that any "increases in workload caused by the system should provide direct clinical benefit" (see Table 3.6). As the project developed it was felt that the functionality and proposal should focus on not increasing workload at all, so the requirement was changed to "The system should reduce clinician workload." The clinicians disagreed with this. They overwhelmingly felt that the proposal could increase workload on the grounds that, if

clinicians are aware of potential patient issues then they must deal with those issues, increasing their overall workload (see Table 7.7). However, they also felt that this extra work would lead to measurable improvements in patient care and, as a result, would still constitute a beneficial improvement to the system. “In a sense we [currently] have an ‘ignorance is bliss’ situation. But [in the case of an unexpected hospital admission] they might not be [caring for the patient] right” [67]. Interviewees also felt that some areas of work would be reduced by the proposal and, as a result, the proposal “would change the workload, perhaps, rather than reduce it” [117].

“Reducing the workload? Yes, I guess it would, somewhat, by doing things in an automated way. More... I think, the improvement in efficiency would be greater than the reduction in workload. In some ways you increase the workload [by] showing people ten things in case they may need one of them, but that’s still what we would prefer to do. Because, at the moment, there’s an absence of information” [113].

A few of the interviewees also made some general closing comments about the proposal overall. Two clinicians in particular were extremely positive about the proposal. “The working model has huge potential.... In terms of patient management it could be fantastic. One could use that system for everything to do with patients. I imagine it would take over all patient-related activity” [67]. “I think this would be really a brilliant development for us” [115]. Although five of the six interviews ended with some positive comment from the interviewee¹⁰, when asked “Do you have anything else to add?” one of these interviewees tempered his positive remarks with this thought:

“No. I think that I did say that most of this ability is almost available now and there [are] many developments that are needed. A number of the changes are process changes... the way we use the IT systems and are allowed to use them, rather than actually new development that needs to be made. So, no. I think it would be great. I think this is all very positive” [113].

7.4 Developer Evaluation

The proof of concept prototype was used to demonstrate feasibility of the conceptual model and to illustrate some of the range of functionality that the conceptual model is able to provide. Interviews with clinicians evaluated whether the proposal addressed an area of need and how well the conceptual model might meet that need. Finally, the developer evaluation was intended

¹⁰The sixth respondent finished the interview with a repetition of some of the concerns discussed above.

	R1	R2	R3	R4	R5	R6
Information Access	✓		✓			✓
If this is all done it would improve information access	✓		✓			✓
Some people would get much more than they currently do	✓					
Information Exchange	✓	✓	✓			✓
This would improve information exchange	✓	✓	✓			✓
Biggest change for information exchange would be to get information from nursing staff into the patient record	✓					
Proactive Support	✓		✓			✓
This improves pro-active support in terms of timeliness of information and having more information	✓					
Pro-active support is more about managing work rather than reducing it						✓
Autosending alerts where people can acknowledge them would be fantastic and an improvement			✓			
Reduce Workload	✓	✓	✓	✓	✓	✓
Reducing workload is the biggest challenge						✓
I'm not sure about reducing workload.				✓		
More information means more work	✓		✓			
This would improve efficiency more than reduce workload			✓			
Improving efficiency of Information access would most reduce workload						✓
Automation would reduce workload somewhat			✓			
This would reduce work in some areas and increase it in others	✓					
Change always increases work, but if it improves quality then it is worthwhile				✓		
This would change the type of work: less hunting, more patient care	✓			✓		
This would reduce duplication of work	✓	✓	✓			
Having the MDT discussion go straight into the record would reduce duplication of effort			✓			
This could improve quality and professionalism of entries into the patient record			✓	✓		
Stuff put in for the sake of it would be a bad trade-off				✓		
Too much information is better than too little			✓		✓	
Other	✓	✓				
I would get better patient management	✓					
Duplicating work can introduce errors		✓				

Table 7.7: Clinician Responses to Requirements Meeting Functionality.

to considered the proposal from a development and maintenance standpoint, with particular emphasis on the practicality of the proposal for consideration within the NHS.

7.4.1 Structure

The developer component of the evaluation consisted of a single, semi-structured interview with three Principal Software Developers currently working at Velindre NHS Trust in Cardiff. As with the clinician evaluation meetings, questions were prepared in advance of the meeting, but interviewees were encouraged to voice comments and questions as they arose. Because this meeting involved multiple interviewees, it was felt that encouraging them to engage in discussion about the proposal, rather than focusing on a specific set of questions, would provide the most useful feedback as it would allow the developers to focus on the issues that they felt were most important.

This approach did give rise to a lively and engaging discussion, but also had some disappointing consequences. The conversation was enthusiastic and the interviewees were clearly interested in the proposal, at least from a theoretical standpoint, but their enthusiasm meant that they often interrupted or spoke over each other, making it difficult to accurately capture all of their points. The rapidity of the conversation and the inexperience of the interviewer also meant that speakers were not distinguished - comments from each of the three interviewees were recorded without reference to which interviewee was speaking. If a similar meeting were undertaken in the future, making a video recording of the interview could potentially reduce the effect of these problems.

In addition, the fluidity of the discussion made time management problematic and the meeting was interrupted before it could be completed. This, combined with the nervousness of the interviewer meant that some key questions were either not asked or were not addressed fully by the interviewees. In retrospect, a series of two or three meetings with the same developers would have been preferable. First, this would have allowed for the proposal to be considered in discreet sections, which would have been better suited to the free-form discussion approach. Secondly, splitting the evaluation over multiple meetings would have allowed time for reflection between meetings. The interviewer could have prepared new questions for each meeting based on the results of the previous meeting. Additionally, this would have allowed more opportunity for raising key questions.

7.4.2 Results

Because interviewees were encouraged to raise points as they were thought of, the conversation was fluid and points were not necessarily raised consecutively. To account for this, as with the clinician interviews, the results of this meeting have been rearranged so that related comments are presented together. The nature of the discussion did not lend itself to a discreet breakdown of the comments into sections (as was done in with the clinician evaluations), so this has not

been attempted.

With regard to tailored/pro-active support, the developers agreed that this would be beneficial and pointed out that the idea of context-based support is “quite popular” [118] and that how, when, and to whom information should be displayed are questions that they must consider as part of their work. “Definitely there’s a tangible need for that kind of a thing in order to improve access to the system” [118]. They indicated that they currently have alerts¹¹ and a side-bar as part of CANISC, but said that improving alerting and notification is important. At the time of the interview, two of the developers were involved in projects to provide tailored access to different parts of the system, providing specialised access for MDT meetings and providing a very different type of tailored access for referrals to palliative care. Both of these examples involve taking information that is already collected in different parts of the system and providing a view that is appropriate for the user’s context.

The developers also highlighted the complexity of determining requirements on a general level as well as what is ‘relevant’ in a specific context. “I am thinking our clinicians would often like it [the system] to be psychic, let alone pro-active” [118]. In particular, they pointed out that what is needed will change as the patient’s treatment moves along the care pathway, “...over a period of time, the amount of interest a particular person has in the patient is going to be different” [118] and that clinicians often aren’t sure what they will want to do with information until it is available through the system.

“One of the key things clinicians are guilty of, all the time, with new requirements, is to say ‘We want access to this information.’ ‘Do you need it to be coded?’ ‘No. Just free text will do.’ Then you give that to them and then they’ll want it reported on. But because their requirement was only for free text [that’s not feasible]... You have to tease out of the clinicians that they might quite possibly perhaps want to report on a certain field. Because otherwise they’d have the entire system as free-text. And it would be a nightmare to extract anything useful out of it” [118].

Interviewees also pointed out the conflict between security and access. They felt that context-based access could be used to protect patient privacy by restricting access, but then went on to discuss exceptions which seem to contravene this principle.

“If you’re a secretary, or even if you’re a bum on the street, you’re not going to have access to all the medical information, whereas a consultant can look at the

¹¹At the time of writing, alerts in CANISC are limited to free-text notes in the palliative care module [3].

same web page, or whatever, and have a complete medical history of everything; they're a consultant"

"Likewise, on the information overload side, clinicians are not interested in seeing lots of [administrative] information."

"But, conversely,... clerks need to be able to input the clinical information but it's important that you don't overload them back with information they're not equipped to deal with. And, for example, with medical images it's simply not appropriate for clerical staff to see it" [118].

This is in line with previous conversations with collaborators where it was pointed out that, ideally, only clinical staff should have access to clinical data, but that exceptions to this rule inevitably occur, eroding the security aspects of role based access. A consultant may ask a secretary to enter information into the patient record, for example, or a clerk will need to enter the results of an MDT discussion [57].

At first glance this seems to contradict the views expressed by clinicians regarding information access and restriction, but this is not necessarily the case. Here, developers were talking about clinical versus non-clinical staff. Restricting the access that non-clinical staff have to patient data is sensible and is not the same as restricting the access of clinical staff. As has been previously mentioned, there are cases where access to certain patient information can and should be restricted, but this has not been the main focus of this research. Access rights and restrictions should be put in place before a unified patient record is made available for use and, therefore, are out of scope for this project. This position was, in a roundabout way, supported by the developers when they pointed out that information sharing and access policies are determined by governmental agencies (at the time, Informing Healthcare) and that any information system used within the NHS must conform to the standards and policies set by those agencies.

With regard to maintainability of the system, interviewees pointed out that "Your configurability is inversely proportional to your maintenance. The more flexible you make it, the harder it is to maintain" [118]. "The holy grail would be to have a self-supporting system that you could do anything with.... You know, we could do that, but then you've got... like a thousand widgets that you've got to support" [118]. Unfortunately, the interview ended before this point could be discussed in the context of configurability and maintainability of the proposal.

When asked whether or not it would be feasible to integrate the proposal with CANISC, the answer was an unequivocal "No." They felt that the proposal would require too much re-design of the database underlying CANISC. This is not surprising, despite the fact that the proposal is specifically designed to be independent of the structure of the patient record database and an older, anonymised version of the CANISC system was included as part of the proof of concept prototype. Recent political changes have resulted in significant changes to development and

management of informatics and ICT projects in the Welsh NHS. The developers interviewed no longer have control over the future or structure of CANISC. Incorporating a separate database is therefore not an option that the interviewees could decide to take.

7.4.3 Discussion

The majority of points raised by the developers confirm the requirements and challenges identified throughout this thesis.

- Requirements are not currently well understood and, until a working system is available, clinicians are unlikely to be able to specify exactly what they need;
- As new functionality becomes available, what clinicians want will continually evolve;
- Context-based access and pro-active support are desirable, but what is relevant is so dependent on the details of a situation that determining what is relevant in a given situation is extremely difficult;
- There are conflicts between the need for access and security/patient privacy;
- There are conflicts between flexibility and maintainability.

The point that it would not be practical to implement the model into CANISC, while it has not yet been explicitly discussed in this thesis, is neither a surprise nor a serious concern. The entirety of this research has been exploratory and the VOICE model is as much a proof of concept as the prototype that implements it, and it was not expected that it would be suitable for full implementation as designed. However, this does not negate the value of the model in helping to understand and define the problem area and to explore the potential of using team information to support care teams.

7.5 Additional Issues

It is worth noting that over the lifetime of this project several concerns were identified in the literature review or were raised during informal conversations with clinicians which did not arise in any component of the formal evaluation. Some of these concerns relate to system aspects which are out of scope for this project and others have been left for future work. However, for the sake of completeness, these concerns are discussed briefly here.

7.5.1 Changing a User's Interface

From a computer science perspective, altering the user interface is a concern worth noting. Conventional wisdom in HCI state that a system's user interface should remain consistent and that altering the interface can confuse and frustrate users. Interestingly, not one of the interviewees, either clinicians or developers, raised variations in the interface as a possible concern with regard to the system, with the exception that the clinicians were concerned about being denied access (see Section 7.3.5, above). It is possible that this is a subject that simply did not occur to the clinicians and that they would have expressed concern if the issue had been raised, but it is also possible that it isn't a concern for them at all. CANISC has some interface variation based on the user's role¹² and organisation [56] and some of the interviewees, at least, interact with multiple systems (in addition to CANISC) as part of their daily work, so it is possible that they are used to dealing with changing interfaces. Additionally, the prototype provides role-based access by changing the available tabs, rather than altering the layout of either the interface in general or the details or layout of the tabs. Finally, it is likely that, especially in the short term, user interfaces and available functionality would vary only minimally between professional roles with each role having the same basic view plus a few extra, 'specialist' tabs tailored specifically for that role. This would minimise the concerns relating to changes to the user interface.

7.5.2 Inclusion of Services Outside the NHS

This work has focused on providing support for a patient's care team - the group of healthcare practitioners providing care to a patient, but this work has been restricted to the patient's *health* care team, and has not considered either social care or mental health. Mental health was excluded for reasons of patient privacy and social care was excluded because it is not part of the NHS and the legal rights of social care workers to access any part of a patient's record are dubious. But, in order to provide the best possible care it is necessary for social and health services to work together and, in this sense, social services providers could be viewed as members of the patient's extended care team. Additionally, there is some pressure from the Government to provide social services with some access to patient records [46, 47]. However, before this can be pursued further, the legal aspects of such a proposal must be tested.

¹²Defined by 'user group.' User groups are generally related to clinical area, such as colposcopy or palliative care, for example [3].

7.5.3 Information Inferred From Team Meta-data

While the idea of using team meta-data to support collaboration has potential benefits for a patient's care team, it also has potential implications for the patient's privacy. If a team member is able to access a list of other team members (as in the current prototype), this has the advantage of supporting team members ability to contact each other, but it also may reveal a great deal about the patient's current condition. If the patient's team contains an oncologist, it can be inferred that the patient is being or has been treated for cancer. Similarly, if a patient's team contains an Obstetrician, one might infer that the patient is, has been, or is trying to become pregnant. Such inferences may or may not be correct - the patient may have had a cancer scare but investigations revealed negative results, for example - but the ability to make them at all must be considered with regard to patient privacy. Admittedly, such inferences can also be made through access to other aspects of the patient record, such as a list of the patient's medications, but listing the patient's healthcare providers makes such deductions easier, simpler, and quicker. This concern may be minimal with regard to most patient diagnoses and may be outweighed by the potential improvements to patient care. Additionally, sensitive services which are currently protected and confidential, such as sexual health, may not be part of the integrated EPR and so would not be part of information presented to the patient's care team. Further, any integrated EPR should involve some form of informed consent or opt-out procedure. This reduces the concern with regard to a patient's physical health, but the problem takes on a different dimension when the issue of providing access to patient records outside the health services is considered. In such a case the potential for abuse of the system increases substantially. It is clear that more emphasis would have to be placed on access restriction if such an extension to the proposal were to be considered.

7.5.4 Generalisability

Although this work has focused exclusively on the healthcare domain, there is reason to believe that the proposal could be applicable to other domain areas where certain criteria are met. Although the proposal could be implemented in any area where information sharing is desirable (and legally allowed), there are additional factors which impact its usefulness in a given situation. Almost any organisation *could* implement the proposal, but many would find that it does not meet their needs. In particular we note that, in order for the proposal to be applicable and provide benefit to an organisation:

- All data should be owned by a single organisation (or umbrella organisation) and the organisation should have both the legal right and the desire to share information between its employees.

- The organisation should use long-term distributed teams and these teams should engage in tasks that require communication, coordination, awareness, and joint decision making, but *not* collaborative creation of objects or deliverables.
- Team members should undertake roles which are sufficiently different to have different information and support requirements.
- Although it is not necessary for teams to evolve over time, the approach is suitable for applications where this is the case.

The level and type of collaboration engaged in by team members is the key consideration for applicability of this proposal to a given domain. The proposal has been tailored for teamwork that emphasises support for asynchronous coordination and awareness tasks. Although the proposal does include the information access and tailoring to support joint decision making, tasks requiring a high degree of synchronous communication or collaborative creation (such as joint creation of artefacts) are not supported. This rules out many commercial applications, which would be better supported by groupware or similar approaches. However, it is believed that the proposal would be suitable for many government and charitable organisations where coordination and delivery of services are carried out by distributed teams (see Section 8.4). The ability to track and store all communications as part of the case file to which they pertain has the added benefit for Government organisations of improving traceability and for accommodating freedom of information requests.

The caveat that all data should be owned by a single organisation is, perhaps, an over-simplification. In this research, for reasons of scope, it has been assumed that issues of data restriction have been handled elsewhere and such issues are not considered here. This means that the approach, as presented here, is not appropriate for applications where information sharing is restricted for either legal or organisational reasons. For example, this approach is unlikely to be appropriate for short-term collaborations between commercial enterprises where information sharing is desirable, but at the same time is highly restricted, as is the case with most commercial endeavors involving VOs. This problem could certainly be overcome with additional research into data protection and security. However, at the heart of this proposal is the idea that it is not intended to hide or restrict information. Adapting the proposal to situations where information restriction is required would require a radical change in point of view and could alter the potential benefits of the proposal.

7.6 Analysis

In Chapter 1 it was hypothesised that:

A healthcare information system that organises and manages data around care teams will have the capacity to provide more effective support for collaborative working within distributed care teams than current approaches are able to provide. Specifically, a team-based framework will allow for pro-active, role-based support for individual care team members, providing improved efficiency of information access and exchange through targeted, tailored, automated communication and information access. This will be demonstrated through:

- Automated generation and sending of communications and alerts, and
- Provision of information organised and tailored to the context of access including factors such as patient condition and professional role of the user with that patient.

Taken together, the proposal and evaluation support this hypothesis. The conceptual model provides the team-based structure laid out in the hypothesis. The proof of concept prototype implements this structure and shows that it can be used to provide both automated generation and sending of communication as well as tailored information access and support. The clinician and developer interviews confirm that the model provides functionality that is not currently available and that the proposed functionality is both beneficial and meets the requirements of providing pro-active, role-based support, improving efficiency of information exchange, and improving efficiency of information access.

In addition to the factors explicitly stated in the research hypothesis, the evaluation also demonstrates that the proposal meets other requirements necessary for acceptance and appropriateness to the domain. The proof of concept prototype demonstrates that implementation of the conceptual model is feasible. User acceptance of new systems is a major factor in the success of healthcare information systems. In the clinician interview, respondents indicated that they would accept the functionality as long as it is perceived as being clinically helpful. Their comments also highlighted some of the potential barriers to acceptance which should be considered if the proposal is to be taken forward.

Although the developers were, overall, positive about the proposal, they also highlighted some challenges to implementation, maintenance, and adoption. While the developers also said that they did not feel the model could be incorporated into the CANISC system, this is neither a surprise nor a serious concern with regard to the value of the research. This project in its entirety has been exploratory and the conceptual model and prototype have served the purpose of sparking discussion and providing insight into the requirements, potential benefits and potential problems with using team information to provide information systems support for care team members. The spirited discussions and feedback provided by clinicians and developers alike support this as much as their overall enthusiastic response to the proposed functionality and requirements.

7.6.1 Welsh Clinical Portal

The results of the evaluation are also supported by recent publications regarding the future of the WCP. As mentioned in Section 2.3.2.2, the WCP is now expected to include some of the functionality proposed within this research, in particular, electronic clinical communications, alerts, and clinical pathways¹³ [53]. Interestingly, the proposal does not yet indicate how notification recipients will be determined or to what extent they will be automated.

These plans for the future of the WCP support the validity of this work by showing that it is ‘on the right track’- that the type of support considered here is in line with what the Welsh NHS now believes will be required. In addition, it is possible that this work has influenced the functionality now proposed for the WCP through conversations with a developer involved with the WCP [119, 120] and through consultation with clinicians and developers at Velindre who are also involved in discussions with developers from the WCP. However, it is impossible to say with certainty whether or not this work has influenced the course of the WCP.

7.7 Conclusion

Evaluating this proposal effectively required a complex combination of evaluation components. First, the prototype was used to demonstrate feasibility of the conceptual model and as a tool for illustrating some of the types of functionality which can be achieved using this approach. Next, clinicians were interviewed to determine the validity of the requirements, reflect on the usefulness and potential problems with the proposed functionality, and to determine whether the proposed functionality met the identified requirements. Finally, developers currently working within the NHS were interviewed to evaluate the architecture, fitness for purpose of the proposal including maintainability and integration with existing patient record systems, and to give further insight into the applicability and practicality of the proposed functionality. The various components of the evaluation were linked together through an analysis of the relationship between the research hypothesis, proposed requirements, and prototype functionality.

Although some concerns were raised about implementation and potential implications of some functions, interviewees were enthusiastic about the proposal, indicating that they felt the high level requirements were appropriate and of high priority and, for the most part, that the proposed functionality would constitute a beneficial addition to CANISC. They also felt that, with the possible exception of reduction of workload, the proposed functionality met the stated requirements. With regard to reduction of workload it was generally agreed that the proposal would

¹³Incorporating clinical pathways is included here as future work. See Section 8.2

decrease work in some areas, but increase it in others. However, if increases in workload resulted in improvements to patient care, interviewees felt that the trade-off would be worthwhile (see Section 7.3.6).

Overall, the evaluation supports the research hypothesis. The proposal can provide a range of functionality for clinicians working in care teams which is not currently provided by healthcare information systems in the NHS. Although more research needs to be done to determine the details of implementation, the provided functionality has the potential to provide significant benefit to healthcare practitioners.

Future Work

Overview

Thus far, this work has introduced and evaluated a conceptual model for information systems to support the work of care teams in healthcare. This work has, however, been necessarily limited in scope to accommodate the time and resource constraints associated with PhD research. This chapter highlights a range of work that could be undertaken to expand on the work begun in this project.

8.1 Introduction

Developing effective and efficient information systems for healthcare practitioners is an enormous endeavour. This work has focused on only a portion of this problem and even then has only scratched the surface. This research has focused on demonstrating proof of concept for a conceptual model to support teamwork among healthcare providers working as members of collaborative care teams. If this work is to be carried further, there are several aspects of the proposal that require further research. In addition, in order to maintain a reasonable scope for this project, many important issues were left for future work. Finally, there are many less critical, but related, areas that it would be interesting to pursue as further research.

8.2 Major Projects

This thesis introduces a conceptual model for supporting teamwork in collaborative care teams, supported by a proof of concept prototype focusing on cancer care. The thesis and the prototype outline a range of functionality, but the fine detail of this functionality has not yet been specified. For example, what information should be recorded as part of a consultation? How should a clinician's daily appointments be displayed and what information should be contained in this display? If this work is to be taken further, the most pressing matters are range and detail. The first step is to expand the range of the functionality, roles, and policies considered in this work. Additionally, the current proposal has focused primarily on cancer care. The needs of practitioners in various professional roles and specialities, working with patients with different conditions and diagnoses, must be considered in more detail. As has been previously noted, this is a major undertaking and involves extending and testing several different aspects of the conceptual model as well as the prototype.

First, a study must be undertaken to identify and define an initial set of professional roles as well as tasks and functionalities required by each professional role. An initial list of potential professional roles could be determined through existing job titles. Similarly, a study of tasks and functionality provided by existing systems would be a good place to start for determining potential functionality for the proposed system. Once these initial lists are compiled, however, it will be necessary to engage with healthcare professionals to determine a final prioritised list of necessary functionality. Ideally, this work should initially involve healthcare practitioners working both in cancer care and at least one other, complementary, speciality such as geriatric medicine. Although current proposals for integrated EPRs do not, in general, include GP surgeries, it is also recommended that the needs of GPs be particularly considered in the next phase of the research since much of the team's communication and coordination involves the patient's

GP. Once a more comprehensive prototype has been developed and the conceptual model has been evaluated with regard to a larger range of specialities, further expansion can be undertaken.

As part of the proposed extension and increased detail suggested above, attention must be paid to presentation of information and the user interface. This project focused on meeting high level requirements. Creating an ideal user interface was deemed out of scope for time reasons. However, the user interface can have a significant impact on whether a new system is used at all as well as how effective that system is for users. During the evaluation, one of the interviewees highlighted this problem, saying that if you alert too much or it all looks the same “as in everything is red or everything is bright blue or something, then that’s just going to be ‘oh, that’s just what this screen looks like... I’m not expecting anything different’ ” [115] and alerts will lose value as alerts. Role-based access, alerts, and communications are of no use if they are not presented in a way that is helpful and meaningful to the end-user. Determining optimal presentation of the various system components is key to the overall success of the proposal.

In addition to these essential next steps, work has already begun on incorporating a work-flow system linking the patient record to integrated care pathway(s) [121, 122, 123]. Incorporating care pathways would allow for a new range of policies, including policies involving timing and coordination. For example, if it is expected based on the anticipated care pathway that a patient will require blood to be drawn for multiple tests in the near future, it will be possible to highlight this and potentially draw blood for all required tests in a single appointment. Similarly, the care pathway could incorporate waiting time guideline data. Using this information, it may be possible to create policies to notify team members when a patient is nearing his waiting time deadline. Timing information could also be useful for indicating the level of urgency of actions and/or alerts, as suggested by clinicians (see Section 7.3.4)¹.

8.3 Areas of Interest

The list of next steps if this work is to be taken forward encompasses a substantial amount of work. However, there is also a range of interesting areas of potential further work which are not as central to the main proposal, including personalisation of a user’s view, allowing patients to have access to their record, handling shift-work, and providing access that incorporates a wider variety of context factors. Additionally, although it is widely out of scope for this project, a review of healthcare literature pertaining to MDTs undertaken during the background research phase of the project highlighted the need for a comprehensive study of MDTs and the creation of

¹Using the integrated care pathway to incorporate a wider range of policies was briefly discussed during clinician interviews as potential future work. Clinician responses to this functionality are included in Table A.9 in Appendix A)

a typology for healthcare MDTs in order to better understand their support requirements. Many different types of MDTs exist and their structure and working practices vary widely (see Section 2.3.1). Having a classification for different types of MDT and understanding the similarities and differences between them would provide a foundation for generalisable research relating to MDTs.

The idea of allowing users to “personalise” the system was discussed at various stages of the project and a potential approach using local settings was considered [116]. Personalisation could include allowing users to modify the user interface in terms of ordering of tasks or what information is displayed in the user’s ‘patients list’, for example. Personalisation could also include allowing users to adjust the number and presentation of alerts received. Indeed, allowing users to adjust receipt of notifications was the most common topic when personalisation was considered. However, as with so many things relating to healthcare information systems, allowing users to adjust their system view raises as many concerns as it addresses, particularly with regard to allowing users to alter which alerts they receive. As discussed in the evaluation (see Section 7.3.4), over-alerting was seen by interviewees as a major concern with regard to the proposed functionality. Allowing users to limit the number and type of alerts received would reduce the risk of information overload from alerts, but could result in some clinicians missing important notifications, undermining the usefulness of the proposal, whereas allowing users to sign up for ‘extra’ alerts has implications for security and patient confidentiality. However, allowing users to adjust some aspects of their interface does have the potential to improve usability. Similarly, allowing site groups (such as a GP surgery, for example) to implement local settings or policies would certainly improve the flexibility of the system and, again, has the potential to significantly improve system usability and the user experience.

The proposal, as currently designed, could allow patients to access their records by simply incorporating ‘patient’ as a professional role with appropriate tasks. However, the issue of allowing patient access to records is more complicated than one might expect. Two main concerns are patients accessing and not understanding information contained in the record, and carers other than the patient accessing the record. In the first case, for example, there is the potential for a patient to access her record in the evening or on a weekend. If test results have been recently updated, the patient may see these results and become concerned, but may be unable to contact her doctor for several days. This could leave the patient in some distress. In the second case, situations where a child, disabled, or geriatric patient may have carers other than themselves looking at their record must be considered. In such a situation, the patient’s expectation of confidentiality may be violated. For example, if a child reports or a doctor suspects abuse, this must be recorded in the patient’s record. However, if the person committing the abuse, such as a parent or other carer, has access to the patient’s record (as could be assumed in the case of a minor), then the abuser could gain access to the report. Potential solutions to both of these

problems are currently being considered (e.g. [124, 125]), but further research is required to determine how any proposed solutions may be included in the current proposal. If the Coalition Government's current plans to ensure that patients have access to their health records [25] go forward then this aspect of future work will increase in priority.

Although the conceptual model is designed to be flexible and to allow for alterations to the patient's care team over time, it does not explicitly address the issue of short-term team members, such as ward nurses or other practitioners who may not see the patient consistently. For example, in some GP surgeries, patients see whichever doctor is available rather than seeing the same doctor at every appointment. In such cases, questions arise about how functionality should be applied. Who should receive a notification about a particular patient? In the case of ward nurses or other practitioners who work in shifts, the question arises of whether it is practical or even beneficial to add and remove them from each patient's care team. One option for addressing such situations is to use policies. For example, when a patient is admitted to a hospital ward, all nurses assigned to that ward could be added to the patient's care team. In the case of a test request, for example, the person who ordered the test is the one who should be notified of results. However, this is not an ideal solution. Following this model, nurses would receive notices for all patients on the ward, whether or not they are currently on duty. This would cause a significant amount of overhead for the nurses in terms of determining which notices have been acted upon and which still require action. On the other side, setting a policy that the person who orders a test should be notified when the test results are returned may mean that notification is delayed if that person is off work when the test results come in. A second alternative would be to exempt shift-workers from the patient's care team altogether. Practitioners who will only be working with a patient for a short time can continue to use existing systems. However, this solution still does not address the question of how, when, and who to notify in case of problems with a patient's treatment. It is suggested that how to provide support for practitioners who deal with a patient as short-term or shift-work should be considered in more detail.

Finally, the conceptual model proposed here provides tailored access based on a user's role with each patient. However, there are many other dimensions which could be considered to tailor user access even further. The user's view could be altered if the patient has multiple diagnoses or depending on when and/or where the user is when accessing the patient's record. When working with a patient who has diabetes, for example, all care team members could have a tab summarising the patient's latest blood-sugar measurements and any complications arising from the diabetes. Altering information access levels depending on where access is taking place is not a new idea, but it has not been considered as part of this proposal. Using location to determine access is sometimes proposed for purposes of security (e.g. [104]), such as providing reduced access outside the hospital network. However, this approach could also be used for purposes of improving usability. For example, a record accessed in an Accident and

Emergency department could always contain a summary record as the main task tab. Inclusion of integrated care pathways as discussed above will add the dimension of ‘current treatment stage’ to the tailoring of access provided by the conceptual model, but inclusion of additional context factors also has the potential to substantially improve the usefulness of the system.

8.4 Application to Different Domains

Lastly, whether and how the proposal could be extended to fields outside of healthcare should be considered. Section 7.5.4 provided a set of general criteria necessary for the application of the proposed approach. Namely, this approach is appropriate for situations where:

- all data is owned by a single organisation (or umbrella organisation) and the organisation has both the legal right and the desire to share information between its employees,
- the organisation uses long-term distributed teams and these teams engage in tasks that require communication, coordination, awareness, and joint decision making, but *not* collaborative creation of objects or deliverables,
- team members have roles which are sufficiently different to have different information and support requirements, and
- teams evolve over time.

It is believed that the conceptual model proposed here could provide benefit in situations where these criteria are met, but this has not been tested and further research into applying the approach to non-healthcare settings should be undertaken. Although the criteria may mean that the proposal is not ideal for commercial settings, governmental organisations such as social services, education, or even social welfare do meet the stated criteria.

Consider, for example, provision of special needs education in public schools in California. Under the Individuals with Disabilities Education Act (IDEA) it is a legal requirement that any student who is determined to have special needs is provided with appropriate services and/or classroom modification [126]. In the Los Angeles Unified School District, this is accomplished through the development of an Individualised Educational Plan (IEP) for each student with special needs [127, 128]. This plan is determined and updated by the child’s IEP team at annual IEP meetings. The IEP team consists of those people responsible for the student’s education for that academic year. This includes the student’s teacher and, often, a range of other educational specialists, such as a speech therapist or reading coach, as well as the child’s parents [127]. Between IEP meetings, the child’s educational team are distributed and members of the team

have a legal right to access the student's record, but different team members will be interested in different aspects of the record. To ensure that the student is progressing appropriately, team members should communicate regularly between IEP meetings, and the IEP team will change over time [129]. This situation meets the criteria for application of the proposed model, and it is believed that a system implementing the conceptual model could provide meaningful benefit to IEP teams, improving communication and, consequently, improving the student's education. However, this belief has not been tested and further research is required.

Because public organisations such as social care, for example, often engage in coordination tasks and because they do not face many of the challenges associated with competition as commercial organisations do, it is believed that public, government, and charitable organisations are more likely to benefit from this proposal than commercial organisations. However, every domain and, indeed, every organisation has its own unique challenges and issues, so each potential application will need to be researched individually to determine the applicability of the proposal and any necessary alterations to it.

8.5 Conclusion

Improving healthcare information systems and providing efficient and comprehensive support for healthcare practitioners is a substantial and multifaceted challenge and many aspects of this challenge have yet to be investigated fully. It is not surprising that a range of potential research areas have been identified but not addressed through this project. If the work presented in this thesis is to be carried further, then there are several next steps which must be undertaken. In particular, the work carried out here has been largely theoretical in nature. Functional requirements have been considered, but more detail is required. The specifics of how the model can be applied to the day-to-day work of practitioners must be considered in more detail. In addition to the 'next steps' for carrying the conceptual model further, a wide range of related questions have arisen which could constitute interesting research projects in their own right. Although the number of potential future research projects identified during this project is somewhat daunting, this was expected. One of the first conclusions drawn in this project was that requirements for future healthcare information systems are, as yet, not clearly defined. Although progress has been made on a number of fronts, there is still a great deal that has yet to be understood.

Conclusion

I never am really satisfied that I understand anything; because, understand it well as I may, my comprehension can only be an infinitesimal fraction of all I want to understand about the many connections and relations which occur to me, how the matter in question was first thought of or arrived at, etc., etc.

-Ada Lovelace

9.1 Introduction

The underlying ethos of what constitutes best practices in healthcare has undergone radical changes over the last thirty years in the UK and around the world, moving from a disease-centred approach, where clinicians from different specialities worked independently, to a patient-centred approach where clinicians are expected to work collaboratively and view the patient as a whole. This shift from working independently to working collaboratively has required substantial changes to working practices. As a result, the information systems support required by healthcare practitioners has also changed dramatically. Unfortunately, healthcare information systems have not been able to keep pace with this change. Two key factors which have contributed to this problem are the widespread use of legacy information systems which were not designed to interoperate, and poorly understood (and evolving) requirements. The use of legacy information systems in healthcare is unavoidable. Not only do they represent a substantial capital investment, but they contain patient data which is needed for ongoing patient treatment. In addition, there are a great many different legacy systems in use, each meeting different needs. Further, requirements for healthcare information systems are not perfectly understood and are constantly evolving. Consequently, although much work has been done to improve information systems support for patient-centric healthcare teams, there is, and perhaps always will be, a great deal yet to be done.

This research hypothesised that organising and managing data around care teams would allow for more pro-active, context-based support than current approaches are able to provide. A model that captures team data and meta-data was proposed, and a proof-of-concept prototype implemented to support the model. During evaluation the proposal and prototype were greeted positively by both clinicians and developers, but the aim of providing appropriate support to healthcare practitioners encompasses many complex and varied challenges, and there are many areas where this research could be extended. Areas of potential future work were identified in different ways; some suggestions for future work were made by clinicians during the evaluation process, some areas, such as the decision not to include patient access, were excluded from the project in order to maintain an appropriate scope, while others, such as personalising access on a user-by-user basis, were excluded because they required further research into legal and ethical issues before they can be fully addressed¹.

¹In the case of personalising access, for example, some clinicians may want to ‘turn off’ the alerts. This is potentially problematic, however, since they may then miss urgent information about a particular patient. While this sometimes happens under the current system, the idea of someone *knowingly*, rather than accidentally, being allowed to not receive information raises new ethical and legal questions which should be considered as part of any research into personalisation of access.

9.2 Setting the Stage

As a state run system, the NHS in the UK is heavily influenced by politics. In the early 1990s, the NHS operated under the internal market model. In 1997, when the government changed, the internal market model was thrown out, and a new approach was adopted, the patient-centric approach. As the name suggests, the internal market model created a ‘free market economy’ within the NHS where healthcare providers bought and sold services to one another. The intention of the internal market model was to spur efficiency and innovation through competition; centres offering similar services would improve in order to compete with one another. In reality, competition led to ring-fencing of patient data and innovation. If a service provider found a more efficient way of working, there were direct disincentives to sharing this insight with other providers. Additionally, because sharing was off the agenda, there was no reason to consider sharing or interoperability when purchasing information systems. In terms of ICT, the legacy of the internal market model and its predecessors is a variety of information systems that do not conform to any common set of standards, and which are not interoperable. This would not have been a problem, except that the patient-centric approach requires a high degree of communication and information sharing and, as a result, requires information systems at different sites to interoperate (see Chapter 2).

In 2010, the government again changed and, again, the new government has new ideas about the way the NHS should operate. At the time of writing it seems that the patient-centric approach will be kept, but there is a push to move even further towards healthcare that is ‘all about the patient,’ with an increasing emphasis on patient choice and patient inclusion in decision-making - “no decision about me without me” [25]. In terms of patient records, the option of personal health records under the control of the patient, has been proposed [130]. Whether this will be taken forward and how such a system might be structured and managed is currently unclear. The new papers also continue to emphasise the need for cross-boundary cooperation, coordination, and collaboration between healthcare practitioners.

Current ICT projects in the NHS focus on making information available. While this is certainly a necessary first step, it does beg the question- is this the only requirement for healthcare information systems supporting the patient-centric approach? We believe that it is not (see Section 2.4), and began this research by examining a range of research areas to determine additional requirements for future healthcare information systems (see Chapter 3).

9.3 Information and Collaboration

In order to identify the greatest possible range of requirements, literature in a variety of areas was considered. At the same time, requirements were discussed with developers and healthcare practitioners working within the NHS. In particular, the literature survey considered requirements from the perspective of care team members, where a patient's care team is defined to be the set of all healthcare practitioners providing care for that patient. The literature survey included research ranging from small group research in social science, to studies of virtual teams in computer science, as well as health informatics. Considering a broad range of research allowed for a much broader identification of requirements than had been discovered considering purely healthcare literature (see Chapter 3).

As a result of this analysis, four central themes emerged as requirements for information systems to support care teams:

- The system should support efficient information access (across multiple sites)
- The system should provide efficient information exchange
- The system should provide pro-active support
- The system should reduce clinician workload.

The WCP and other projects are moving towards provision of a shared EPR. Rather than compete with these projects, it was decided that this research would take a shared EPR as a starting point. We assume that a shared EPR will exist and that it will provide access to patient information across organisational boundaries. We then consider how such a system could be extended to meet the remaining requirements.

This approach did cause some additional challenges. In particular, because a true shared EPR is not yet available in the NHS, it is difficult for practitioners to know how they will use such a system and, as a result, what they will want from such a system. To handle this challenge, a very evolutionary approach was adopted (see Section 4.6). Each phase of the project from requirements gathering to implementation underwent several iterations, often overlapping. Although only one prototype was developed, it evolved over the course of the project as new ideas and problems were raised. Collaboration with Velindre NHS Trust also helped to minimize this challenge. The CANISC system was developed and is currently in use at Velindre Trust. This means that practitioners working at or with Velindre Trust have experience with a shared EPR, albeit a relatively focused one², and that technical staff at Velindre Trust have experience developing and maintaining a system which is highly successful and well thought of by clinicians.

²CANISC primarily focuses on cancer patients and cancer related patient data (see Section 2.3.2.3).

9.4 Meeting the Requirements

To address the identified requirements, a conceptual model was proposed that records and tracks care team membership and roles. Using this data, the VOICE model creates associations between each patient, the roles of the practitioners on his care team, and the individual practitioner who is taking on each role. This information can be used to provide each practitioner with a view of the patient record which is tailored to his current role with the current patient (see Section 5.4.1).

The VOICE model also incorporates a policy component for achieving pro-active support and to reduce required maintenance (see Section 5.3.3). Each policy consists of role, event, and action components. The role indicates the professional role(s) affected by the policy, while the event indicates when the policy should be activated, and the action indicates what action should be taken as a result of the policy activation. The role attribute provides a link between policies and care teams and can be used to resolve generic policies into actions affecting specific individuals. Policies can also be used to update team data. If a patient is electronically referred to a new clinician, he can automatically be added to that patient's care team within the system. Because team membership can be automatically updated, the model is able to provide dynamic support. If a team member's role changes, the record view and alerts received will update to reflect the new role. Similarly, if a practitioner plays different roles with different patients, his record view will automatically adjust to reflect the appropriate role when he switches to a different patient.

In the proof of concept prototype, which was developed to support the conceptual model, demonstrate its feasibility, and facilitate discussions with clinicians, the identified requirements were translated into a variety of end user functionality. These included tailored patient record access based on each members' current role within the team, user generated communications and pro-active support in the form of alerts and notifications regarding changes to the patient's status. All communications, whether manual or automatic, are recorded as part of the patient record (see Chapter 6).

This proposal moves beyond current proposals by considering how contextual factors and unexpected changes to a patient's care may impact the information systems requirements of healthcare practitioners. The VOICE model uses a practitioner's role for each patient's care team to determine what information is most likely to be relevant to that practitioner at a given time with the given patient. By considering the team aspect of patient care, the VOICE model allows for individualised pro-active support for each team member based on his or her role within the team. This includes tailoring each team member's view of the patient record to reflect the needs of his professional role with the given patient, support for automated, partially automa-

ted, and user generated communications which can be sent to individual clinicians based on professional role. While other proposals, such as the WCP, propose to incorporate some of the functionality offered by VOICE (such as alerts), these proposals do not consider the team aspect of patient-centric care. Additionally, there is currently no indication of how alerts and other communications will be addressed. In the VOICE proposal, a clinician can identify other team members, address notes to team members based on either name or team role, and communications (both automated and manually generated) can be automatically tailored to meet the needs of the recipient based on his team role. This provides improved practitioner awareness, reduction of information overload, and improved patient security.

9.5 What Next?

Evaluation of the proposal was a complex process involving multiple stages. The proof of concept prototype demonstrated that the conceptual model can be implemented, but it also served as a link between the evaluation components as well as bringing together the requirements, hypothesis, and conceptual model. Interviews with clinicians and developers within the NHS provided qualitative feedback on the proposal and the range of functionality that could be provided through the conceptual model (see Sections 7.3 and 7.4).

Overall, interviewees were extremely positive about the proposal and the range of functionality offered. One clinician went so far as to say, “In terms of patient management it could be fantastic. One could use [the proposed] system for everything to do with patients.... I imagine it would take over all patient related activity” [67]. Clinicians did have some concerns about aspects of the proposal in practice. The potential for too many alerts and communications is significant if communication policies are not carefully defined. Additionally, clinicians had serious concerns about the potential for being excluded from patient information if they were left off of a patient’s team. This concern came through even though interviewees were told that a patient search option would be available (as it is in their current system) and that the proposal is not intended to restrict access. This reinforces the results of the background research which indicated that access to patient information is currently the highest priority for clinicians. Despite some concerns about implementation, the results of interviews with clinicians were, overall, highly positive. Clinicians felt that the proposed functionality would be a positive addition to their current system, that the requirements are high priority, and that, with the exception of reducing workload, the proposal did meet the requirements. With regard to reducing workload, clinicians felt that some areas of the proposal may decrease workload by making information available that they currently have to ‘chase.’ Improved communication and alerts could increase workload, but it was felt that the potential increase in work would be worthwhile as impro-

ved communication would also provide improved patient care. The developers interviewed, while positive about the proposal, also highlighted concerns about implementation as well as challenges to both implementation and adoption.

Although the proposal and the suggested functionality was well received, the model and prototype are proof of concept only and there is still a great deal of work to be done if the proposal is to be taken forward. The work should be extended to consider how the needs of clinicians outside the cancer area may differ from cancer specialists. In particular, the needs of GPs and allied health professionals should be considered in more detail as these roles are likely to vary in terms of working practices and, therefore, information and collaboration requirements. Defining professional roles, the view for each role, and developing policies for pro-active support in greater detail is also necessary (see Section 8.2). In addition to the major steps for extending the research, a variety of interesting, but less pressing research topics were identified, such as extending the proposal to allow individuals or sites to personalise the system (see Section 8.3).

9.6 Discussion

This research took a long-term, big picture approach to viewing shared EPRs. Because access to information across organisational boundaries is such a pressing need in patient-centric healthcare, and because shared EPRs are not yet widely available in many healthcare systems, the potential consequences and new requirements arising out of such a high degree of information access have not yet been comprehensively considered in health informatics literature. As a result, it was necessary to take a non-standard approach to this project. First, a wide range of research areas were considered during the literature review. This approach meant sacrificing depth in each area, but provided a broader range of perspectives and potential requirements than focusing on a single domain would have identified.

Second, a fluid, evolutionary development methodology was adopted for the project. While the evolutionary approach was somewhat messy in that the various stages were not well defined and design and implementation had to adapt to constantly evolving requirements, it had some key advantages over other methodologies that could have been chosen. In particular, regular consultation with healthcare professionals including developers meant that concerns about functionality and implementation could be addressed as they arose. It also meant that the clinician perspective remained at the heart of the proposal. As a result, feedback from the evaluation was largely positive. Clinicians interviewed felt that, by and large, the proposal focused on important areas and that the chosen functionality met the identified requirements. Additionally, recent information published by Informing Healthcare (now NWIS) shows that functionality similar to that proposed in this research is being considered for future phases of the WCP [53].

Far more importantly, however, this project has contributed to understanding of the problem and demonstrated some of the potential benefits of taking a team approach to information systems support for patient-centric care teams. This project was exploratory in nature and the results of the research, both positive and negative, provide valuable insight into an area that remains highly dynamic and not fully understood. Despite the challenges and concerns raised throughout the project, results of the evaluation were positive and show that the research is worth pursuing further. Whether or not development of the WCP has been influenced by this research, the selection of functionality for implementation within the WCP that is similar to that which has been proposed here supports the conclusions derived through this research, validating both the requirements/research aims and the functionality chosen to support these goals.

9.6.1 Conclusion

While there is novelty in the VOICE model, the real success of the project lies in the insight gained through the research process. The VOICE model proposed here is unlikely to ever be considered for adoption in the NHS, but that was not the aim of the research. Early in the project, collaborators at Velindre indicated that they were interested in moving their current EPR from a “passive repository” of data to a more pro-active system [107]. At the time, however, it was unclear exactly what a ‘pro-active’ system would look like. Additionally, at the start of this project, literature indicated that access to information across organisational boundaries was (and is) a high priority for information systems in the NHS, but what requirements might exist for healthcare practitioners beyond simple provision of information was not widely discussed.

In recent months there have been indications that additional requirements are being considered, but the needs of care teams as defined here remain largely untouched in healthcare literature. Throughout this project, requirements and specific functionality have emerged so that there is now a much clearer picture of the priorities and potential pitfalls involved in moving to a more pro-active system as well as an outline for potential functionality, particularly with regard to the needs of collaborative care teams. Although there are still many challenges to be overcome, by emphasising the team perspective this research has been able to contribute to understanding of the requirements and challenges associated with supporting the work of healthcare practitioners working as members of patient-centric care teams and illustrated some of the potential benefits of using team-based approach as the model of working to be supported in future healthcare information systems.

Appendix A

Supplemental Evaluation Data

A.1 Information Presented to Clinicians

This section contains information provided to clinicians during the presentation portion of the clinician evaluation interviews.

A.1.1 Patient Pathway Scenario

Treatment Stage	System Action
Patient visits GP with symptoms	Automatically generate and send referral for investigations
Specialist sees patient	Provide access to patient record
	Request investigation electronically
Investigations returned	Notify requesting clinician
	Display within system
Patient to be discussed at MDT	Add patient to MDT meeting list
	Add MDT members to care team
Patient referred for surgery	Generate referral
	Add surgery clinicians to care team
Patient referred to Velindre for treatment	Generate referral
	Patient flagged if no referral or appointment within a set time
	Add Velindre clinician(s) to patient team
Patient admitted to hospital through A&E	Remove surgery clinicians from care team
	Alert treating doctor that patient is undergoing chemotherapy
Patient preparing for discharge from hospital	Alert Velindre team members that patient has been to hospital
	Display discharge checklist w/completion
Patient discharged from hospital	Notify GP
	(if necessary) Notify Velindre so that outpatient treatments can be resumed/rescheduled
Patient deceased	Notify all team members
	Close team

A.1.2 Questions Asked During Clinician Interviews

Main Requirements

1. Would you consider these requirements to be useful? Important?
2. Do you feel that there are other requirements of higher priority? (Is there anything we have missed?) If so, please elaborate.
3. (Other comments made voluntarily by the interviewee)

Functionality

These questions were asked once for each functionality grouping - notifications, alerts, and team management.

1. Would you consider this functionality to be a beneficial addition to CANISC?
2. Do you have any concerns relating to this functionality? If so, please elaborate.
3. Do you have any suggestions on how to improve this functionality?

Functionality and Requirements

1. To what extent, if at all, does the described functionality meet the original requirements?
2. Do you have any other comments or thoughts you would like to add?

A.2 Clinician Feedback

A.2.1 Initial Responses to Interview Questions

Following the evaluation interviews with clinicians, the first attempt to process their feedback involved extracting clinician's immediate answers to the questions listed above. As noted in Chapter 7, answers were often given out of order - sometimes before a question was asked and sometimes long after - so responses were not considered chronologically in the main evaluation. However, for completeness and as a matter of interest, clinician's initial responses to each evaluation question are presented here.

High Level Requirements	Comments	R1	R2	R3	R4	R5	R6
Useful?	<p>A. It sounds an impossible task.</p> <p>B. “What people want” will vary from person to person.</p> <p>C. “What people want” will vary from situation to situation.</p> <p>D. Cross boundary element is especially important/ current gap.</p> <p>E. Information is vital in making good decisions about patient treatment.</p> <p>F. Information exchange is currently a major gap.</p> <p>G. You shouldn’t have to hunt for the information you require.</p>	Yes	Yes	Yes	Yes	Yes	Some
Any missed?	<p>a. Out of hours receipt of notifications</p> <p>b. Alerts to alternative devices (mobile/pager)</p> <p>c. Alert forwarding (if recipient is unable to receive)</p> <p>d. Response; Not just to send information, but to be able to indicate to other team members that it has been viewed/is taken care of.</p> <p>e. **Access – device types/network points</p> <p>f. **Interface usability</p> <p>g. Support for MDTs</p> <p>h. Clinical trials functionality</p> <p>i. **Access to information from other care sites</p>	f, g, h	No	No	No	a, b, c, d, e	i
Other Comments/Concerns	<ol style="list-style-type: none"> **Training Personalising/ modifying (e.g. What if I want to alter a letter template?) Cross boundary element should be highest priority. Change nearly always increases workload but if it improves quality, then it is worthwhile. Speed/timeliness of information exchange 				3, 4	1, 2	5

* Concern/suggestion already handled by the system

** Concern/suggestion out of scope

Table A.1: Immediate Answers to Clinician Interview Questions - Main Requirements.

	Comments	R1	R2	R3	R4	R5	R6
Notification Functionality Beneficial?	A. This functionality alone would make a significant difference. B. Lack of info can cause embarrassment / a major cause of complaint currently C. Would be more secure/ fewer concerns than using e-mail. D. GPs would find this particularly helpful. E. Currently we only get notices by phone, if at all. F. Incorporating the ICP is especially exciting. G. Could save time H. Getting information in a timely way (would be great) I. Push notifications would be helpful (currently have to go and look)	Yes A, B, C, D, E, F	Yes	Yes B, D, G	Yes H, I	Yes	Maybe
Concerns?	a. Ensuring that team information is up-to-date. b. Has the potential to contribute to information overload. c. Raises question of whether I need to do anything about the notification, or is being aware of it enough. d. Could increase workload (as a result of increased awareness) e. Time to learn what action to take in response to a notice. f. Need to look in two places for the same thing (i.e. e-mail and 'notices' list) g. Training h. Over use of 'send notice' functionality i. If some things aren't notified, they may be missed	b, c, d, e, f	a	b	No	g, h	b, i
Improvements?	1. The ability to send a response to a notification 2. Need to think carefully about how different users would use the system. 3. *Possibly have different lists for different roles 4. Show status of other team members (out of office, on leave, etc.) 5. Cancel appointments automatically (if patient is deceased, in hospital, etc.) 6. Ability to send copies to the patient on request 7. Edit/check (spelling and grammar), and save forms/letters. 8. Integrate disparate formats, codes, etc. (ICD10, etc) 9. *Flexibility in alert granularity (individual, department, etc.) 10. People should be able to individualize what they get	1, 2, 3, 4	6, 7	8	9	5	10

* Concern/suggestion already handled by the system

Table A.2: Immediate Answers to Clinician Interview Questions - Notification Functionality.

Alert Functionality	Comments	R1	R2	R3	R4	R5	R6
Beneficial?	A. Timeliness of information is important. B. This has been a priority for a while C. Some alerts are obvious, but others will need careful consideration D. Patient data would be kept within the system – security and future access.	Maybe C, D	Yes	Yes B	Yes A	Yes	Yes
Concerns?	a. Could increase stress (pressure to 'do it right now') b. Potential for over-alerting / alert at wrong time – alerts ignored/ information overload c. Difference of opinion on what is 'important.' d. Could slow down access time to patient information (pop-up alert) e. **GUI usability f. Timeliness of receipt (if recipient is out of office, etc) g. Would cause major cultural change h. Raises question of does this information require action from me. i. Implementation would need to be managed with organizational regulations (i.e. no patient details in Outlook) j. Balance between missing alerts and information overload (medico-legal concerns) k. Users may become overly reliant on alerts (miss information that is not alerted) l. **Informed consent for record sharing	b, g, h, i, j, k	l, b	No	a, b, c, d	b, e, f	f, k
Improvements?	1. Highlighting different types of alerts (i.e. 'traffic lights') 2. Electronic sign-off ("This has been handled") or *flag for someone else's attention. 3. Alert if out of hours personnel alter/add to patient record 4. Colour code alerts so they can be used as a 'to-do' list 5. Have an area for 'today's red alerts'		3			1, 2	1, 4, 5

* Concern/suggestion already handled by the system

** Concern/suggestion out of scope

Table A.3: Immediate Answers to Clinician Interview Questions - Alert Functionality.

High Level Requirements	Comments	R1	R2	R3	R4	R5	R6
Useful?	<p>A. It sounds an impossible task.</p> <p>B. “What people want” will vary from person to person.</p> <p>C. “What people want” will vary from situation to situation.</p> <p>D. Cross boundary element is especially important/ current gap.</p> <p>E. Information is vital in making good decisions about patient treatment.</p> <p>F. Information exchange is currently a major gap.</p> <p>G. You shouldn’t have to hunt for the information you require.</p>	Yes	Yes	Yes	Yes	Yes	Some
Any missed?	<p>a. Out of hours receipt of notifications</p> <p>b. Alerts to alternative devices (mobile/pager)</p> <p>c. Alert forwarding (if recipient is unable to receive)</p> <p>d. Response; Not just to send information, but to be able to indicate to other team members that it has been viewed/is taken care of.</p> <p>e. **Access – device types/network points</p> <p>f. **Interface usability</p> <p>g. Support for MDTs</p> <p>h. Clinical trials functionality</p> <p>i. **Access to information from other care sites</p>	f, g, h	No	No	No	a, b, c, d, e	i
Other Comments/Concerns	<ol style="list-style-type: none"> **Training Personalising/ modifying (e.g. What if I want to alter a letter template?) Cross boundary element should be highest priority. Change nearly always increases workload but if it improves quality, then it is worthwhile. Speed/timeliness of information exchange 				3, 4	1, 2	5

* Concern/suggestion already handled by the system

** Concern/suggestion out of scope

Table A.4: Immediate Answers to Clinician Interview Questions - Team Functionality.

Requirements	Comments	R1	R2	R3	R4	R5	R6
Did we meet them?	<p>Certainly information exchange.</p> <p>(If this is done) some people will get far more than they currently do.</p> <p>Could provide better patient management.</p> <p>Would help stop duplication of work.</p> <p>Would both reduce as well as increase workload. (More information = more work)</p> <p>Would involve massive change of culture.</p> <p>Would involve massive training requirements</p> <p>Lists are especially good</p>	Yes A, B, C, D, E, F, G	A	E	E	Yes H	Yes
Other comments?	<p>Incorporate more clinical trials functionality</p> <p>Needs to link to triage system</p> <p>Many changes are more process/admin (how we are allowed to use the system) than actual changes to functionality</p> <p>We have CANISC. People who aren't used to a good system may have more concerns about it.</p>	a	No	c	d	b	No

Table A.5: Immediate Answers to Clinician Interview Questions - Meeting the Requirements.

A.2.2 Additional Comments

As noted in Chapter 7, it was not practical to discuss every clinician comment in the main evaluation. Comments considered out of scope or the result of a miscommunication were omitted from the main body of the thesis and have been included here.

	R1	R2	R3	R4	R5	R6
Hardware						
What type of device would this be available on?					✓	
Network access points are a problem					✓	
Tablet computers are very practical for us					✓	
There is no point in using a device that you can't access all information on					✓	
Training						
There is already functionality that people aren't aware of					✓	
Training is generally insufficient with healthcare information systems					✓	
It would be useful for IT staff to spend time with clinicians in practice					✓	
I am concerned about receiving sufficient training for new functionality					✓	
Design and Implementation Methodology and Challenges						
It should be phased in incrementally					✓	
The principle is good, but how to achieve it is difficult	✓					
Information is collected so differently, it is hard to process						✓
To get alert levels right you need to talk to a lot of people to find out what they want						✓
Integrated EPR						
It is important that patient data is up-to-date		✓				
Integrate codes and standard formats			✓			
There are medico-legal concerns if patient information is editable		✓				
If people have too much information they may talk to the patient less						✓
Not everything is recorded in the notes. If people have access to an integrated record, they may think they have everything.						✓
Other						
User interface isn't right/needs to be improved					✓	
Alerts should be colour coded					✓	
There is a lot of political pressure					✓	

Table A.6: Out of Scope Clinician Comments.

	R1	R2	R3	R4	R5	R6
Things that should be simple aren't always	✓					
Is not always user friendly	✓					
Sometimes I have to change accounts to get the information I need	✓				✓	
Needs to move to another level	✓					
Some aspects aren't organised well	✓					
Has not fulfilled its potential across organisational boundaries	✓					
Doesn't handle groups of patients well	✓					
Some other systems have better MDT support	✓			✓		
Has an audit trail, but changes to the record are not immediately obvious		✓				
We are lucky to have CANISC				✓		
We trust CANISC				✓		
We have alerts with CANISC and that is useful						✓
Red alerts' can be used to prioritise work						✓
I like the way blood results are displayed in CANISC					✓	
I would like a simple way to get audit statistics through CANISC						

Table A.7: Clinician Comments Regarding CANISC.

	Respondent
Nurses keep care pathway information on paper	R1
It would be great to have electronic access to nurses' pathway information	R1
Access to electronic diary information would improve safety	R1
Timing can be very useful for some treatments	R2
Timing can be essential for some treatments	R2
I am especially excited about incorporation of the integrated care pathway	R1

Table A.8: Clinician Comments Regarding Care Pathways and Timing Functionality.

	R1	R2	R3	R4	R5	R6
Keeping medications up-to-date is a challenge		✓				
I tend to give out more relevant information than I receive						✓
Some of our systems do this well, some don't			✓			
Getting approval for patient transfers is a problem				✓		
It's hard to know what you will think of it/want until you actually use it				✓		
If it's clinically efficient, then it will be used					✓	
Be sure it's cohesive and all ties together well					✓	
Overall, this is almost moving CANISC to a multi-patient mode	✓					
Currently, the GP has to ring Velindre to get certain information	✓					

Table A.9: Miscellaneous Clinician Comments Not Included Elsewhere.

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