The Role of Information Communication Technology (ICT) Towards the Management of Patients with Cancer as a Chronic Disease

AOIFE RIORDAN

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DECLARATION

I declare that the work described in this dissertation is, except where otherwise stated, entirely my own work, and has not been submitted as an exercise for a degree at this or any other university.

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ABSTRACT

The burden of chronic diseases management is tremendous. Statistically chronic diseases are one of the biggest causes of death world wild. The medical community, in addition to academic medical journals, now accept treating cancer as a chronic disease. The rate of cancer diagnoses is rising; the population of cancer survivors are increasing globally accordingly. Subsequently, this cohort of patients, now considered, as a patient with cancer as a chronic disease, is a growing demographic. This "new" type of patient now needs to be looked at differently.

Due to the multifaceted nature of oncology services, a multi-disciplinary team approach is committed to the care of every cancer patient from diagnosis to treatment to survival and end of life care. Emphasis is beginning to be placed on intensive user and computer interactions to resolve many problems associated with the fragmentation of care. The successful application of Information Communication Technology (ICT) enhances communication between provider and patient, provider and provider, and provider and system, thus facilitating in the improvement of coordination, and the quality of care delivered.

Exhibited in this dissertation is a systematic approach for developing a Software Requirements Specification (SRS) for user-centric software in an Oncology setting. The document conforms to the well-recognised IEEE software requirements process model. During the process of creating the SRS, functional requirements derived from the literature and semi-structured interviews with oncology staff were presented according to the IEEE template.

A member of the hospital IT team, a consultant, and a clinical nurse specialist evaluated the SRS document against requirements outlined in the interviews in addition to required functionality. The SRS document was validated against the IEEE SRS template and an iterative process was used to refine the document.

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Table 0-1 List of Abbreviations

Acronym	Description
CCM	Chronic Care Model
COPD	Chronic Obstructive Pulmonary Disease
CDMP	Chronic Disease Management Plan
CSO	Central Statistics Office
DMAA	Disease Management Association of America
DMP	Disease Management Plans
HER	Electronic Health Record
EPR	Electronic Patient Record
EMR	Electronic Medical Record
EU	European Union
FHBHRU	Flinders Human Behaviour & Health Research Unit
GP	General Practitioner
HIQA	Health Information and Quality Authority
HSE	Health Services Executive
HIS	Health Information System
HIT	Health Information Technology
HITs	Health Information Technologies
ICT	Information & Communication Technology
IOM	Institute of Medicine
IS	Information Systems
IT	Information Technology
ITPA	Interactive Tailored Patient Assessment
MRN	Medical Record Number

NCCP	National Cancer Control Programme
NCIS	National Cancer Information System
NCRI	National Cancer Registry of Ireland
NCU	Norwegian Cancer Union
NHS	National Health Service United Kingdom
SACT	Systemic Anti-Cancer Therapy
SCP	Survivorship Care Plan
SCS	Sheehan Disability Scale
SDLC	Software Development Life Cycle
SDS	Software Design Specification
SRR	Software Requirements Review
SRS	Software Requirements Specification
SWOT	Strengths, Weaknesses, Opportunities, Threats
TCD	Trinity College Dublin
UPMC	University of Pittsburgh Medical Centre
US	United States
WHO	World Health Organisation

CHAPTER 1: INTRODUCTION

1.1 INTRODUCTION

This dissertation focuses on research undertaken in a multidisciplinary oncology environment of a Private "High-Tech" Hospital in South Dublin.

The research examines the potential application of Information and Communication Technology (ICT) in a clinical environment, in order to support clinicians who are responsible for patients who have undergone treatment for cancer and are now living with cancer as a chronic disease. It generates the requirements set of a cohort of clinical users of their desired software functions. These users are consultants, surgeons, and nurse specialists who have regular dealings with cancer patients in the areas of Radiotherapy and Medical Oncology and more specifically in Gynaecology, Genitourinary, Gastrointestinal, Colorectal, Melanoma, and Breast Care departments.

Concentrating on this cohort of individuals aims to give a comprehensive overview of the patient journey through each department, from diagnosis to treatment, to follow up and living with cancer as a chronic disease, and finally to end of life care. In addition to this journey, focusing on each end user will give a better understanding of where to usefully apply ICT.

The research also explores the potential roles, benefits, barriers, and accelerators of ICT in the area of cancer as a chronic disease. The research undertaken to achieve this included a comprehensive review and critical appraisal of the available scholarly literature in addition to semi-structured interviews conducted with three consultants, one surgeon, and six nurse specialists.

1.2 STUDY BACKGROUND

Meeting the multifarious needs of chronically ill patients is notably one of the most challenging aspects facing medical professionals (Wagner 1998). Chronic diseases are notably the most common cause of death worldwide (World Health Organization 2013a). They decrease the patient's quality of life, threatening many patients and their families with a restrictive and uncertain futures (Wagner, Austin, *et al.* 2001). Chronic Disease care causes a significant economic burden on the patient, their family, hospitals and society (Polisena et al. 2009). In Ireland, it is estimated that approximately 280,000 people, who were diagnosed with cancer between 1995 and 2009, have survived (Irish Cancer Society 2014a) and now living with cancer as a chronic disease.

Through appropriate support from physicians and external resources in the management of their illness, research suggests that the use of ICT could result in many benefits to patient, physician, and hospital. Such benefits may include a reduction in costs (Fishman *et al.* 1997; Wagner EH *et al.* 2001), reduction in medical errors (Bates *et al.* 2001; Bates and Gawande 2003), reduction in hospital readmission (Lorig *et al.* 1999; Celler *et al.* 2003), better use of resources (Okoroh *et al.* 2001), and could potentially improve the patients' quality of life (Lorig *et al.* 1999).

The prevalence of technology is continuously growing in healthcare and specifically in the cancer environment. Developing integrated IT systems for cancer patients and their carers is complex due to the multifaceted nature of medicine, including the physical, emotional, spiritual and psychosocial dimensions (Kuziemsky et al. 2008). It is therefore, vital that any technology implemented in these settings meet the needs of its users and adds significant clinical value. By obtaining clinical user requirements for a cohort of patients that are emerging as a growing demographic brings a new approach to cancer care.

1.3 RATIONALE FOR STUDY

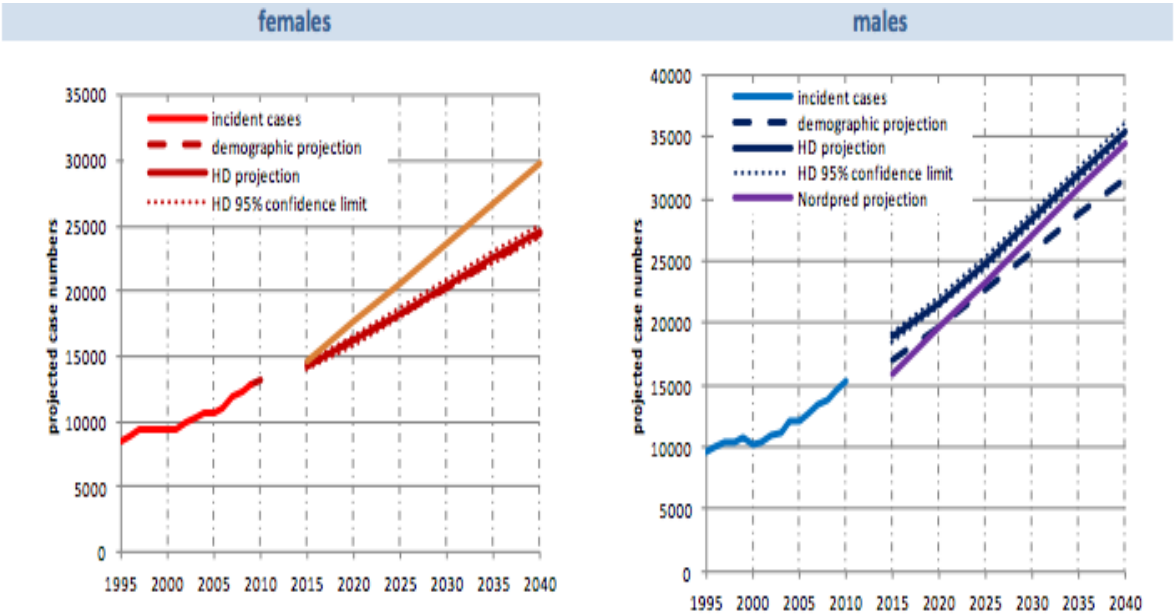

Figure 1.1 Projected numbers of incidents cases of all invasive cancers 2014-2040 (with % increase/decrease compared to 2010) (National Cancer Registry 2014).

The National Cancer Registry of Ireland (NCRI) estimates that the rate of incidences of Irish cancers diagnosis will almost double by 2040 (Figure 1.1) **(National Cancer Registry 2014).** The report suggests a 107% increase (n=15295 to n=31704 cases) in all invasive cancer diagnosis for Irish men **(National Cancer Registry 2014),** and an 84% increase (n=13185 to n=24287 cases) for Irish women between 2010 and 2040.

Survivorship of cancer is globally increasing due to advancements in both health care and the use of information systems **(Clauser et al. 2011)**. In Ireland, the NCRI reports that survival in Irish males has statistically improved 18% over ten years, and 10% in Irish females **(National Cancer Registry 2014)**.

Additionally, The Irish Central Statistics Office (CSO) report assumes that mortality rates are expected to decrease between 2011 and 2041. This decrease will result in a gain in life expectancy from 76.7 years in 2005 to 86.5 in 2041 for men and 81.5 years in 2005 to 88.2 years in 2041 for women **(Central Statistics Office 2008)**. There is an assumption that this increase in life expectancy could

mean that there will be an increased burden on the Irish health system to treat patients for long-term chronic diseases.

This financial burden, as it is in other countries, could be spread across the Irish population burdening even further a recovering economy. The present cost of chronic illnesses in several low and middle-income countries is already high and often borne by patients (Strong et al. 2005). The management of chronic diseases cost economies billions of euros each year. In 2009, cancer services cost the European Union (EU) €126 billion. This was equivalent to €102 per EU citizen (Luengo-Fernandez et al. 2013). In Ireland the health-care costs of cancer treatments were €130 per citizen of which 67% of costs were absorbed due to inpatient care (Luengo-Fernandez et al. 2013).

While the majority of diagnoses of cancer presented are over 65 years of age, a prevalence of younger diagnosis is emerging for certain cancers (National Cancer Registry 2014). This cohort of patient, now living with cancer as a chronic disease, needs long-term follow up and monitoring. Survivorship and chronic-care programmes can support individuals after surgical, radiation and chemotherapy treatment have been completed or as an aid for on-going hormone therapy treatment. These programmes, as a result can provide both the physiological and psychological support a patient requires when faced with the turmoil of a cancer diagnosis (Hoffman and Stovall 2006).

ICT can play a vital role for patients, yet, it can also play a significant role for their physician in the management of their disease. The use of ICT to monitor and document patients' progression is particularly needed for evidence-based medicine. Medicine is undisputedly an information-intensive business with Health Information Technology (HIT) relied upon for accurate readily available information. One study by Hesse *et al.* (2010) calls on Health IT to be "predictive, pre-emptive, personalised, and participative" in order to meet the day-to-day requirements of healthcare professionals.

1.4 OBJECTIVES OF RESEARCH

The aim of this dissertation is to explore *the role of Information and Communications Technology (ICT) towards the management of patients with cancer as a chronic disease*. In addition, the dissertation focused on obtaining clinical user requirements for a cohort of patients that are emerging as a growing demographic. The focus of this dissertation is on how Information and Communication Technology could potentially be used to support clinicians in the long-term management of patients with cancer as a chronic disease.

The dissertation proposes a Software Requirements Specification (SRS) document focusing on the requirements set out by a selection of Oncology consultants, surgeons, and nurse specialists. The qualitative methodology allows the researcher to explore the role ICT has in the management of this growing demographic.

1.5 RESEARCH QUESTIONS

The aim of this dissertation was to generate a body of knowledge exploring *the role of Information and Communications Technology (ICT) towards the management of patients with cancer as a chronic disease.*

Using this body of knowledge and semi-structured interviews a Software Requirements Specification for a system to manage and support those living with cancer as a chronic disease from a clinical perspective has been created.

This work has been undertaken to answer the following research questions:

- What roles does ICT have in the management of cancer as a chronic disease?

- What are, from a clinical perspective, the user requirements of an ICT system to support clinicians caring for patients with cancer as a chronic disease?

1.6 OVERVIEW OF DISSERTATION

This chapter presented the background to the research, rationale for the research, the research questions, and an outline of the dissertation.

Chapter 2 will focus on research methodologies employed to conduct this study. The chapter will introduce the research design, search methods, and criteria. In addition to this, the chapter presents the user requirement gathering methods, participant selection, validation, study analysis, and ethics process.

Chapter 3 presents the literature review as conducted by the researcher. The emphasis of this chapter is on background information. The chapter looks at what is cancer, what the profile of cancer is in Ireland, and how cancer has become accepted as a chronic disease. In addition to this, the chapter looks at cancer survivorship and survivorship care plans, chronic disease management and chronic disease management models. The chapter draws on ICTs potential roles in the handling of cancer survivorship and chronic disease management.

Chapter 4 presents an additional literature review focusing primarily on the role of ICT and the management of cancer as a chronic disease. The chapter highlights what ICT services is currently available, adoption of ICT by industry, the barriers preventing the adoption of ICT and implementation strategies for ICT. The chapter draws on ICTs potential roles in the management cancer as a chronic disease.

Chapter 5 presents the practical elements of the dissertation. It outlines proposed application domain focusing on the outstanding research question. The chapter focuses on literature-supported methods of data collection and gathering of user requirements, interview techniques, prototype development, and validation.

Chapter 6 focuses on the presentation of the findings. The findings, drawn from the semi-structured interviews and from the previous chapters, are synthesised to form the functionality presented in the Software Requirements Specification (SRS) document.

Chapter 7 focuses on the evaluation and validation of the findings from Chapter 6 against the IEEE standard in addition to an IT representative and key informants from the semi-structured interviews.

Chapter 8 presents the study limitations, recommendations for future work and conclusion of the dissertation.

The reference list and appendices subsequently follow Chapter 8. The appendices covers a range of additional information including the Interview Guide, Requirements gathering, pilot interview transcript, letter of invitation, consent form, ethics approval, section one of the SRS and additional chronic care models.

CHAPTER 2: RESEARCH DESIGN & METHODOLOGY

2.1 INTRODUCTION

This chapter will provide detailed information, on the rationale for the choice of research methodologies and design adopted for this study. A qualitative approach using primary and secondary data is used to answer the research questions and investigate user requirements.

The chapter will begin by outlining the research questions, an overview of research methodology and study design. The chapter then describes the search criteria, data collection process, interview structure and design. It will be concluded discussing data validity and limitations of the study design.

2.2 RESEARCH QUESTIONS

The aim of this dissertation was to generate a body of knowledge exploring *the role of Information and Communications Technology (ICT) towards the management of patients with cancer as a chronic disease*. In particular, the study will focus on design and development of an ICT system to manage and support those living with cancer as a chronic disease from a clinical perspective, while in addition, providing background information to answer the following questions.

The questions to be answered by this research are:

- What is the role of ICT in the management of cancer as a chronic disease?

- What are, from a clinical perspective, the user requirements of an ICT system to support clinicians caring for patients with cancer as a chronic disease?

2.3 RESEARCH METHODOLOGY

The proposed research questions infer exploratory research as the study is attempting to identify the potential roles ICT can play and the functional requirements of an ICT system rather than measure the implementation of a system. In order to ascertain successfully these research objectives, the assimilation of knowledge from wide-ranging sources is required. As a result, the researcher chose to approach this dissertation with a purely qualitative methodology. Qualitative Research is "any information the researcher gathers that is not expressed in numbers" (Tesch 1990). Creswell (2012) describes qualitative research as the process of applying a theoretical or interpretive framework in order to study a problem by inquiring and collecting data in a natural setting.

Qualitative Research embodies a positivist philosophy, a philosophy based on deductive theory, which puts forth a proposition, which is tested and empirical proof is sought to prove findings (Babbie 2012). Qualitative Research is concerned with "understanding and insight rather than measurement" (McGivern 2006). The motivation for doing qualitative research, as opposed to quantitative research is down to the flexibility of qualitative research. Qualitative Research offers an accessible and theoretically flexible approach to analysing qualitative data (Braun and Clarke 2006). While Quantitative Research provides precise, numerical data, qualitative research methods allow the researcher to understand the people and environmental context (Myers and Avison 1997). The qualitative methodologies used are a mixed scientific research study encompassing a combination of elements of Ethnography, Grounded Theory (GT), Participatory Design (PD), and Action Research.

Ethnography is described as flexible, subjective and draws perceptions and views of individuals (Cohen *et al.* 2000). Ethnography is deemed descriptive and focuses on multiple perspectives, which is vital when designing a user-centric software system (Cohen *et al.* 2000). Subsequently the adoption of appropriate user-centred design techniques to approach the practical element of the dissertation was applied. GT was chosen to develop a context-based, process-oriented description of the proposed software. GT is a "qualitative research method that uses systematic set of procedure to develop an inductively derived Grounded Theory about a phenomena" (Kuziemsky et al. 2008).

The researcher chose PD as it is a method of understanding traditional approaches to the way individuals performs their daily tasks. Subsequently the choice of Action Research was primarily due to the collaborative elements. Action Research has been widely used in both computer and the medical

science (Baskerville 1999). Action Research defined by Rapoport (1970) "aims to contribute both to the practical concerns of people in an immediate problematic situation and to the goals of social science by joint collaboration within a mutually acceptable ethical framework".

2.4 RESEARCH DESIGN

Research design introduces the plan for the study Creswell (2012). Research design is "the entire process of research from conceptualising a problem to writing research questions, and on to data collection, analysis, interpretation, and report writing" (Bogdan and Taylor 1975; Creswell 2012). The research approach to this dissertation was the scientific method. Scientific Method described by Creswell (2012) as introducing a problem, the questions (hypotheses), and data collection, the results and the conclusion. Qualitative Research fits within this scientific framework.

Primary and secondary data sources are used to address the research questions. A systematic literature review was the basis of the secondary data and semi-structured interviews providing primary research data. The findings from the literature and semi-structured interviews formed the basis for the production of a Software Requirements Specification (SRS) document. These interviews also formed the basis of the use-case models included in the SRS document.

For this dissertation, the Software Development Life Cycle (SDLC) consisted of three main phases:

- Definition of systems objectives and context of use
- Specification of user requirements
- Development, evaluation and validation of the SRS document and Prototype

The following iterative-design diagram outlines the user requirements gathering process; the arrows represented in the diagram below indicate the findings at each phase of the development lifecycle. These findings will be discussed in Chapter 6.

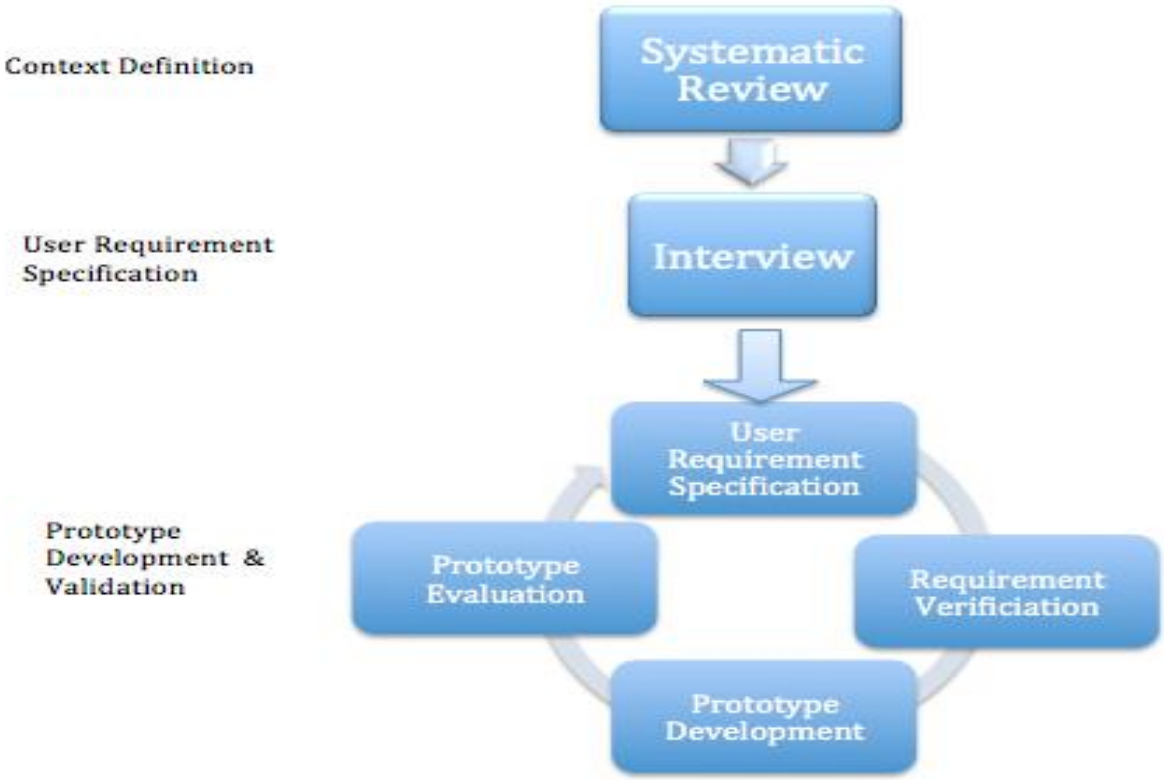

Figure 2.1 Schematic of user requirement process adapted from (Brownsweel et al. 2012)

The three stages of the process are described in the sections following.

2.5 CONTEXT DEFINITION

Context definition was required for both research questions. The researcher understanding the need for an extensive literature review identified a new cohort of patients that are emerging as a growing demographic. This in turn identified the focus of the dissertation. To provide a baseline of software presently available for clinicians, the researcher conducted a systematic literature review of systems, tailored to cancer patient management.

The researcher also conducted a study on current policy and procedure of processes within the Oncology subgroups of the private hospital. However, no policies and procedures were found to handle patients after their treatment. The following section identifies the search methodology used to collect both theoretical and empirical data.

2.5.1 SYSTEMATIC REVIEW

In an effort to collect secondary data, a comprehensive review, and critical appraisal of the available literature was undertaken in key areas. The researcher conducted a series of systematic searches on available online databases including Science Direct, PubMed, Wiley Online Library, BMJ Journals Online, Springer Link, Google Scholar, and IEEE. In searching these databases, a combination and variants of the following keyword terms, as outlined in Figure 2.1 were used.

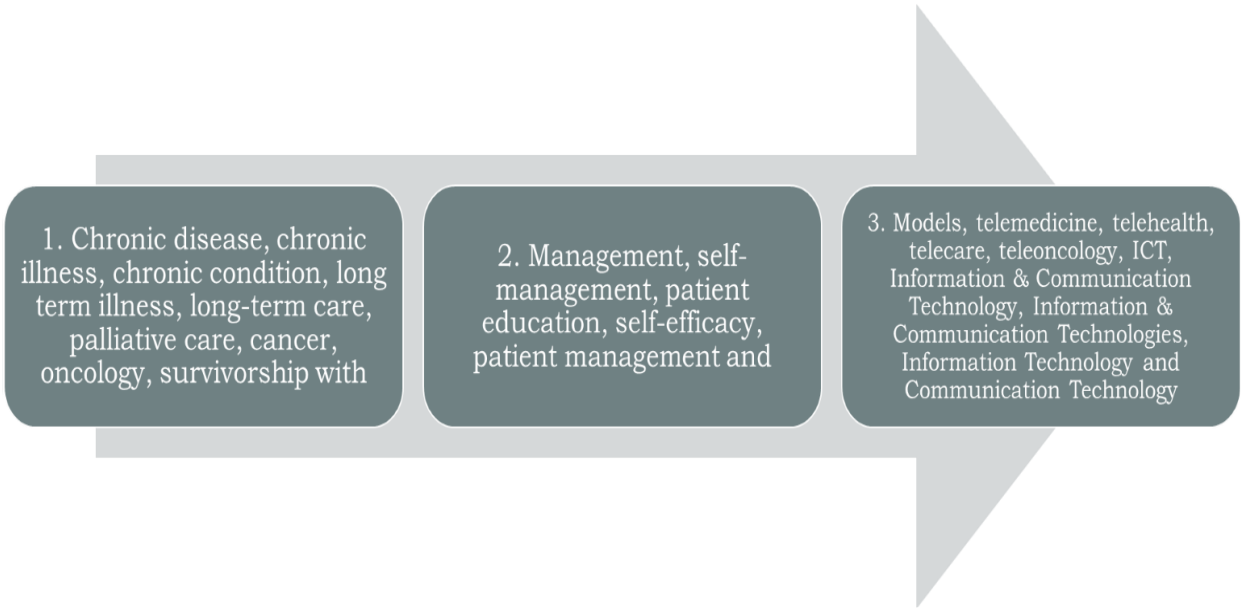

Figure 2.2 Systematic Search Criteria

The researcher, excluded studies that did not meet the criteria, which included articles not written in English or testing a device. Once articles had met the criteria, references of interest were followed up and a snowball search strategy occurred to discover additional studies of interest. The snowballing approach requires forward (finding citations to the papers) and backward (from the reference lists) snowballing to discover new papers not found by an initial search strings (Jalali and Wohlin 2012).

In addition to the theoretical secondary data obtained to form the basis of first of the research question, the researcher also conducted a similar series of searches on the aforementioned search engines in order to ascertain the correct methodologies to conduct the practical element of the research. A second comprehensive review and critical appraisal of the available literature was undertaken in key areas such as conducting in-depth semi-structured interviews, user requirement gathering, data collection, and analysis.

2.6 USER REQUIREMENT SPECIFICATION

2.6.1 DATA COLLECTION

As the research questions infer exploratory research, primary as well as secondary data collection is required to ascertain empirical data. Requirements' gathering establishes the earliest phase of the software development life cycle (Kotonya and Sommerville 1996). In order to determine the type of delivered software, it is imperative to obtain a good comprehensive knowledge of the users' prerequisites. Due to the nature of cancer's multi-disciplinary setting, the socio-technical aspects were included to understand the current organisational workflows in which the implemented software would exist.

The researcher employed, an iterative, user-centred design approach, to obtain the user requirements for the development of the Software Requirements Specification and prototype. Using participatory design and grounded theory principles, end-users were involved throughout the software development lifecycle. Through semi-structured interviews, the researcher collected primary empirical data. All interviews were recorded and written notes were taken.

Secondary data included data obtained from policies and procedures employed by Oncology Services in the hospital. The researcher chose to follow the IEEE standard 830-1998 recommendations for SRS development and chose to organise section 3 of the SRS document by use class diagrams. User class was deemed the most appropriate template as the software would deal with individual user groups, different user rights and different tasks rather than functions and versions.

2.6.2 SEMI-STRUCTURED INTERVIEWS

Interviews are an essential requirements elicitation technique, where by the interviewers pose questions and ask users for software requirements throughout a systematic process to gain information about the users' needs in respect to the expected new software (Jabbar *et al.* 2007). Semi-structured interviews were chosen as it captures both in-depth information regarding users'

needs but also determines perceptions, passions, opinions, reactions and solutions to a proposed software system (Jabbar *et al.* 2007). Ulrich and Eppinger (2000), suggest using a prepared interview guide to structure the discussion used in software requirements gathering, these prompts should focus on the tasks rather than the product itself.

A pilot interview was used to gain feedback on interview style and allow reworking of questions if required. The questions for the subsequent interviews were drafted based on the results of the initial interview but will cover the six main types suggested by Patton (2005); Experience, Opinion and Value, Feeling, Knowledge, Sensory and Demographic (Saunders *et al.* 2011). The aim of the researcher was to use a funnel sequence (general-specific). Funnel sequence allows the interviewer to ask broad, open-ended questions and moves to narrower, closed ended questions.

In total eleven semi-structured interviews were conducted with key oncology informants who have day-to-day dealings with patients with cancer as a chronic disease. These informants, deemed end users of the proposed ICT software system, included consultants, surgeons and nurse specialists. The interviewees assisted with answering both research questions, gave an indication what they would like the software to do, how ICT currently plays a role in their daily operations and their perceived potential benefits and challenges with the proposed ICT software.

All interviews were face-to-face and all but the pilot interview was recorded. The pilot interview (IA) requested not to be recorded and as a result, the interview was transcribed during the discussion. The pilot study was useful as the researcher was provided feedback on how to improve for the next interview and had the ability to revisit and rework questions. Feedback was requested from three of the interviewees in order to improve for following interviews. The duration of the interviews ranged from 25 to 45 minutes, written notes in addition to recording were taken at each interview. Interviews were conducted in adherence to the interview protocol outlined in Appendix A.

The interviewees were encouraged to talk about their current workflow, experience with using technology in their day-to-day activities, and if ICT could play a part in management of patients after treatment. Questions, however, tended not to be in the same running order during all interviews as the flow of conversation often lead onto a more appropriate question. While the interviewer endeavoured to maintain focus during the interview, some of the interviewees drifted from the topic. The interviewer found at times interviews particularly difficult where the interviewer attempted to

gain insight from interviewees through a series of questions, but did not answer in a way the interviewer had anticipated.

On commencement of each interview, the researcher presented participants with an overview of requirements gathering (Appendix B) for building an entire system. This diagram by (Sommerville 2007) was used as an aid, to highlight where what part they played and how the information they provided would be used.

During the interview, the researcher used diagrams of key chronic care models (Section 3.4.1) to steer the interviews. The models were used to explain specific care models in addition to presenting users with potential benefits of applying a hybrid of the available models. The diagrams allowed users to reflect and to formulate their own requirements that mirrored their current processes and needs. The diagrams also allowed the participants to identify elements of the models they currently undertake, which put many participants at ease.

In addition to the diagrams of the key chronic care models, the researcher presented participants with Clauser et al.'s (2011) - Patient, Provider, and system applications of information technology for cancer care (Figure 4.1) diagram. This showed participants how ICT could sit in the middle between all elements of cancer care, while depicting the complexity and potential of IT to integrate into the health care environment seamlessly.

Finally, the researcher asked participants to complete an adaptation of a Strengths, Weakness, Opportunities, and Threats (SWOT) analysis (Appendix F-1) of a proposed software based on the discussions had during the interviews. This analysis allowed the researcher to formulate requirements in addition to those mentioned during the interview. It also allowed users to ask themselves questions about the software system. A completed analysis can be seen in Appendix F-2.

Data analysis from the interviews was interpreted from the interview transcript, identification of key themes, and assessed if there were commonalities and differences from all interviewees. The transcribed interview data from both the recordings and written interviews was coded using both content and grounded theory analysis. Data collection through interviews is labour intensive but allows the researcher to ask clarifying questions in addition to interview data. Quotes from the interviews were then grouped together; these groups formed the basis of conclusions, which were

discussed as the themes identified in the interview findings in Section 6.2. In addition to these findings, requirements formulated from the interviews are discussed within the SRS document in Section 6.4.

2.6.2.1 PARTICIPANTS AND RECRUITMENT METHODS

Participants were chosen at random from the individual oncology disciplines. Participants were deemed key oncology informants if they had day-to-day dealings with patients with cancer as a chronic disease. Other disciplines including physiotherapy and front-desk staff were not included in the scope of this study, but should be included for further research.

Participants were invited to partake by a letter of invitation (Appendix E-1) to which a consent form (Appendix F-1) was attached. The letter of invitation outlined the purpose of the study and requesting their voluntary participation. Each letter included the statement "All participants have the right not to take part or to withdraw from the study at any stage without penalty". Consent was received from all participants including those who responded via email. The latter kindly responded either by email or faxed the consent forms directly to the researcher.

Of the twenty people invited to participate, four participants had to withdraw due to personal reasons or unprecedented workload. As an alternative to participants who were unable to meet face-to-face or by telephone, participants were offered to email or write responses to the researchers interview questions and made themselves available for any follow up questions via email.

A cover letter and consent form (Appendices E-1 & F-1) informed interviewees that answers were confidential, they would be non-identifiable during the research study, and that their data is protected under the data protection act. All data was transcribed and a copy kept by the site gatekeeper.

2.7 VALIDATION

For the purpose of this dissertation, validation of the SRS document includes evidence that all outlined software requirements are true and accurately depicted. The SRS document was validated against IEEE

standards of correctness, ambiguity, completion, ranking of importance and/or stability, stability, verifiability, modifiable, and traceability. A conclusion that the software requirement specification is valid was highly dependent upon a comprehensive inspection by a member of the Hospital IT staff and the end users. An established Software Requirements Specification is required for software validation process to be completed. Once all validation and findings were drawn, the researcher noted the final conclusions, limitations, and future research areas.

2.8 ETHICAL APPROVAL

Ethical approval was granted by University of Pittsburgh Medical Centre (UPMC) Beacon Hospital, Sandyford, Co. Dublin. The Ethical approval from the Beacon Hospital was twofold. The preliminary part of the approval has granted ethical permission to interview their oncology staff members and healthy volunteers, in order to derive user requirements that could potentially be used to develop a management system for patients with Cancer as a Chronic Disease. The subsequent part of the permission allows, after a prototype has been developed from the user requirements, to survey a separate cohort of oncology staff and healthy volunteers to gain user acceptance of the prototype. A condition of the approval requests that the prototype should be submitted to the ethics committee on completion.

Ethical approval was also obtained from the School of Computer Science and Statistics, Trinity College, Dublin.

2.9 LIMITATIONS

While the researcher acknowledges that due to the nature of the interview participants being colleagues, the validity of the study may become compromised. The participants could have potentially behaved differently or answered in a way, that they feel was correct and to suit the study may have introduced bias. While research has suggested that 'insider knowledge' can make interviewees more comfortable and willing to talk more openly than they would with a stranger (Tierney and Gitlin 1994).

As mentioned previously, qualitative research is subjective, this subjectivity can lead to misinterpretation of data and introduce researcher bias (Burnard 1991), however to prevent this, an IT representative reviewed the proposed document.

The number of participants included in the study is quite low, though all oncology services were covered additional interviews should be conducted.

2.10 CONCLUSION

This chapter has outlined the methodologies employed to successfully conduct this research study and answer the proposed research questions. The mixed methods approach delivered a variety of data providing validity to the studies' findings. Information from the study's literature review together with interview data was synthesised to form this dissertation.

The next chapter will introduce the proposed application domain used to answer the specific research questions previously outlined, and it will focus on summarising findings, conclusions, gaps in knowledge on all aspects of ICT's role towards the management of Cancer as a Chronic Disease.

CHAPTER 3: LITERATURE REVIEW

3.1 INTRODUCTION

Developments in ICT during the past 25 years have heralded an information technology era in which economic, health and social activities have dramatically transformed (Maserat 2008). In addition to these developments in ICT, medical advancements in early detection and screening and treatment interventions now increase one's chances of becoming a cancer survivor (Khan et al. 2008). Moreover, as survival, rates continue to improve, and population continues to increase it is necessary to look at how information and communication technologies can play a role in the rehabilitation and survivorship of those living with chronic disease such as cancer while supporting those providing care.

Eurostat published population projection figures in 2011 indicating that the population of the European Union will increase from 501 million in 2010 to 525 million in 2035. (Eurostat Commission 2011; Lanzieri 2011). Although the magnitude, rate and timing of aging populations are likely to vary between country to country it is possible that for some countries they have surpassed their peak speed and have already entered their slowdown phase (Lanzieri 2011).

This chapter will introduce the extensive literature review undertaken by the researcher pertaining to the proposed research question "*the role of Information and Communications Technology (ICT) towards the management of patients with cancer as a chronic disease"* and analyse *ICT's role towards the management of patients with Cancer as a Chronic Disease*. This chapter will focus on the relevant scholarly literature available specifically concentrating on what are chronic diseases, how cancer is a chronic disease, and how physicians are currently supporting patients with cancer as a chronic disease. The research subsequently explores the potential roles, benefits, barriers, and accelerators of ICT in the area of cancer as a chronic disease.

3.2 CHRONIC DISEASES

Chronic conditions encompass a disease condition or conditions that people may 'live with' over an extended period of time (Lawn and Schoo 2010). Chronic disease is a subset of chronic conditions and refers to a specific medical diagnosis (Lawn and Schoo 2010). Chronic diseases are prolonged conditions that have slow progression (World Health Organization 2013a) and typically do not improve over time and are seldom cured entirely (Polisena et al. 2009).

Chronic disease is defined on the basis of the biomedical disease classification (Martin 2007); it does not imply severity of disease and includes heart disease, stroke, cancer, chronic respiratory diseases and diabetes. Chronic illness therefore is the personal experience of living with the condition that often accompanies chronic disease (Martin 2007).

Chronic disease affects the quality of a patient's life, and requires continuous treatment and support. Patients ordinarily do not present with a single Chronic Disease but in fact multiple comorbidities such as nausea, pain, and depression (Wensing et al. 2009). These comorbidities require regular follow-up surveillance through scans and tests, which are costly and time consuming for physicians (Wensing et al. 2009). Follow-up appointments typically involve history taking, physical examination, blood testing and/or radiologic testing (Miedema et al. 2003).

Chronic Diseases are the most prominent cause of death in the world today (De Bruin et al 2011) . The World Health Organisation (WHO) estimates that chronic diseases are the cause of 63% of all worldwide deaths. In 2008, cancer accounted for approximately 13% (7.6 million) of world deaths (World Health Organization 2013b) and expects this number to increase a further 17% in ten years.

3.2.1 WHAT IS CANCER?

The medical community, in addition to academic medical journals, now consider cancer as a chronic disease. Cancer is defined as "a generic term for a large group of diseases that can affect any part of the body… [It is] the rapid creation of abnormal cells that grow beyond their usual boundaries and which can then invade adjoining parts of the body and spread to other organs" (World Health Organization 2013b).

This overgrowth develops into what is known as a tumour. A tumour can be benign or malignant. Benign tumours do not spread but can be still be detrimental to organs and therefore can be surgically removed (Irish Cancer Society 2014b). Malignant tumours can spread to other sites and organs where multiple growths can occur, these growths are what is known as secondary cancers or metastatic (Irish Cancer Society 2014b).

There are over 200 different types of cancer, which can be further grouped into additional categories including carcinoma, sarcoma, and lymphoma. Carcinomas are malignant tumours that develop from cells lining the surfaces of the body such as stomach lining or breast ducts (Irish Cancer Society 2014b). Sarcomas are malignant tumours that develop from cells supporting structures of the body such as muscle, bone or cartilage (Irish Cancer Society 2014b). Lymphomas, myelomas and leukaemia are all malignant tumours that develop from blood cells or make up blood cells (Irish Cancer Society 2014b).

3.2.2 PROFILE OF CANCER IN IRELAND

In Ireland, the National Cancer Registry of Ireland (NCRI) estimates that Irish cancer rates will double by 2040 (National Cancer Registry 2014). The latest report from the NCRI shows that more than 19,000 invasive cancer cases are diagnosed on average each year in Ireland (National Cancer Registry 2014).

The report suggests that Ireland will see an increase in the number of citizens diagnosed with lung cancer by 2040 suggesting a 136% increase in female (n=1068 cases to n=2260 cases) and 52% (n=1232 to n=1987 cases) in male diagnosis (National Cancer Registry 2014). Cancer of the colon and rectum has increased by 10% in just the last 4 years (National Cancer Registry 2014). The NCRI, as graphically depicted previously in Figure 1.1, estimates that there will be a 107% increase (n=15295 to n=31704 cases) in all invasive cancer diagnosis for Irish men (National Cancer Registry 2014). In addition, the report estimates an 84% increase (n=13185 to n=24287 cases) for Irish women between 2010 and 2040 based solely on fluctuations in population size and age distribution (National Cancer Registry 2014).

Figure 3.1 and Figure 3.2 below outlines the main diagnostic categories for Irish male and females between 2008 and 2010 as depicted by NCRI. The charts indicate that non-melanoma skin cancers such as basal cell carcinoma is the most prominent invasive cancer present in the Irish population between 2008 and 2010, while breast cancer is the second most common in Irish females, it is prostate cancer in Irish males that is second to non-melanoma skin cancers.

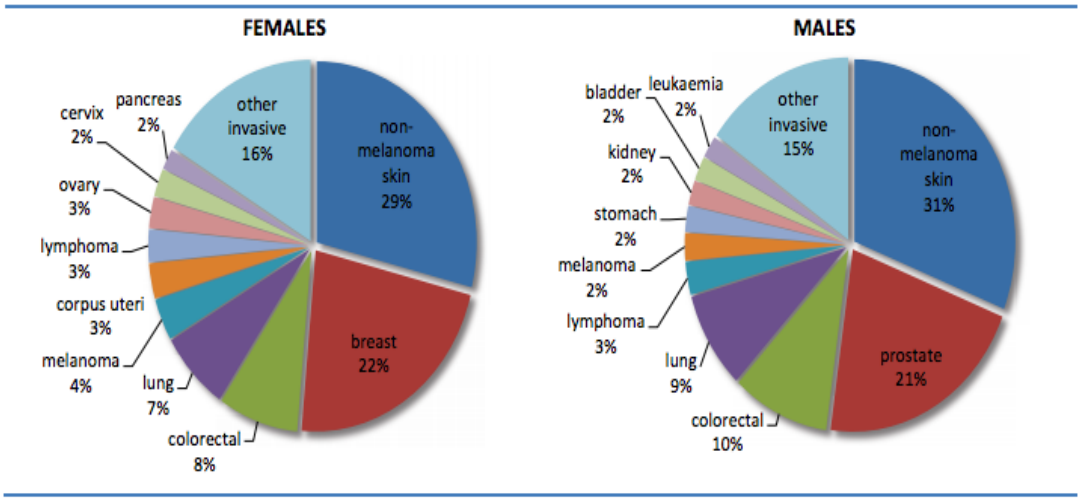

Figure 3.1 Relative frequency of the foremost invasive cancer diagnosis 2008-2010 (National Cancer Registry 2013)

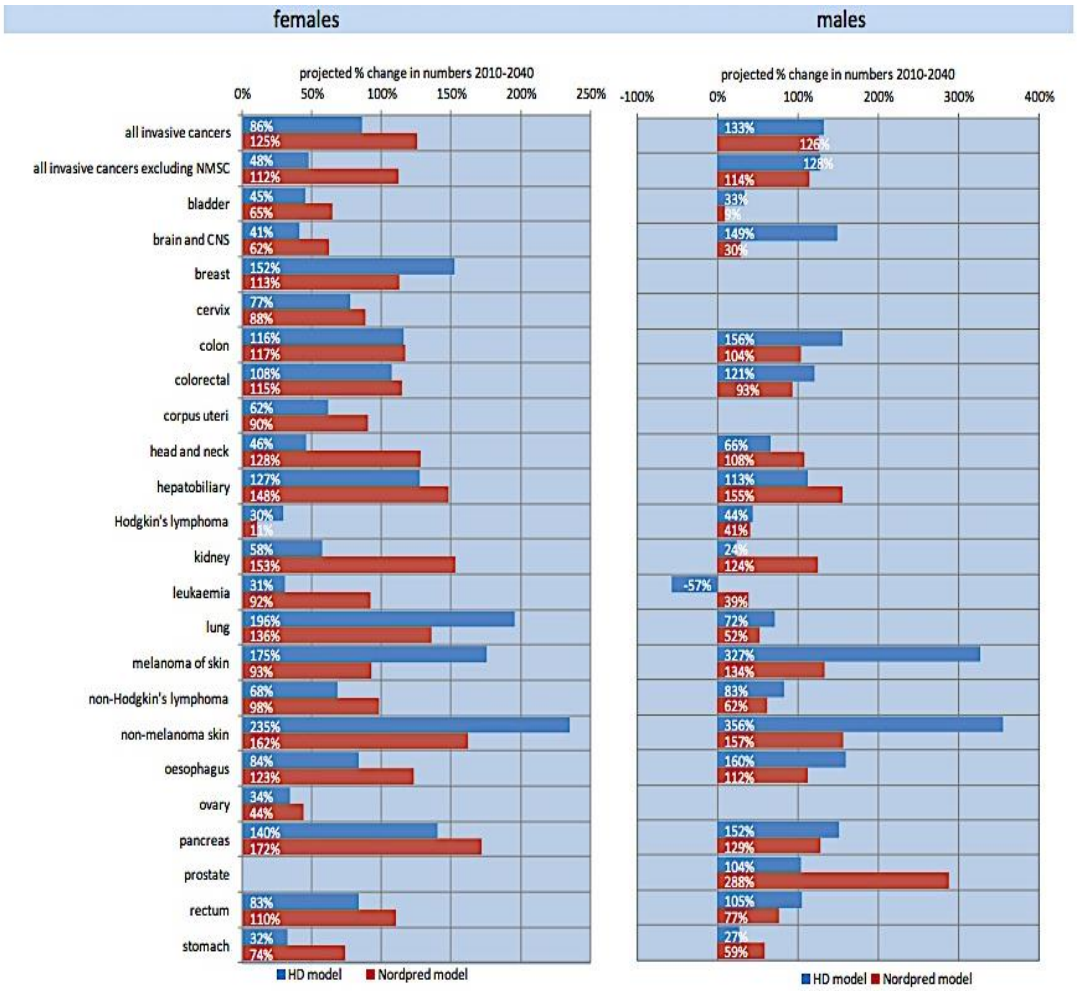

Figure 3.2 "Projected Percentage increase in number of cancer cases 2010-2040, by cancer site and sex" (National Cancer Registry 2014)

There are currently over 100,000 cancer survivors in Ireland (National Cancer Registry 2014). The NCRI reports that survival in Irish males has statistically improved from 42% in 1994-1999 to 60% in 2005-2009; likewise the report shows the improvement in survival in females from 51.6% in 1994-1999 to

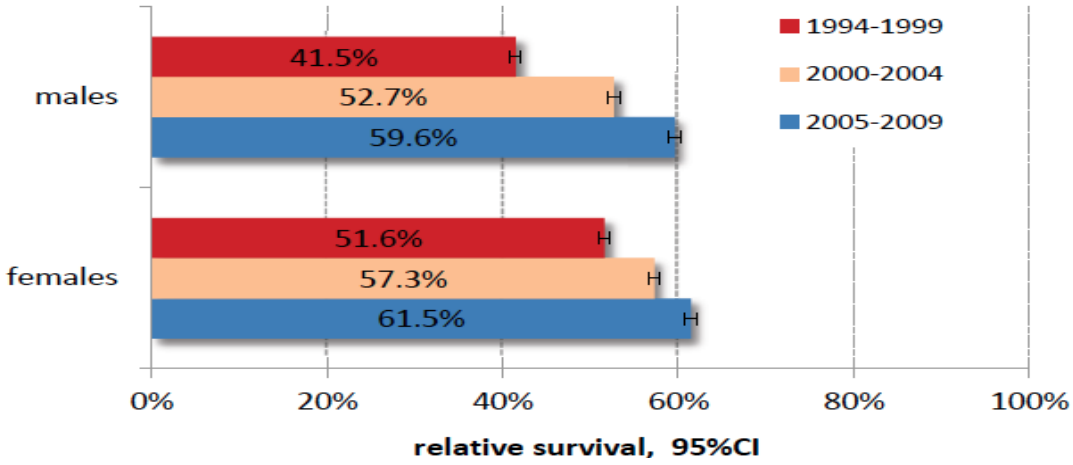

Figure 3.3 Five year relative survival for males and females diagnosed with all invasive cancers (National Cancer Registry 2014).

61.5% in 2005-2009 (National Cancer Registry 2014). These statistics are graphically depicted in Figure 3.3. While the majority of diagnoses of cancer presented are over 65 years of age, a prevalence of younger diagnosis is emerging for certain cancers (National Cancer Registry 2014) this will be discussed further in Section 3.3.

Figure 3.4 illustrates the Ireland's presence in the incidences and mortality rates of cancer excluding non-melanoma skin cancers in Europe for 2012 (National Cancer Registry 2013). Statistically speaking, Ireland has a higher incidence rate of cancer than the EU average placing fifth on this scale. However, Ireland placed just under the average EU level of mortality in 2012, per 100,000 cases.

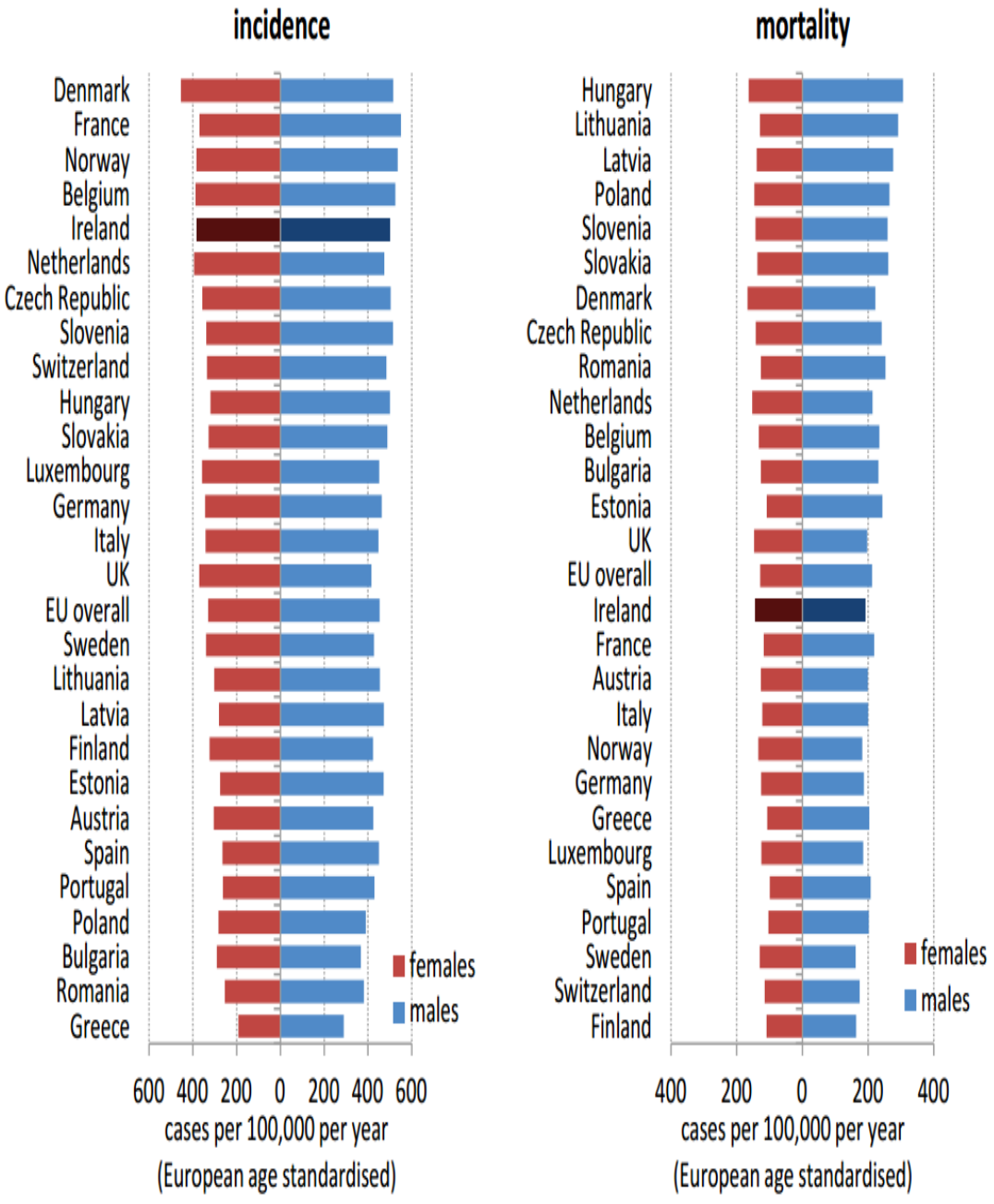

Figure 3.4 Estimated all invasive cancer (excluding non-melanoma skin) incidence and mortality in Europe 2012 (National Cancer Registry 2013).

3.2.3 CANCER AS A CHRONIC DISEASE

Due to the advancement in early

detections, diagnosis and treatments, a significant increase in the volume of patients surviving the acute phase of the illness and now living with cancer has evolved over the last number of decades (Miedema et al. 2003; Phillips and Currow 2010). The same is true in Ireland as statistically the number of instances of cancers compared against the instances of mortality is significantly higher suggesting that survival rates in Ireland are increasing. Cancer has only recently been categorised as a chronic disease (Khan et al. 2008; Phillips and Currow 2010). " Tritter and Calnan (2002) argued that cancer is not actually an illness but rather a categorisation of "uncontrolled replication. However, this is not a new school of thought, as Morton Jr and Morton (1953) concluded that upon studying 17 case studies of increased survival cancer could, in fact, be treated as a chronic disease.

Cancer, like other chronic diseases such as Chronic Obstructive Pulmonary Disease (COPD) and diabetes, can be incapacitating, cause intense pain, fatigue, be distressing, stigmatise and induce premature menopause (Tritter and Calnan 2002; Earle 2006).

The diagnosis of cancer somewhat contrasts with the diagnosis of other types of chronic diseases, where the diagnosis of cancer is often a rapid process between a specialist referral and treatment, unlike many other chronic disease that emerges over a slower period of time such as diabetes (Tritter and Calnan 2002). Furthermore, the complexity of cancer treatment involves multidisciplinary medical care teams in multiple locations preventing, monitoring and maintaining treatments (Tsiachristas et al. 2011) which contrasts with the majority of other chronic illnesses where it is often a slower onset (Tritter and Calnan 2002).

Furthermore, it is evident that cancer survivors tend to require significant on-going care and support in key areas such as prevention, surveillance, intervention for side effects and coordination between services (Phillips and Currow 2010). In addition to the multidisciplinary approach - clinically, patients and their physicians must constantly remain vigilant of recurrence of cancer at the original site or the occurrence of a new secondary or metastatic cancer at a new site (Hesse et al. 2010). For these people, cancer survival now entails living with a complex and chronic condition (Phillips and Currow 2010) suffering significant physiological, psychological and psychosocial changes throughout the duration of their illness.

Research conducted by Teunissen *et al.* (2007) who reviewed 46 different studies that included 26,223 patients presented 37 symptoms that occurred in ≥10% of cancer patients with fatigue, pain, lack of

energy and appetite occurring in >50% of patients (Teunissen et al. 2007). Somatic symptoms burden such as those listed above need to be recognised and managed in order to improve the quality of life of a cancer patient (Kroenke et al. 2010). Scales such as the physical symptom scale Patient Health Questionnaire (PHQ-15) somatic scale, the symptom prevalence scale Memorial Symptom Assessment Scale, the cancer symptom prevalence scale Anderson Symptom Inventory, or the functional impairment scale Sheehan Disability Scale (SDS) have long been used to assess patients. By incorporating ICT into somatic scales, physicians would be in a better position of identifying patients with somatic symptoms using a hybrid of these scales.

Cancer as many believe, however, may not immediately mean death; it may not even be a one off occurrence. Unfortunately, it has been found that while many cancers can repeatedly reoccur, they can be managed as an on-going illness. One such cancer is ovarian cancer, which has the tendency for the cancer to reoccur and then enter remission; this cycle can translate into survival over many years (American Cancer Society 2013). Management of chronic disease cancers can include but not limited to shrinking tumour size, alleviating pain, and other symptoms such as nausea and insomnia. These comorbidities are considered non-chronic aspects of their cancer yet they still need to be managed by clinicians.

Literature suggests that there has been a global shift from traditional methods of cancer treatment, where potentially only one type of treatment was given (Arruebo *et al.* 2011; American Cancer Society 2014). Should this treatment not be successful, attentions would then focus on end of life care. With the advancement in cancer treatment and detection through clinical trials and evidence-based practice, a shift to a more multifaceted approach is being undertaken (Arruebo *et al.* 2011; American Cancer Society 2014). Patients are now potentially offered more and often combined treatment types that effectively prolong, maintain, and improve the quality of a patient's life. It is in this area that ICT could be potentially adapted to aid clinicians towards the management of patients after they have completed their treatments. This could result in improving the long term the long-term outcomes of patients' with cancer as a chronic disease.

3.3 CANCER SURVIVORSHIP

As a result of a growing aging population and advancements in early detection and treatment, the prevalence of cancer survivors is successfully increasing globally (Khan et al. 2008). As previously discussed in Section 3.2.2, the NCRI reports that survival in Irish people has statistically improved, depicted previously in Figure 3.3. (National Cancer Registry 2014). Latest estimates from the NCRI indicate that over 90% of prostate patients have survived for at least 5 years post diagnosis (National Cancer Registry 2014). Pancreatic patients had the poorest 5-year survival rates with less than 10%, whilst brain, lung, liver, oesophageal, and stomach cancer patient had less than a 20% 5-year survival rate post diagnosis (National Cancer Registry 2014).

While, the majority of cancer diagnoses in Ireland are over 65 years of age, a prevalence of much younger patients are presenting with in situ cervical cancer, invasive testicular cancer and Hodgkin's lymphoma, with a mean age of 31, 33, and 32 respectively (National Cancer Registry 2014). Long-term survivors of cancer need to continuously manage their health by participating in preventative care and screening due to the potential of late onset side effects of chemotherapy and radiotherapy, the risk of recurrence and secondary diagnoses (Khan et al. 2008). Studies have shown that cancers survivors have significantly poorer health and productivity outcomes compared to similar individuals without cancer (Yabroff et al. 2004).

Many articles have defined the term 'survivorship' as those who have completed a treatment plan and are living with or beyond cancer. Mullan (1985) argues that there was a need to make clear the difference between those who were 'cured' and those 'living with overt or covert disease'. As a result, he coined the term of 'survival' as it was applicable to both cases (Feuerstein 2007). He maintained that 'Survivorship' was an essential concept needed to help explain, manage, and prevent a series of challenges that those who are living with a cancer diagnosis are now facing (Mullan 1985; Feuerstein 2007). He denoted three phases or seasons a 'survivor' would move through. Acute Survival – the diagnostic and treatment state, Extended Survival - the remission or completion of treatment and the final Permanent Survival – which is essentially the cure (Mullan 1985). Similarly, Feuerstein (2007) surmises that survivorship focuses on "populations and individuals with a diagnosis of cancer who have completed primary treatment for cancer".

During these phases of survivorship, it is imperative for the lines of communication to remain open within the hospital setting, in the event of a patient encountering new or post-treatment symptoms, showing signs of recurrence or failing to deal with the emotional and psychosocial impact of a cancer diagnosis (Khan et al. 2008; Madhavan et al. 2011).

3.3.1 SURVIVORSHIP CARE PLANS

As a standard, oncology services focus on the triangulation of treatment, surveillance and amelioration of symptoms and side effects (Cheville et al. 2009). An influential report written by the Institute of Medicine (IOM), titled "From Cancer Patient to Cancer Survivor: Lost in Transition" was published in 2005 (Hewitt et al. 2006). The report called for the need for a health care system from "the period following first diagnosis and treatment and prior to the development of a recurrence of cancer or death"(Hewitt et al. 2006). The report details ten recommendations largely needed to address the chronic effects of cancer, but specifically states the need for a Survivorship Care Plan.

This Survivorship Care Plan (SCP) was defined as a "comprehensive care summary and follow-up plan" to be "written by the principal provider or providers who coordinated oncology treatment" (Hewitt and Ganz 2007). The care plan would be a reference guide for both the patient and their physicians. The care plan should be educational material on the long-term effects of their diagnosis, treatment summary and should identify local support resources within their community (Earle 2006; Hewitt and Ganz 2007; Hoverman 2013). The plan should also provide the patient with guidance on follow-up care, prevention and maintaining their personal health (Earle 2006; Hewitt and Ganz 2007; Hoverman 2013).

While it is worth noting that not all patients will be willing to, or in a position to, accept and participate in these survivorship care plans, they should be offered to all patients in all circumstances after treatment (Mullan 1985; Earle 2006).

3.3.1.1 DEVELOPMENT OF SURVIVORSHIP CARE PLANS

Phillips and Currow (2010) state that survivorship care is vital for all cancer care Survivorship care plans are considered as a three-step process (Silver 2011). The first is the assessment of cancer patients' issues, following this is recommending specific interventions, and thirdly re-evaluation of

cancer survivors' needs are fulfilled and arrange further follow-ups or recommendations as required (Silver 2011). Rehabilitation of cancer patients is an intrinsic aspect of a cancer survivorship programs. With the increasing rates of cancer survival, it is necessary to consider those who have finished treatment and returning to routine life after cancer and in need of rehabilitation (Doyle and Kelly 2005).

Many patients often feel as though they have to rehabilitate themselves (Silver 2011) and are not sure of which services are suitable to their condition or where to go to find these services (Silver 2011). Studies such as Cheville et al. (2009) highlight the need for functional problems to be addressed. It is therefore, important for health care professionals to recognise the need for rehabilitation referrals. There are two types of rehabilitation interventions, one that "enhance medical attention" such as physiatrist or physical therapy and the second is complimentary supportive therapies such as acupuncture, massage and exercise classes (Silver 2011). Doyle and Kelly (2005) suggest the philosophy of rehabilitation as 'preventative, restorative, supportive, and palliative'.

The goal of the Survivorship Care Model is to optimise coordination and continuity of care between the patient and across all the multidisciplinary providers (Earle 2006). Continuity of care has been defined as the "The systematic assurance of uninterrupted, integrated medical and psychosocial care of the [cancer] patient, in accord with the patient's wishes, from assessment of symptoms in the pre-diagnostic period, throughout the phase of active treatment, and for the duration of post-treatment monitoring and/or palliative care" (Lauria 1991). To develop these plans, one needs to have all information readily available in one place to be in a position to formulate accurately a plan of care within a multidisciplinary team. The need for an electronic record of a patient's history, diagnosis, treatment, and follow up plan is vital to obtain a full working knowledge of a patient's status, which in turn will help in decision-making. This document should include a diagnostic and treatment summary, information on lifestyle, nutrition and exercise resources, information relating to side effects, recovery, signs, and symptoms of recurrence, recommended follow-up schedules, knowledge of available support groups, knowledge of information sent to GPs. In addition, Earle (2006) suggests that the plans keep patients informed on research findings if involved in trials, or a change to management practice.

Communication is an intrinsic part of all aspects of oncology treatment, and no more so in the development of Survivorship Care Plans. Multidisciplinary teams need to work in collaboration to develop the best possible care that can be given to a cancer patient. In fact, Phillips and Currow

(2010) state that SCPs need to be on-going, well-coordinated, effectively maintained by a whole-system-approach focusing on prevention and surveillance, whilst alleviating the long-term effects of cancer treatment and other comorbidities associated with their cancer. A comprehensive report written by Smith et al. (2011) details patients' perspectives' on survivorship care planning, the report identifies the need for personalised information for the patient on key psychological and psychosocial effects, and also as a communication improvement.

3.3.1.2 IMPLEMENTATION OF SURVIVORSHIP CARE PLANS

SCPs require ICT to help coordinate and manage care. SCP's need to be recognised as an essential component of cancer care especially after post-treatment care (Earle 2006) in order to gain acceptability and be used as standard practice. Fundamentally, however, as Silver (2011) stated "a survivor care plan is only as good as the services that it documents". Real tangible services need to corroborate the recommended follow up plans outlined by physicians (Silver 2011). A study conducted by Shalom et al (2011) suggested that physicians found that SCPs saved them time, having essentially an executive summary of a patient's "external and historical cancer treatment information" all in one place. Shalom et al. (2011) also found that physicians found evidence-based information on examinations helpful in determining follow-up plans.

However, in contrast to these studies, a study conveyed by Grunfeld et al (2011) disproved the hypothesis that SCP's are beneficial for improving patient-reported outcomes in breast cancer patients. The study deemed that there were no statistical or clinical differences between the control group and those assigned to a programme. However, the study did elude that if a more "in need" cohort of Breast Cancer patients were used the results could have been different and subsequently felt that survivorship care plans could be more beneficial to other oncology groups such as colorectal or prostate cancer (Grunfeld et al. 2011).

Nevertheless, the underlining problem with many survivorship programmes is funding, reimbursement, and monetary payments for services that cancer patients need. These barriers prevent both patient and physician participation in survivorship programmes and trials. Survivorship programmes frequently include health care services that are not reimbursed by insurance companies. Both the creation of these plans and many services necessary in the post-treatment stage are not covered by insurance providers (Silver 2011). In addition, the lack of consistency amongst care plans

as well as the amount of time it takes to create a plan have hampered the acceptance by industry users (Salz et al. 2012; Hoverman 2013).

3.3.1.3 SURVIVORSHIP CARE PLAN SUMMARY

In summary, to implement successfully a Survivorship Care Plan Programme into the oncology workplace, a number of key elements need addressed in order to do so.

1. A clinical practice needs an extensive knowledgebase of a patient's history, condition, treatment, and follow-up plan preferably in the form of an Electronic Health Record (EHR) or Electronic Patient Record (EPR).
2. A well-established reimbursement scheme is required with insurance providers.
3. An extensive open dialogue between all departments is imperative for the collaborative approach and development of the best patient care.
4. A care plan needs to be a comprehensive personalised document. The use of ICT is required here to play a pivotal role in the building of these care plans.

3.4 CHRONIC-DISEASE MANAGEMENT

Meeting the multifarious needs of chronically ill patients is notably one of the most challenging aspects facing medical professionals (Wagner 1998). Chronic Disease care exists in a triangular environment of the community, the health care system and the provider organisation (Thomas *et al.* 2002). This triangulation is necessary in order to successfully manage, maintain, and coordinate the care of patients with chronic diseases. Despite the remarkable improvements in the prognosis of cancer, it is well documented that cancer and chronic diseases patients develop symptoms that impair their quality of life and independence (Cheville et al. 2009). Studies extensively show that physical pain, nausea, fatigue, and the need for emotional support and rehabilitation services are still a common need across all the chronic diseases subtypes.

It would be illogical to presume that all cancers are treated in the same way. Likewise, it would seem ludicrous to postulate that a one-size fits all approach could be taken in order to deliver a means of managing cancer survivors. Therefore, individually designed management plans should and need to be derived for each patient presenting at clinic. These plans need to be tailored to the specific physical, emotional, and clinical requirements a patient may have. However, in order to do so, clinicians must have a full understanding of a patient's disease, symptoms, history, treatment and social situation so as to effectively help patients to manage their illness (Børøsund et al. 2013). Børøsund et al (2013) raises the issue that for many clinicians, this information is neither readily available nor correctly completed thus leaving the clinician unable to accurately provide information and care which a patient may require. Elsewhere, Michel Wensing *et al* (2009) reiterates delivery of chronic care requires extensive planning, coordination, improved use of technology and enhanced support in the area of disease-self management.

While many definitions of disease management exist, the most frequently cited definition of Disease Management Plans (DMP) is by the Care Continuum Alliance (formerly known as the Disease Management Association of America (DMAA)), which defines it as "A system of coordinated health care interventions and communications for populations with conditions in which patient self-care efforts are significant. Disease management supports the physician or practitioner/patient relationship and plan of care, emphasises prevention of exacerbations and complications utilising evidence-based practice guidelines and patient empowerment strategies, and evaluates clinical, humanistic, and economic outcomes on an on-going basis with the goal of improving overall health." (DMAA: The Care Continuum Alliance 2014). In the majority of instances, these DMPs, incorporate or are based on a

chronic-disease management model, this provides a structured framework of elements that can aid in their development. Often some patients feel that once treatment has been completed, they no longer have the physical and emotional support that they once had whilst on treatment (Miedema et al. 2003; Stevenson et al. 2007). Some studies have expressed patients' beliefs that their general practitioner (GP) does not fully understand their diagnosis and treatment to the same extent as their primary oncologist does and this for some individuals and their families can be infuriating and exasperating (Miedema et al. 2003; Stevenson et al. 2007). However, local support services are left to bridge this notable gap. Therefore, with well-designed and tailored care plans and summaries, GPs will be more informed alleviating some of the frustration felt by the family. Primary care physicians can choose to approach the management of these patients through chronic care models. Physicians can implement one or all, available chronic-care models (CCM) incorporating ICT into the process to enhance their practice. A discussion outlining these care models will be conversed in Section 3.4.1 with additional models discussed within the Appendix.

Due to its pivotal role in CCM interventions, Green *et al.* (2006) identified ICT as a key critical success factor in promoting compliance, tracking patients, obtaining information and measurement data whilst bridging the gap between what physicians were doing and what guidelines suggested.

3.4.1 CHRONIC DISEASE SELF-MANAGEMENT MODELS

Chronic disease self-management models are adaptable frameworks that can be applied to certain patients with chronic diseases. Many chronic disease management models can potentially be applied to cancer survivors. This dissertation will focus on the four models that the researcher considered were most applicable to this study, and which were strongly referenced by in the literature. Details of additional models, not discussed in the body of this text can be seen in Appendix H. The models the researcher will discuss in further detail are:

- Wagner's Chronic Care Model
- 5A's Model
- The Flinders Program Model
- The Kaiser Permanente Risk Pyramid

These management models, while focusing primarily but not entirely on self-management can in fact, reduce anxieties associated with the uncertainty after treatment for patients living with chronic diseases, in addition to reducing hospitalisation and making savings in health care (Lorig *et al.* 1999). Wagner (1998) states that chronic disease models tend to be categorised into two areas, "targeting and case management", sometimes referred to as carve-in or carve-outs, and "comprehensive system change". Moreover, Wagner (1998) argues that it is this "comprehensive system change" that is required to successfully address the needs of chronically ill patients and only then this reconfiguring of the health system will actual improvements in outcomes occur. Targeting and case management, Wagner (1998) argues, has focused on four main assumptions – reductions in cost equal improvements in health, focusing on the high-cost chronically ill patients will reduce costs, primary care cannot manage chronic illness care and finally patients will have better outcomes if taken from primary care and delegated to a case manager.

These assumptions, Wagner (1998) feels need rigorous research before they become an industry norm. Wagner et al (1996) continues to suggest that a successful chronic disease care programme relies heavily on non-physician interactions to support counselling and self-management projects, which could be potential barrier for adoption. The focus on outcome improvement, Wagner (1998) argues, is often overshadowed by these subsidiary benefits.

3.4.1.1 WAGNER'S CHRONIC CARE MODEL

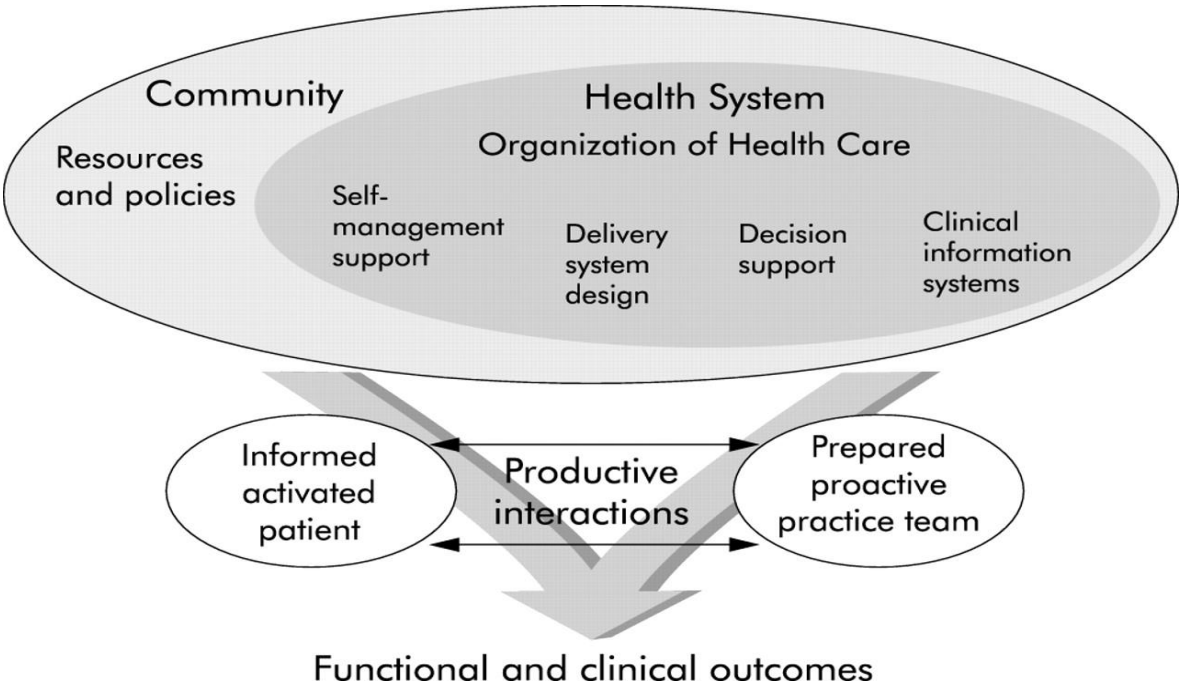

Figure 3.2 Wagner's Chronic Care Model ((Epping-Jordan et. al 2004); 13:299-305)

3.4.1.1.1 OVERVIEW

Recommended by the World Health Organisation, Wagner's Chronic Care Model (CCM) is considered by the majority of researchers as the most influential and habitually adopted of the chronic care models available. It is a heuristic evidence-based framework of six interrelated elements designed to work together to improve patient outcomes while strengthening the patient-physician relationship (Coleman et al. 2009; Oprea et al. 2010). The CMM focuses on how to effectively manage patients with chronic diseases, transforming these patients from "acute and reactive" to "proactive, planned and population-based" (Coleman et al. 2009). The CCM is not an abstract concept like other models, but a concrete framework to improving health care practice. It encompasses the needs of patients with chronic illness under six key elements – community resources and policies, health care organisation, delivery system design, decision and self-management support, and clinical information systems. Figure 3.4 shows a modern graphical representation of Wagner's model, which outlines the six elements of the model. This chronic care model could potentially be adapted to integrate ICT and could subsequently be applied to the management of patients with cancer and those living with cancer as a chronic disease in survivorship

Many of the individual elements of the model have been implemented as standalone processes. However, the most common of elements implemented are the self-management, decision support, delivery system design and clinical information system pillars (Bodenheimer et al. 2002). These elements have the potential of reducing health care costs while improving the management of chronic disease patients (Bodenheimer et al. 2002).

The six elements of Wagner's CCM include *Self-management support*, which prepares patients to understand their collaborative role in establishing goals. *Community Resources* address the barriers to attaining these goals. *Clinical Information Systems* provide clinicians with patient information and improve practice performance by employing *Decision Support* systems that ensure that clinicians have the relevant clinical and preventive knowledge available to them. While knowledge and patient data are essential, without the correct *Delivery system design* the chronic care model will fall short in areas such as appointment scheduling and follow-up, continuity of care and a fully integrated practice team. Finally, none of this would be possible without a *Health Care Organisation* and the leadership needed to drive forward the quality improvements.

3.4.1.1.2 BENEFITS

The CMM is a functional blueprint for chronic care models, it provides a set of organisational principles for patient-centred evidence, and population based care (Glasgow *et al.* 2001; Wagner, Glasgow, *et al.* 2001). CMM removes the fragmentation that traditionally is seen occurring in primary health care by advocating cohesion and multidisciplinary coordination (Oprea et al. 2010) improving quality in healthcare (Hung *et al.* 2008). The model improves the outcomes of patients by altering traditional methods of ambulatory care to a primarily patient-centred, evidenced based care model (Coleman et al. 2009). Alerts are regularly applied to the model to identify appropriate tests to order based on available information (Coleman et al 2009). What makes Wagner's CMM stand out from the rest is the model's focus on the doctor-patient relationship. The model relies heavily on the communication pattern of information giving, feedback, negation and contracting, and verbal persuasion (Oprea et al. 2010). This is essential in promoting mutual trust and encouraging patient empowerment and self-management of their disease essentially improving on their health outcomes. Studies suggested that in practices where the CMM was successfully applied, benefits included a 35% decrease in the number of hospital days for admissions, declines in emergency department attendance and an overall improvement in conditions (Coleman et al. 2009). The framework translates organisational ideas of change into specific distinctive applications (Coleman et al. 2009).

The model however falls shorts in aspects of mental health treatments for anxiety and depression (Cimpean and Drake 2011), health promotion and should be enhanced by ICT to enhance decision-making (Cimpean and Drake 2011). However, studies also suggested some negative outcomes related to the adopting of the model. Reports indicated that in some instances, users often felt no benefit to the model, seeing little or no difference to traditional methods of care (Coleman et al. 2009). Low participation rates, the short follow-up period, and possible contamination of sample data, however, was listed as the main reasoning behind the negative outcomes (Coleman et al. 2009). In addition, Michel Wensing *et al.* (2009) argues that it is practice size rather than chronic care coordination that determines physicians workload, suggesting that physicians in larger practices use time more efficiently than their smaller practice counterparts.

To better integrate aspects of prevention and health promotion into Wagner's Chronic Care model, Barr *et al.* (2003) set out to enhance the model, introducing the Expanded Chronic Care Model in 2003 in British Columbia. The model retains the original six components but adds activities on health promotion.

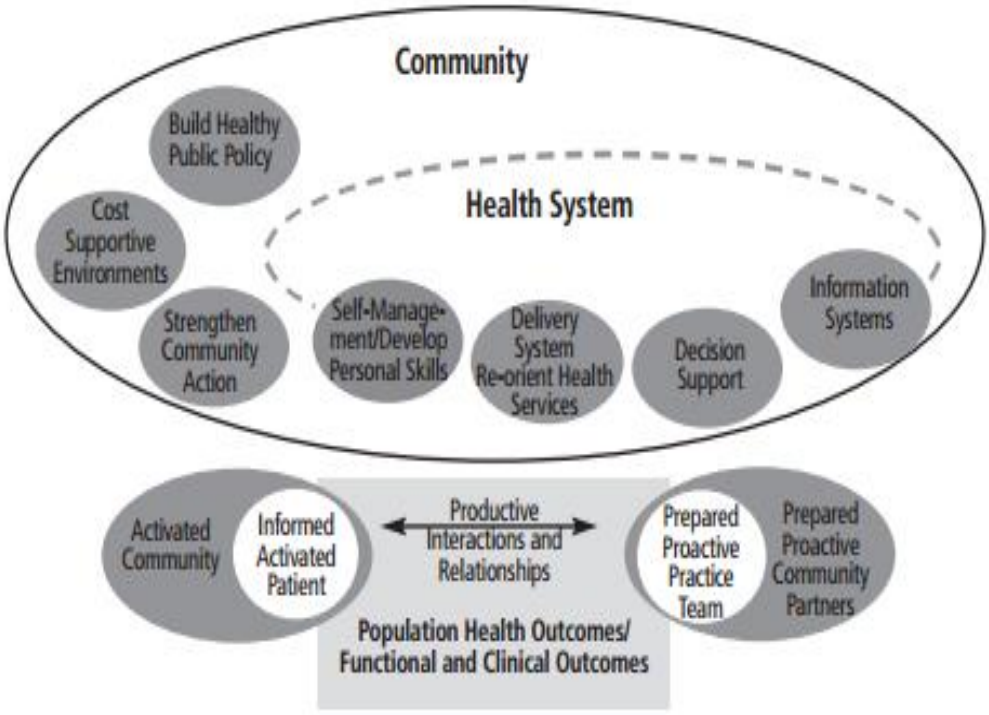

Figure 3.3 The Expanded Chronic Care Model: Integrating Population Health Promotion (Barr et al. 2003)

3.4.1.2 THE 5A MODEL

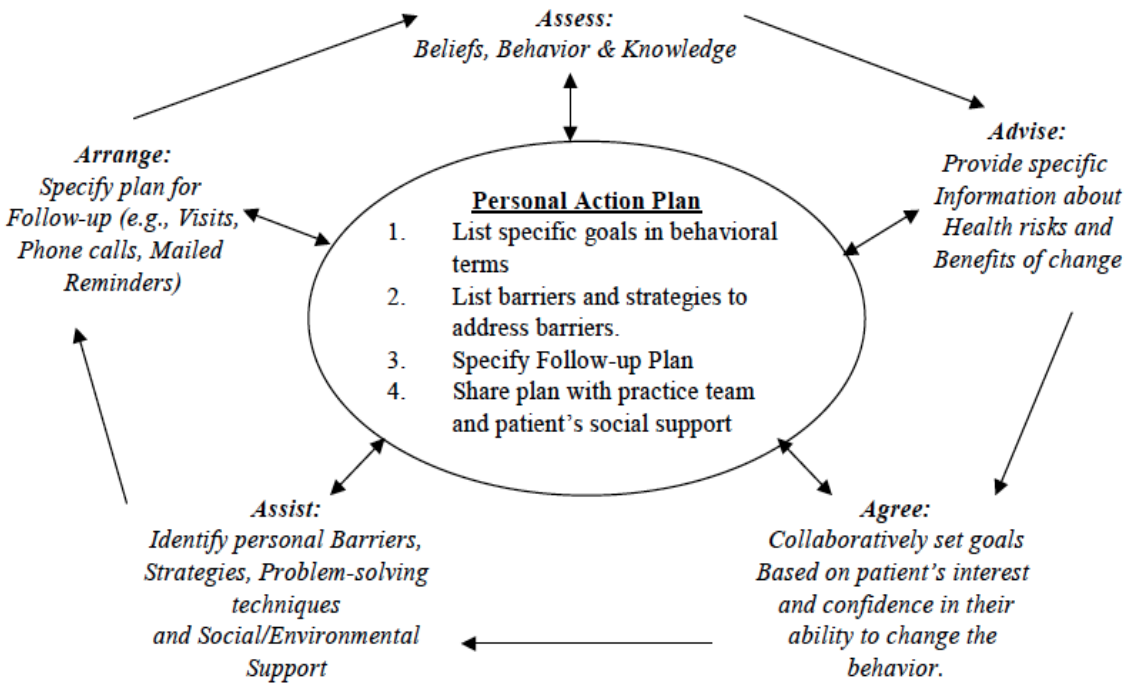

Figure 3.4 Self-Management Model with 5 A's (Glasgow, et. al, 2002; Whitlock, et al. 2002)

3.4.1.2.1 OVERVIEW

In 2000, the United States (US) Public Health Service released an updated national clinical guideline, from which the 5-As model was developed by the Department of Health US.

While this model was originally developed to for detection, assessment and management of smoking, nutrition, alcohol and physical activity (SNAP) the model has been adapted into other fields including chronic health management. The 5As are as follows – Assess behaviour, Advise change, Agree goals, Assist in growth and knowledge and Arrange and schedule referrals or follow-ups (Lawn and Schoo 2010).

3.4.1.2.2 BENEFITS

This model is considered straightforward and easy to remember due to the acronym for application in health service environments. The model is transferable regardless of the workers discipline and level of expertise and experience. It is easily understood and matches expectations by patients akin to

standard medical practices such as advice giving, referrals and follow-ups. In addition, the model acknowledges the expertise of patients in living with their condition (Lawn and Schoo 2010).

3.4.1.2.3 LIMITATIONS

The 5A model does not always meet the needs of people with complex psychosocial issues and health conditions. Review of progress or effectiveness of the support given does not always occur which may lead to a missed opportunities for feedback from patients (Lawn and Schoo 2010). Little accountability in how the steps are delivered to ensure patient-centeredness versus health professional directed care (Lawn and Schoo 2010).. The model remains largely an organisational construct with limited practical use (Lawn and Schoo 2010).

3.4.1.3 THE FLINDERS PROGRAM ™ MODEL

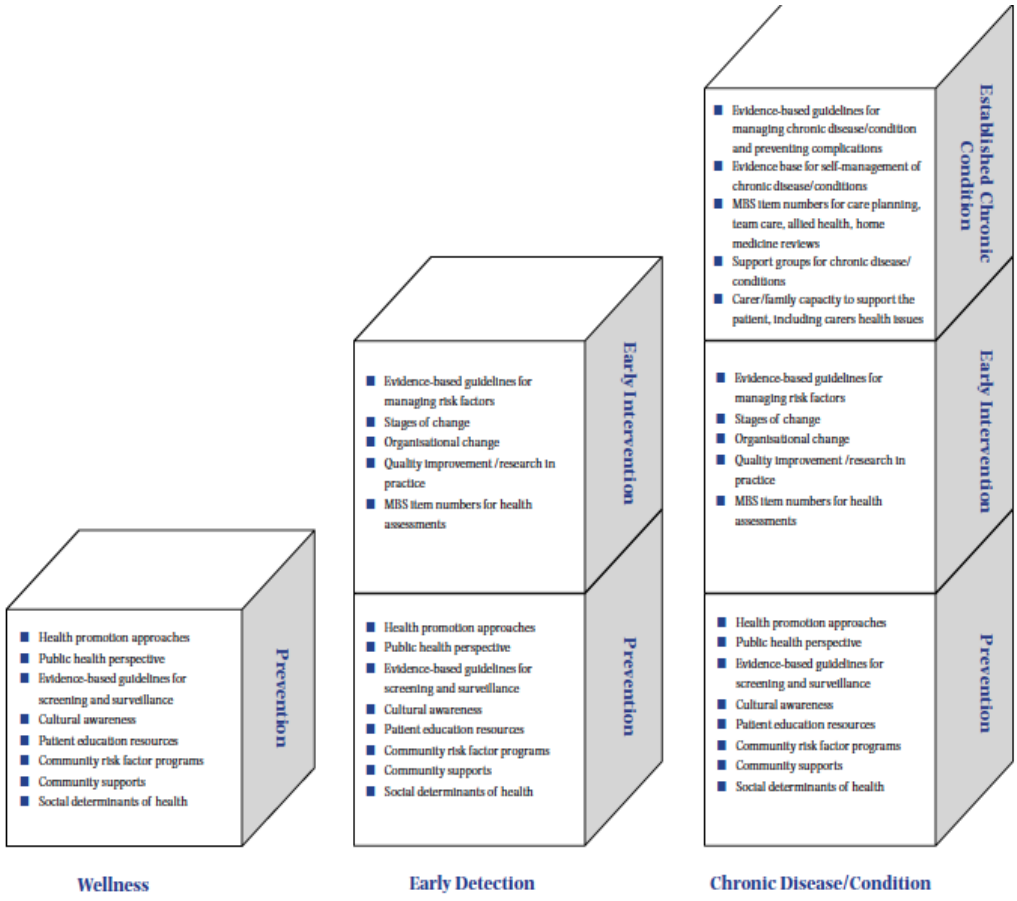

Figure 3.5 Example of Self-Management Support: Knowledge Required Blocks

3.4.1.3.1 OVERVIEW

Developed during the 1990s, 'The Flinders Programme', led by Malcolm Battersby, developed by the Flinders University of South Australia, Human Behaviour, and Health Research Unit (FHBHRU). The Flinders Chronic Care Model is an individualised and patient-centred interaction. The model emphasises the role that clinicians have in shaping patient self-efficacy, through cognitive behaviour therapy used during patient-doctor interactions. It consists of six principles – knowledge of your condition, follow a treatment care plan, participate in decision making with your physician, monitor and manage signs of your psychosocial and psychological states and adopt a healthy lifestyle (Regan-Smith et al. 2006; Lawn and Schoo 2010). In addition, the model provides clinicians with tools to assess the self-management capability and develop collaborative care plans with their patients. Tools incorporated in the model include the partners in health scale, cue and response questionnaires, problem and goals and care plans (FHBHRU Flinders University 2010).

3.4.1.3.2 BENEFITS

The model is designed so that each care plan is individualised to the patient this promotes a person-centred focus and moves from a more clinical goal focus to a patients goal focus. The model promotes system change within organisations to enhance chronic disease management. The tools provided by the Flinders Programme are generic and can be adapted to different populations and contexts so that it can be used for a wide range of chronic diseases often in patients with multi-comorbidities which is common with in a cancer diagnosis (Lawn and Schoo 2010). The interview and care planning process captures the complexity and interdependencies of these comorbidities (Lawn and Schoo 2010).

3.4.1.3.3 LIMITATIONS

The model is very labour intensive when implemented in its full format with the use of all tools. Some patients with chronic disease find this approach intimidating and need matched with other patients who are equally willing to accept the changes to the lifestyles. Training does not adequately equip professionals with mechanisms for supporting on-going self-management and behavioural change (Lawn and Schoo 2010). Effective use of the tools requires practice and mentoring and modelling to support health professionals to gain proficiency in their use (Lawn and Schoo 2010). The approach also assumes that all health professionals across the collaborative 'team' will 'play' as a result there has been a slow uptake by industry (Lawn and Schoo 2010).

3.4.1.4 THE KAISER PERMANENTE PYRAMID (TRIANGLE)

3.4.1.4.1 OVERVIEW

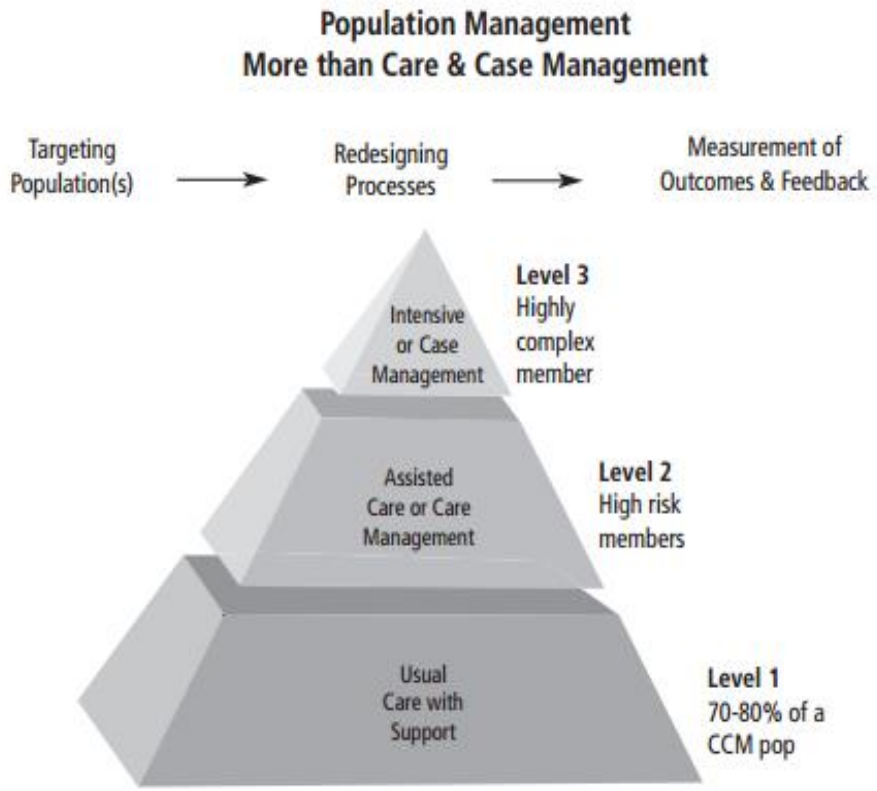

Figure 3.6 Kaiser Permanente Risk Pyramid(Pan American Health Organization 2012).

Developed by Kaiser Health Plan and Permanente Medical Group, the Kaiser Permanente Risk Pyramid was launched in 1999 as part of the Chronic Care Management programme targeting chronic diseases in North California. The integrated-delivery programme hoped to improve health outcomes creating savings through fewer hospitalisations and emergency department visits (Thomas *et al.* 2002). The programme works on the principle that the organisation collects health insurance payments from their clients and provides them with care in return (Pan American Health Organization 2012). The model splits individuals into three levels. Patients at level 1 tend to have their chronic condition under control this is the majority (70-80%) of the population who are receiving care through their primary physician (Thomas *et al.* 2002). Patients at level 2 are considered high risk members, their condition is poorly controlled and need assisted care or care management (Thomas *et al.* 2002). Patients at Level 3 however are considered highly complex members, these are patients with complex multi-diagnoses and who need on-going intensive or case management care (Thomas *et al.* 2002). In some instances, you may see a fourth level on the base of the pyramid, this represents the relatively healthy population, in which the focus is on prevention and wellness promotion.

3.4.1.4.2 BENEFITS

The Kaiser Permanente Pyramid model focuses on care and case-management of patients across all levels. The model uses a 'population wide prevention' and 'risk stratification' to promote public health to the wider community and for identifying patients at risk. The triage element can mean more reliable and consistent care because of standardised tools of assessment. In the United Kingdom, the NHS implemented the Kaiser Permanente model and noted a faster throughput of patients by adopting the model (Feachem et al. 2002). In addition, (Ham et al. 2003) analysed 11 common conditions and found admission rates, length of stay and bed day less when the model was adopted. While a controversial and heavily criticised report, Feachem *et al.* (2002) did identify investment in Information Technology as a key element in more advanced aspects of the model, reducing administrative time, history taking, dictation of letters and locating patient records. Information exchange is made possible by 'KP Health Connect' an EHR that supports "two-way patient contact" to contact patients due for follow up, overdue for mammogram or pap smears or for those having difficulty managing their condition (Strandberg-Larsen et al. 2007; Porter and Kellogg 2008).

3.4.1.4.3 LIMITATIONS

The mutual exclusivity of the Kaiser Permanente Medical Group means that only those who have insurance with Kaiser Permanente can only benefit from the model directly (Porter and Kellogg 2008). Kaiser Permanente does not practice medicine outside of their organisation and are not in contact with other groups.

3.5 CONCLUSION

This chapter emphasised background information of cancer and chronic disease. The chapter showed how survivorship care and disease management plans, together with chronic care models, could integrate with ICT to coordinate effectively the care of patients with cancer as a chronic disease.

The literature emphasises the developments of ICT in medicine and its effect on the reshaping of how care and care coordination is delivered. The literature has exposed how chronic diseases affect the lives of patients, their families, and their friends. The diagnosis of cancer is particularly traumatic with patients requiring emotional, as well as physical support. Even still, on completion of treatment, these patients now living with cancer as a chronic disease require significant long-term support, follow-up appointments, and surveillance. Therefore, it appeared necessary to focus on the role of ICT towards the management of patients with cancer as a chronic disease.

In summary, the literature identifies some key areas ICT can play a role to support clinicians in the management of patients with cancer as a chronic disease. These are as follows,

- ICT could be used for the assessment and surveillance of new or post-treatment symptoms, signs of recurrence and remission, and non-chronic aspects such as insomnia, failing to deal with emotional and psychosocial impact of a cancer diagnosis.
- ICT could be used in the monitoring of somatic symptoms with the integration of somatic symptom scales.
- ICT can open the lines of communication, between patient and physician, physician and physician, and physician and system optimising care coordination and continuity of care.
- ICT could be used to generate personalised, patient specific follow-up plans, Survivorship Care Plan (SCP), or Chronic Disease Management Plan (DMP) established from evidence-based information obtained during examinations.
    - SCPs are a reference guide for both the patient and their physicians, that includes educational material on long-term effect of their diagnosis, diagnostic and treatment summary, local support resources, guidance on follow-up care, rehabilitation, prevention and maintain their personal health
    - DMPs are a systematic approach to coordinated health care intervention and supporting communication between the physician and patient, plan of care,

prevention, and complications by utilising evidence-based practice guidelines, empowerment strategies on an ongoing basis.

- Elements from Chronic Care Models such as Wagner's, 5As Model, Flinders Program and the Kaiser Permanente Pyramid can be concatenated and adapted to integrate ICT to effectively coordinate and manage patients, easing communication, shared decision-making, prompt and alert for guideline adherence and continuous care improvements
- ICT is critical in the areas of promoting compliance, tracking patients, obtaining information and measurement data while bridge the gaps in communication.
- ICT can aid in clinical trials and evidence based medicine.

CHAPTER 4: THE ROLE OF ICT & THE MANAGEMENT OF CANCER AS A CHRONIC DISEASE

4.1 THE ROLE OF ICT & THE MANAGEMENT OF CANCER AS A CHRONIC DISEASE

Information and Communication Technologies (ICT) has increasingly become part of health care delivery in the cancer domain, but it can do more than just inform a patient they have or are living with cancer. In fact, ICT has been accredited to resolving the fragmentation associated with medical delivery across multiple sites (Hesse et al. 2010). Modern ICT encompasses an extensive range of technologies that theoretically can be used in the exchange of information. Weber and Kauffman (2011) have defined ICT as 'technologies that support data and information processing, storage and analysis, as well as data and information transmission and communication, via the Internet and other means'. Earle (2006) emphasises the need for IT to be developed to ensure the portability of treatment records should a patient move away from their current locality.

Through its adoption, ICT is redeveloping how the care, coordination, and involvement of patients are delivered. In fact, a study by Hung *et al.* (2008) suggested that there is an increased awareness and vested interest in chronic disease monitoring, and a notable transition from paper-based recording to electronic clinical management systems. Consequently, the use of ICT has shown to share the burden of health care delivery. Subsequently, the benefits of ICT have been recognised as a potential tool to support patients in their homes (Koch 2006). The use of telephone, Internet, and mobile applications has begun to change the way health assessments and support is delivered. However, it is not just in the patient home where ICT can play a vital role in the cancer environment. ICT based self-management systems can provide a support for both monitoring chronic disease health status and in delivering therapeutic interventions in order to help patients adapt to the prospect of living with cancer as a chronic disease (Rosser et al. 2009).

ICT has changed how society can interact with health services, altering how patients access information and providing support to patients in a non-traditional format. Increasingly patients are turning to the Internet for information to further their knowledge and understanding (Stevenson et al. 2007). Frequently the quantity of information available can overwhelm patients and especially when they are unable to find the information that, they require. However, support groups are

increasingly and continually making themselves readily available online (Norum et al. 2002) to support cancer patients and their relatives. The nature of this type of social network creates an online community of support for patients offering them increased security during initial, throughout and post treatment. When patients are more informed they feel more empowered, show signs of reduced anxiety and subsequently give the patient a sense of control (Wilkes et al. 2000) which patients with chronic diseases often feel they have lost during their initial diagnosis. While and Dewsbury (2011) argue that we are advancing from the "face-to-face age of health care" to the "information age of health care" moving staff into a more technical role, dealing with patients in a non-face to face role from an information hub. Norum et al (2002) also suggest that because of this information age we are seeing a "new type of cancer patient and relatives" who is more informed and curious about their illness.

Adoption of ICT within a clinical context can complement traditional medical practices. ICT can be used to support the clinical practices related to patient assessment, treatment, education, and health promotion. Personal planning tools, Hesse *et al.* (2010) feels should be made available to both patients and physicians in order to aid in the forward planning of follow-up appointments, examinations and anticipating services. Evidence from literature has shown that the remote assessment of chronic diseases compares more favourably than that of any other illness (While and Dewsbury 2011). "Health Portals" could allow physicians to conduct remote virtual appointments over the Internet, discussing over a secure connection details of a patient's illness, whilst providing physical and emotional support (While and Dewsbury 2011).

Moreover, While and Dewsbury (2011) claim it will not only be patients who will benefit from the adoption of ICT but also will allow a greater opportunity for nurses to access evidence based information not currently available. The necessity for the communication between and the coordination of a heterogeneous cohort of medical professionals makes the cancer setting a very complex environment with a need for a vast amount of information in varying forms (Mohammadzadeh et al. 2013). The need for this accurate, timely and comprehensive information is a fundamental element for physicians to expand their knowledge of the disease, detect trends and determine the most effective course of treatments (Mohammadzadeh et al. 2013).

ICT can facilitate in the improvement of communication, coordination, and quality of care delivered. Wallace (2007), an advocate of the potential Health IT, suggests Health IT has transformed cancer care, in terms of "pace, scale, and scope" – the process of responding to cancer-related queries, ability

to "comprehensively capture rich patient data" and "to directly support care standardisation". Health Information Technology, or Health IT, defined by the US Federal Government's Office of the National Coordinator for Health IT (ONC) as, *"hardware, software, integrated technologies or related licenses, intellectual property, upgrades, or packaged solutions sold as services that are designed for or support the use by health care entities or patients for the electronic creation, maintenance, access, or exchange of health information."* (Health Information Technology for Economic and Clinical Health (HITECH) Act, 2009).

ICT can be used throughout a patient's journey from diagnosis, to treatment decisions, to symptom management in the survivorship phase and subsequently during palliative end of life care (Clauser et al. 2011). Health care providers can also use ICT to transform care coordination, continuity of care and decision support. Given the complexity of cancer care throughout a patient's life, the numerous decision points regarding a person's health does not stop once a patient has received treatment. In fact, the surveillance of disease, disease progression, disease reoccurrence, and other side effects are key factors in the management of patients with cancer as a chronic disease. The use of ICT can be used to monitor these symptoms and side effects concurrently facilitating in decision-making.

Often, patients consider themselves the instigator of their own care coordination becoming overwhelmed by the task of organising their own follow-up appointments, making decisions on their care and even dealing with the concept of a cancer diagnosis (Carroll *et al.* 2010). While clinical coordinators and navigators can alleviate much of this anxiety, incomplete information can often cause a patient to "fall-through-the cracks" (Carroll *et al.* 2010; Clauser *et al.* 2011). This is especially true when treatments occur in different cancer centres and information is not always readily available or complete (Clauser et al. 2011). The multidisciplinary approach to cancer means that information gathering is often quite difficult for staff to coordinate. Development of treatment summaries as discussed previously are one of the many solutions to this inevitable problem promoting continuity and collaborative care between specialists and patients (Clauser et al. 2011).

Research has shown that ICT, often in the form of eHealth, can be applied to end-of-life palliative care patients (Madhavan et al. 2011). Palliative Medicine focuses primarily on caring for those facing serious illness, alleviating symptoms, improving the quality of life of patients, and proving psychosocial support to patients and their families (Madhavan et al. 2011). Palliative Care is an unfortunate yet intrinsic element of the cancer care lifecycle. Palliative care patients require long term monitoring and care for the duration of their lifetimes due to risk of relapse and treatment-induced side effects.

However, literature has recognised gaps in communication between physicians and patients and a lack of personalised treatments available to patients, however, research has indicated ICT initiatives that have the potential to bridge these shortfalls (Madhavan et al. 2011). Communication becomes increasingly more difficult when caring for paediatric palliative care patients. A study by Madhavan et al (2011) indicated the critical need for seamless personalised flow of information among multidisciplinary care teams and external parties for example families, social workers, and schools through Health Information Technology (HIT) systems. HIT incorporates a collective range of clinical applications enabled by an existence of a meaningful use for Electronic Medical Records (EMR) (Madhavan et al. 2011).

Where ICT can facilitate greatly is in the area of compliance. The ability of IT to enforce standardisation of information by using coding tools such as the use of Systematized Nomenclature of Medicine -- Clinical Terms (SNOMED CT) or International Classification of Diseases, Tenth Revision (ICD-10) for diagnosis improves the quality of data recorded about a patient's care.

Clinicians are increasingly seeing the benefits of ICT in terms of the availability of rich patient data that can be used to support the standardisation of care (Wallace 2007). Thus, ICT can play a pivotal role in the area of cancer research. It is greatly recognised that there are significant inefficiencies in the accrual of patients to clinical trials. Research has shown that one of the most common barriers surrounding physician participation in clinical trials revolves around the area of communication. The study identified the need for improved communication between departments about trial availability (Hornbrook 2005).

The use of ICT contributes significantly in the increase in recruitment levels to clinical trials. This increase is a direct result of ICT's ability to promote awareness of available trials, eligibility requirements, recruitment processes and direct patient enrolment in clinical trials (Wallace 2007). In-built alerts to current EHR systems can highlight availability to physicians of patients' eligibility to participate in trials. ICT can also encourage collaborative research in cancer care through research networks. This collaborative research can improve cancer awareness promotion and prevention, early detection, treatment, long-term care and post diagnosis monitoring by facilitating in data sharing (Wallace 2007).

4.2 WHAT ICT SERVICES ARE ALREADY AVAILABLE?

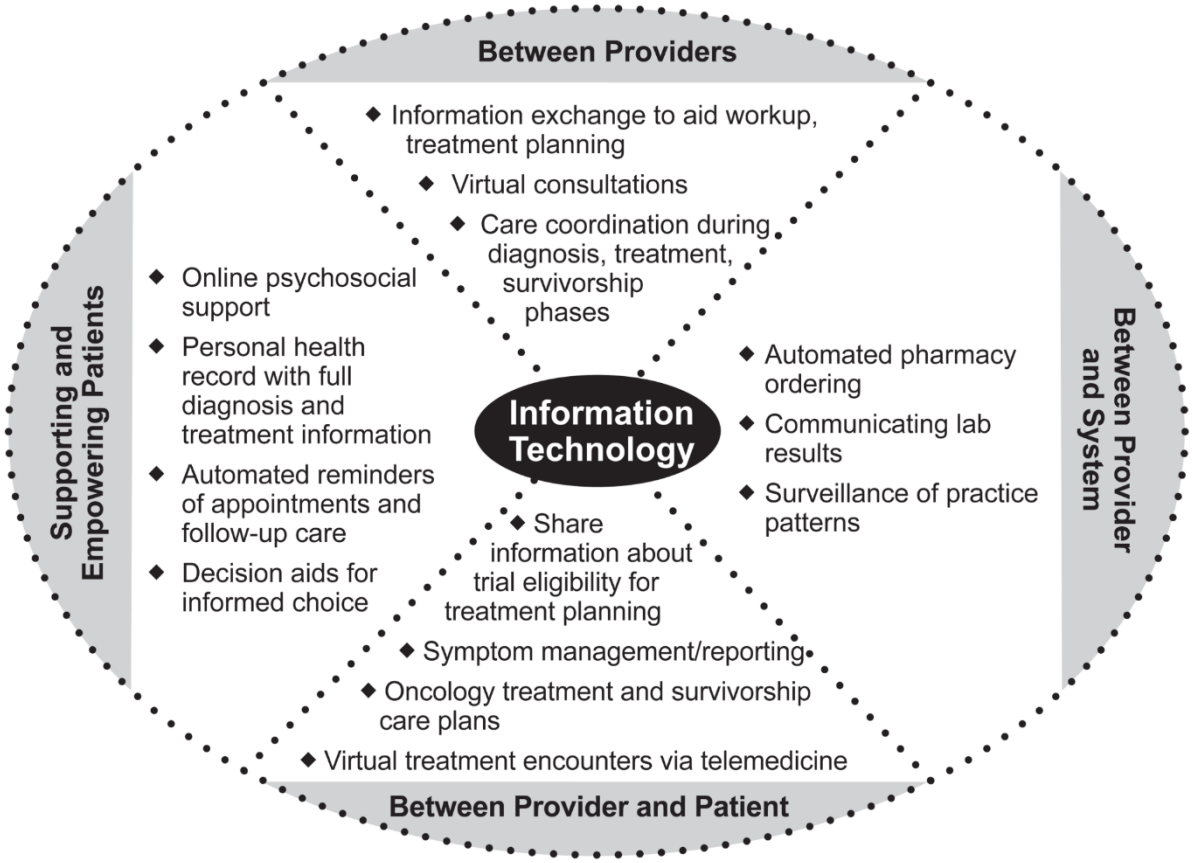

Figure 4.1 Patient, Provider, and system applications of information technology for cancer care (Clauser et al 2011)

ICT has become a central focus in the management of cancer patients. Figure 3.9 above, depicts the complexity and potential of IT to integrate into the health care environment.

While ICT, has become considerably more established and now heavily used in the management of patients in the form of Electronic Health Records (EHR) and Health information Systems (HIS). Studies have suggested that the use of web-based mobile applications will become more of prominent feature in cancer care and management (Clauser et al. 2011).

The Internet may be awash with cancer support groups. However, groups such as the Comprehensive Health Enhancement Support System (CHESS), have been paving the way for online support especially with woman surviving breast cancer (Baker et al. 2011; Clauser et al. 2011). CHESS was established on the principle of "making high-quality information and social support accessible and useful," and permitting patients to "become…actively involved in their treatment and recovery" (Baker et al. 2011; Clauser et al. 2011; Center for Health Enhancement Systems Studies 2014). The system provides educational and social support resources, access to decision support tools, and tailors a

personalised information page to better manage their health (Center for Health Enhancement Systems Studies 2014). The CHESS system has proven to improve a patient's quality of life, reduce demands on physician time and reduce costs (Center for Health Enhancement Systems Studies 2014). In Norway, the Norwegian Cancer Union (NCU) set up a telephone support system 'The Cancer Line' and website offering information, guidelines and support to all affected by cancer (Norum et al. 2002).

There is some evidence to suggest that ICT is efficacious when it comes to the continuation of care, disease and care management and coordination of care (Wootton 2012). ICT can play a leading role in providing education on self-management, enable information exchange between physicians, facilitate in the coordination of follow-up appointments and benefit the documentation of electronic health records (Wootton 2012).

An evaluation of an Interactive Tailored Patient Assessment (ITPA) and communication tool, *Choice*, implemented to support clinicians in the management of cancer patients was conducted by Børøsund et al (2013). The evaluation found that having assessment information of a patient's current symptomatic problems prior to a patient's appointment increased a patient's engagement in appointments, improved communication between clinicians and patients, while also mentally preparing the clinician to deal with the arising problems (Børøsund et al. 2013).

4.3 ADOPTION OF ICT

Adoption of ICT is increasing globally, connecting more individuals to more services than ever before (Weber and Kauffman 2011). Increasingly organisations have turned to Information Technology (IT) as a solution to reduce costs and increase productivity. However, the medical industry has always been deemed as a late addition to the movement in adoption of IT. It is still common practice in the majority of health care institutes to complete medical charts and ordering of medication and examinations on paper. Nevertheless, the introduction of Health Information Systems (HIS) and especially Electronic Patient Records (EPR) within this domain has in fact seen a transformation in the delivery of healthcare.

So why and how does adoption happen? Many theories suggest diffusion, economic development and competition whilst others suggest human behaviour, and an individual's willingness to adopt IT as the key factor (Weber and Kauffman 2011). Beal and Bohlen (1957) outlined five mental stages people go through during acceptance of new ideas such as Technology, as outlined below in Table 4-1, but states that individuals go through these phases at different times and tends to depend on the complexity of the practice.

Table 4-1 Beal and Bohlen (1957) Mental Stages of Technology Adoption

Stage	Stage when an Individual
Awareness	Becomes aware of a new idea, lacks details concerning it
Interest	Gathers information and contemplates personal benefits
Evaluation	Analyses mentally the idea
Trial	Experiments with the technology & gather information concerning it
Adoption	Full scale continued use & satisfaction with idea

While we know that people do not adopt at the same rates Beal and Bohlen (1957) were the first to show that technology diffusion occurs across five different adopter categories and at different rates as outlined in Table 4-2 and as seen in Figure 4.2.

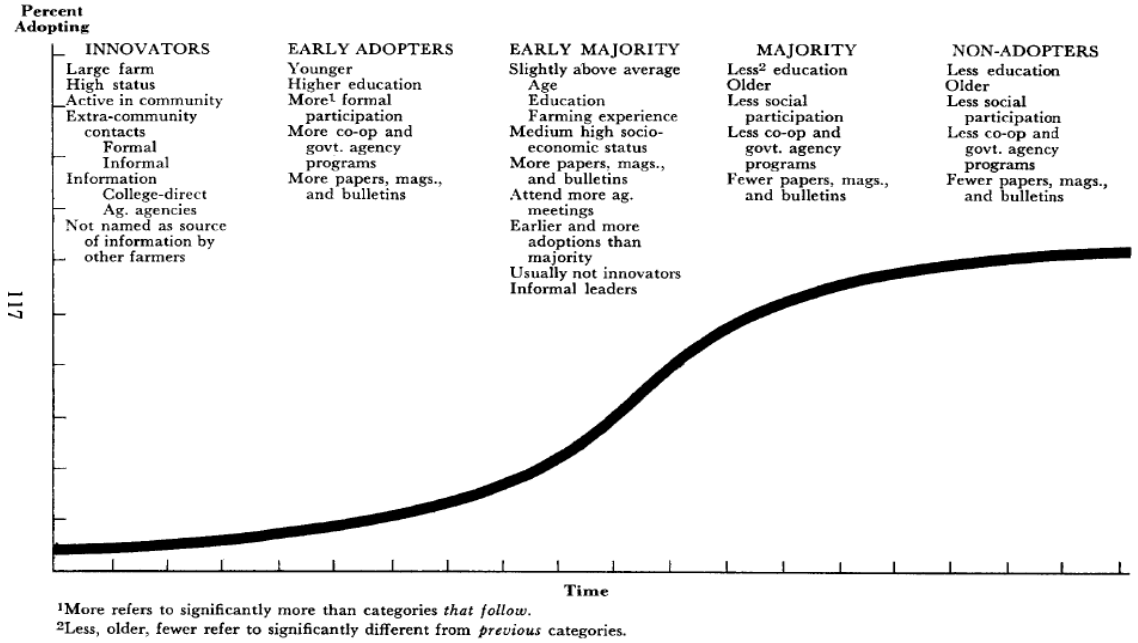

Figure 4.2 Summary, Adoption Cure and Time Categories (Beal & Bohlen 1957))

Table 4-2 Beal and Bohlen (1957) Adopter Timing Categories

Stage	Adopter Timing
Innovators	The first people to adopt a new ICT
Early Adopters	People adopting ICT immediately after innovators
Early Majority	Beginning to adopt ICT about the same time as Majority
Majority	Late adopters
Non-Adopters	Non-adopters and those adopting much later than majority

Moreover, White (2008) argues that the current medical paradigm, founded in 1910 by Abraham Flexner, is in need of a drastic change. The Flexner Report was embraced as the definition of medical academia, reforming the standards, culture and curriculum of medical education in the United States of America and Canada (Flexner 1910). The paradigm falls short however, White (2008) suggests, in key areas of medical knowledge, prevention, quality, costs and manpower. White (2008) recommends that the adoption of Health Information Technology (HIT) is a solution to these shortfalls.

On multiple occurrences, the literature has backed up that the implementation of HIT reduce costs (Fishman *et al.* 1997; Wagner EH *et al.* 2001), reduce medical errors (Bates *et al.* 2001; Bates and Gawande 2003), reduce hospital readmission (Lorig *et al.* 1999; Celler *et al.* 2003), improves safety

(Cheperli *et al.* 2013), and could potentially improve the patients' quality of life (Lorig *et al.* 1999). Turan and Palvia (2014) also echo these remarks suggesting that Health Information Technologies (HITs) has single handily improved both the safety and efficiency of patient care.

Reimbursement for the use of telemedicine services such as non-face-to-face consultations and via "store and forward" telecommunication services are becoming more prevalent in the United States (US) (McLean et al. 2011; While and Dewsbury 2011).

4.4 BARRIERS OF ICT ADOPTION

While IT is often considered a "saviour" by healthcare professionals (Turan and Palvia 2014), it can cost organisations substantial quantities of money to both establish the infrastructure and to implement (Hesse et al. 2010). Green *et al.* (2008) described it best by characterising the required change as a 'chicken-and-egg' scenario, the change necessary requires capital for the acquisition and remodelling, but capital is conditional on the change previously being acquired. Furthermore, it can potentially take years before an organisation can see any of the cost reduction benefits IT promised to solve.

Wagner *et al.* (1996) suggests that the way in which care is organised around the patient visit is incorrect, that inadequate training and lack of incentives are amongst the most common barriers in high-quality chronic illness care. Norum et al (2002) agrees with Wagner and claims some physicians will not answer patients' emails unless financially rewarded for doing so. Turan and Palvia (2014) reiterate the fact, that there is a lack of compensation for physicians, who must embrace and learn how to use these new systems. In addition, insurance companies often do not recognise these visits as a billable follow up consultations and reimbursement may not be possible (Earle 2006).

While there is a growing need for the use of ICT towards the management of patients with cancer as a chronic disease, many variants potentially prohibit such an implementation. For some, computers and the Internet is not something that they are comfortable with using. Hesse *et al.* (2010) argues that when Healthcare Systems do not address the daily needs of health care professionals, this in turn causes health related improvements to become stagnated, effecting workflow and distracting to practitioners.

Other barriers include the need for standardisation of content (Earle 2006). However, even with successful implementation of these standards, the creation and communication of plans with the relative parties would be time consuming and costly (Earle 2006). Earle (2006) emphasises the need for a cultural change in order to successfully apply these care plans, suggesting that physicians need to accept care planning as a standard and as a result patients will recognise the significance of post-treatment care and adherence to long term follow up.

Børøsund et al (2013) expressed that there were several organisational, ethical, educational and system interaction challenges associated with implementing a new system. It has been found that it is often difficult to fit new technologies and solutions into daily routines. New IT solutions can take a considerable length of time, if ever, to fully integrate and gain acceptance from local users. Architectural failures such as lack of software interoperability between systems often becomes a significant challenge when multiple standalone systems are used in an environment (Mohammadzadeh et al. 2013). The lack of cohesion between systems often leaves a user completing the same task on multiple systems and can lead to ambivalence surrounding even simple daily tasks.

Whilst, HIT systems are introduced to tackle omitted data and cause a process to be revaluated, it can also unwittingly introduce new errors caused by human error due to lack of experience with the system (Cheperli et al. 2013) or in fact poor interface design (Mohammadzadeh *et al.* 2013). Often it is the lack of user-centred design that is the attributed to the cause of repudiation of a health care system (Hesse *et al.* 2010). Legal elements such as patient confidentially, security and privacy are also considered key factors in the failure of ICT projects (Mohammadzadeh et al. 2013). Lluch (2011) suggests that ICT projects can decrease the face-to-face interactions between patients and their physicians. Madhavan *et al.* (2011) identified four issues regarding HIT adoption in paediatric palliative care, (1) need for flexibility, (2) standardisation of information distribution, (3) dynamic information representation and finally (4) advancing patient care within a fully functioning "cyber-infrastructure".

4.5 ICT IMPLEMENTATION STRATEGIES

In order to implement any ICT software or any of the aforementioned care plans and models as discussed in Chapter 3, Ham (2010) points to a number of implementation strategies that can contribute change.

Physician leadership is required in order to orientate health services from acute care to chronic care, as illustrated by the Kaiser Permanente model (Ham 2010). Measurement and use of patient outcomes are required to drive quality improvements especially in preventative and chronic care (Ham 2010). Adoption of incentives to support strategies in addition to community engagement are also needed for successful implementation (Ham 2010). Whereas it is evident from literature, that ICT can be used to support these strategies at a basic level, the focus needs to be on exploiting potential benefits from ICT adoption through population-management, easing communication, effective coordination, shared decision-making, prompts and alerts for guideline adherence ;for continuous care improvements (Ham 2010).

While physician leadership is required, end-user involvement is essential to the successful development and implementation of any new system. Developing integrated IT systems for cancer patients is complex due to the multifaceted nature of medicine, including the physical, emotional, spiritual and psychosocial dimensions (Kuziemsky et al. 2008). It is therefore, vital that any technology implemented in these settings meet the needs of its users and adds significant clinical value. Subsequently, the use of a Software Requirements Specification (SRS) document and use-case modelling can be used to drive discussion and formulate the requirements for a system. This will be discussed further in Chapter 5 and Chapter 6.

4.6 CONCLUSION

This chapter focused primarily on answering the research question – "***What roles does ICT have in the management of cancer as a chronic disease"***. The literature emphasises the roles of ICT in the management of cancer as a chronic disease. This chapter showed the successful implementation of ICT applications in the area of cancer patient management and support, follow-up coordination, and use in continuity of care. The researcher concludes the chapter with the challenges, acceptance and implementation strategies towards ICT adoption. Thus, having focused on these literature findings, it appeared necessary to concentrate on what ICT requirements clinicians in the medical industry felt were applicable towards the management of patients with cancer as a chronic disease.

In Summary, the literature identifies some key findings surrounding ICTs roles in supporting clinicians in the management of patients with cancer as a chronic disease. These are as follows,

- ICT based self-management systems can provide a support for both monitoring chronic disease health status and delivering therapeutic interventions.
- ICT has changed how society can interact with health services, cancer centres can provide their own online support with information being managed and directed by clinicians.
- Personal Planning tools can aid forward planning of follow-up appointments, examinations and anticipating services.
- Health Portals could allow physicians to conduct remote virtual appointments providing physical and emotional support
- ICT can allow physicians to expand their knowledge of a patient's disease, detect trends, and determine the most effective course of treatment.
- ICT can be used throughout a patient cancer journey facilitating in the improvement of communication, transformation care coordination, and quality of care delivered, in addition to providing decision support.
- ICT can provide comprehensive rich patient data and support care standardisation and compliance. Thus playing a pivotal part in cancer research, clinical trials, collaborative research, and evidence based medicine subsequently improving cancer awareness promotion and prevention, early detection, treatment, long-term care and post diagnosis monitoring by facilitating in data sharing. ICT can aid in accrual of patients through alerts.
- ICT can be used to concurrently monitor symptoms, side effects, signs of recurrence or progression, while also facilitating in decision-making.
- ICT can be used to prevent a patient 'falling-through-the-cracks'.

- ICT can provide personalised treatment plans, bridging the gap between the multidisciplinary cancer care teams.
- ICT has improved both safety and efficiency of patient care.

CHAPTER 5: EVIDENCE & DATA COLLECTION

5.1 INTRODUCTION

This chapter will introduce and explore the proposed application domain used to answer the proposed research questions. Relevant scholarly literature will look at methods of gathering user requirements, prototype development, validation processes, and methods of conducting interviews. The researcher, acknowledging the importance of a literature review at this point, undertook an extensive review in the area in order to support the following question:

"What are, from a clinical perspective, the user requirements of an ICT system to support clinicians caring for patients with cancer as a chronic disease?"

5.2 USER REQUIREMENT GATHERING

The prevalence of technology is continuously growing in healthcare and specifically in the cancer environment. Developing integrated IT systems for cancer patients is complex due to the multifaceted nature of medicine, including the physical, emotional, spiritual and psychosocial dimensions (Kuziemsky et al. 2008). It is therefore, vital that any technology implemented in these settings meet the needs of its users and adds significant clinical value.

Requirements' gathering establishes the earliest phase of the software development life cycle (SDLC) (Kotonya and Sommerville 1996). A software development life cycle is "the period of time that begins when a software product is conceived and ends when the software is no longer available for use" (ISO/IEC/IEEE 24765:2010(E) 2010) . The software life cycle typically includes a concept phase, requirements phase, design phase, implementation phase, test phase, installation and checkout phase, operation and maintenance phase, and, sometimes, retirement phase (ISO/IEC/IEEE 24765:2010(E) 2010). However, while there are significant differences between the various SDLC methodologies for example, Waterfall, V-Model, Spiral, Agile, and Unified Process model, the requirements gathering phase is the primary phase across all process models. A Software Requirement Specification (SRS) document is the primary deliverable from this phase.

In order to determine the type of delivered systems, it is imperative to obtain a good comprehensive knowledge of the users' prerequisites. The primary cause of over half of ICT projects being cancelled, completed late or over budget is due to insufficient, impractical or unrealistic expectations of user requirements (Brownsell et al. 2012). Johnson *et al.* (2005) echo these sentiments suggesting that healthcare ICT systems, in many instances, do not incorporate user-centric design principles but rather implement ad-hoc developments resulting in dissatisfied users, and discarded systems. At the same time, Scandurra *et al.* (2008) advises that due to the lack of structured end-user involvement there is not enough focus put on the context of use. In addition, Kuziemsky *et al* (2008) suggests that due to the complexity of cancer care, these complexities of interdisciplinary care are not effectively captured. Brownsell et al (2012) suggests adopting a pluralistic approach to identify and evaluate user requirements in order to improve holistic design and applicability of the system. While historically, user-centred design methodologies and techniques are associated with remarkable improvement in safety of modern aviation systems, other disciplines can successfully apply user-centred design methodologies and techniques.

User needs can be defined as the "difference between users' goals and the present condition, which is manifested by user problems and possibilities; and the context of use, which includes the characteristics of the intended users, users' present tasks and environment" (Kujala et al. 2001). User requirements can subsequently be defined as "the formal descriptions of the user needs which the design and development of the product ought to be based upon" (Kujala et al. 2001).

Due to the nature of cancer being a multi-disciplinary setting, the socio-technical aspects were included to understand the current organisational workflows in which the implemented system would exist. Kuziemsky *et al* (2008) introduces the use of a hybrid concept of Grounded Theory (GT) and Participatory Design (PD). This approach focuses on the relevance of using the two methods in order to drive a complete understanding of user requirements. This is especially necessary in the area of health care and more specifically in the areas of cancer treatment, survivorship, and end-of-life palliative care due to the fundamental multidisciplinary complexity associated with this area. Grounded Theory is a "qualitative research method that uses systematic set of procedure to develop an inductively derived Grounded Theory about a phenomena"(Kuziemsky *et al.* 2008). GT provides the means of analysing and coding data associated with processes and activities. Participatory Design is a method of understanding traditional approaches to the way individuals performs their daily tasks. PD provides the means of a more comprehensive data rich perspective due to the engagement of end-

users (Kuziemsky et al. 2008) and can show in theory where ICT can support the needs of the participants.

By applying appropriate methodologies to gather user requirements, this potentially can lead to a more efficient and user accepted system (Herbst 1974).

5.3 METHODS

The researcher employed, an iterative, user-centred design approach, to obtain the user requirements for the development of the prototype. Using participatory design principles, end-users were involved throughout the system development lifecycle. A system development lifecycle contrasts with the software development life cycle and defined as *"period of time that begins with the decision to develop a system and ends when the system is delivered to its end user"* (ISO/IEC/IEEE 24765:2010(E) 2010). For this dissertation, the development life cycle consisted of three main phases:

- Definition of systems objectives and context of use
- Specification of user requirements
- Development and validation of a prototype
- The following diagram outlines the user requirements process.

Figure 5.1 Schematic of user requirement process adapted from (Brownsweel et al. 2012)

5.4 CONTEXT DEFINITION

To provide a baseline of systems presently available for clinicians, the researcher conducted a systematic literature review of systems, tailored to cancer patient management. The researcher also conducted a study on current policy and procedure of processes within the Oncology subgroups of the private hospital. This information assisted in the clarification of the project's need within the hospital setting. As previously discussed, an initial literature review identified a new cohort of patients that are emerging as a growing demographic. This demographic is of patients with cancer as a chronic disease who are living longer but who need continuous clinical follow-up and management.

5.5 USER REQUIREMENTS & SPECIFICATION

Having derived the context of use, the next phase involved the views of end-users. The researcher asked the users to identify what their individual system requirements, and how they may use the system. This process often referred to as the software development process is the process of translating user needs into software requirements, transforming the software requirements into design, implementing the design in code, testing the code, and sometimes, installing and checking out the software for operational use (IEEE Computer Society 1998). To specify the user requirements for this dissertation, in-depth face-to-face discussions gathered the views of potential end users.

Key informant interviews are a typical approach used to gather qualitative data in order to derive information from key informants toward process change, improvement and implementation of new systems. They provide valuable inputs in terms of understanding current processes and underlining issues on a more personable level from a limited number of well-informed people. Face-to-face interviewing is perceived to be the most frequently used approach, as it is more conducive to free exchange of ideas.

User involvement in terms of input and feedback is a vital element to improving or adopting a new process. Recommended by literature, that appropriated representation of stakeholders or key informants in addition to the early involvement of IT departments is vital for an implementation to be a success (Berg 2001; Brownsell *et al.* 2012; Mair *et al.* 2012).

Interviews conducted with oncology staff consisting of doctors, consultants, surgeons, and nurse specialists. A letter of invitation invited all staff members to participate. Participants were eligible if they worked within the oncology services of the hospital. Excluded participants included the staff not involved in the area of oncology services. The study received the appropriate ethical approval for this process to take place and the study gatekeeper supervised the processes to ensure no breach in ethics. The research used a topic guide and visual aids in order to steer the discussions. The interviews were recorded and subsequently transcribed and analysed using framework analysis.

The triangulation of data from the literature reviews, policies and procedures and interviews identified the common user requirement in order to prioritise the system features. The literature review assisted in identifying features, which were common in systems already available on the market.

The information formed the basis for a Software Requirements Specification (SRS) document. This document specifies the user needs on which the design and development of the prototype was developed. The researcher held additional meetings with those who conducted the preliminary interviews to review and refine the document. A member of the hospital IT team reviewed the final SRS document, which chapter 6 outlines. Chapter 7 is a summary of the validation process and outcomes following the review by the IT team.

5.6 SOFTWARE REQUIREMENTS SPECIFICATION DEVELOPMENT

A requirement can be any need or expectation of a system or software stated or implied by the needs of the customer. Typically derived from the system requirements documents, the software requirements specifications outlines the system functionality, typically stated in functional terms, and are defined, refined, and updated as a development project progresses (IEEE Computer Society 1998).

A requirements specification defined as *"a document that states requirements for a system or component"* (ISO/IEC/IEEE 24765:2010(E) 2010). It may refer to or included drawings, patterns other relevant materials or information to form the basis whereby conformity to verify criteria. Written specification documents can include System Requirement Specification, Software

Requirement Specifications, Design Specification, Test specification, and so forth. All these documents establish "required specifications" whereby design outputs are verified.

A Software Requirement Specification (SRS) defined as *"documentation of the essential requirements (functions, performance, design constraints, and attributes) of the software and its external interfaces* (ISO/IEC/IEEE 24765:2010(E) 2010). The Software Requirements Specification document contains a written definition of the software functions. The SRS document is required to validate that software to meet the requirements. SRS documents contain details on all software systems inputs and outputs, system functions, performance requirements, definitions on all external and user interfaces, user interactions, error definition and handling, required response times, operating system requirements and constraints, all default values and ranges, and any safety related requirements or specifications (IEEE Computer Society 1998).

5.7 PROTOTYPE DEVELOPMENT

During the design process, the translation of the SRS document into a logical and physical representation of the proposed software occurs. Derived from the SRS document, the development of a Software Design Specification (SDS) outlines what the software should do and how it should do it.

A prototype, consisting of a conceptual mock-up of a system should be developed and subsequently evaluated with potential users. A letter should invite a second cohort of individuals, to evaluate the prototype. Invited participants, randomly selected from the cohort of oncology staff members from the hospital, should complete a short semi-structured questionnaire on their opinions of the prototype. A prototype within iterative, user-centred design allows end users to visualise and conceptualise how a system may appear and operate (Brownsell et al. 2012).

5.8 EVALUATION

Due to the high monetary costs and negative impact to staff and patients associated with ICT System failures, there is a great need for rigorous evaluation of ICT systems in health care (Ammenwerth *et al.* 2003). Heinrich (1999) defines evaluation as the decisive assessment of defined objects, based on a set of predefined criteria, to solve a given problem.

Evaluation of each requirement identified in the Software Requirements Specification document for accuracy, completeness, consistency, testability, correctness, and clarity (Department of Health and Human Services and Food and Drug Administration 2002) is essential. SRS documents should be evaluated to verify that there are no inconsistencies among requirements (Department of Health and Human Services and Food and Drug Administration 2002). All performance requirements are clearly stated, completeness of safety, fault and security specifications, software functions are accurate and complete, requirements are appropriate for the environment it will be placed in, and all requirements are expressed in terms that are measurable or objectively measurable (Department of Health and Human Services and Food and Drug Administration 2002). A Software Requirements Review (SRR) defined as "*a review of the requirements specified for one or more software configuration items to evaluate their responsiveness to and interpretation of the system requirements and to determine whether they form a satisfactory basis for proceeding into preliminary design of the configuration item"* (ISO/IEC/IEEE 24765:2010(E) 2010)

5.9 CONCLUSION

This chapter evaluated the purpose of user requirements gathering. From the outset, the chapter focused on the methods used to gather effectively user requirements. By defining the life cycle and context of the system, the research outlined the purpose of a software requirements specification document, and set about developing a prototype. The next chapter will focus on the findings, results, and analyses that occurred during the steps taken in chapter 2.

CHAPTER 6: FINDINGS, RESULTS AND ANALYSIS

6.1 INTRODUCTION

This chapter will reintroduce the research questions and focus on formulating a conclusion to the research questions. A discussion on the findings derived from the methodology outlined in Chapter 2 will ensue. As discussed previously, the proposed research questions infer exploratory research, as the study is attempting to identify the potential roles ICT can play and the functional software requirements rather than measure an implantation. In order to ascertain successfully the research objective the assimilation of knowledge from wide ranging sources is required. As previously discussed, the research questions are as follows:

- What roles does ICT have in the management of cancer as a chronic disease
- What are, from a clinical perspective, the user requirements of an ICT system to support clinicians caring for patients with cancer as a chronic disease

This chapter opens by presenting the qualitative findings from the semi-structured interviews collected by the researcher as outlined in Chapter 2. The data collected from semi-structured interviews will form the basis for the first two out of the three phases – context definition and Software Requirements Specification. The third phase validation of the SRS by an IT representative and interview participants is outlined in Chapter 7.

6.2 INTERVIEW FINDINGS

As indicated in Section 2.6.2, eleven semi-structured interviews were conducted with key oncology informants who had day-to-day dealings with patients with cancer as a chronic disease. The interviewees assisted in answering both research questions. In addition, the informants gave an indication what they would like the system to do, how ICT currently plays a role in their daily operations and their perceived potential benefits and challenges with the proposed ICT system. All interviews were semi-structured and implemented a limited number of pre-determined questions (Please see Appendix A for examples). The transcribed interview data from both the recordings and written interviews was coded using both content and grounded theory analysis. Interview quotes were subsequently grouped together; these groups form the basis of this section, where the themes identified in the interviews are outlined accordingly. The Oxford English Dictionary Online (2014) defines perception as the way in which something is regarded, understood, or interpreted . The informant's perceptions are outlined in the following tables.

Perceived usefulness is the degree to which an individual believes that by using information technology it would enhance their job performance (Davis 1989). Additionally, Rogers (1995), defines usefulness as the total value a user perceives from using a new technology.

Table 6-1 Interview Theme 1 : Perceived Usefulness

Interview	Perceived Usefulness
I_1	"Would be really helpful if there was, say, alerts to say who was for follow up today, or next week or who I need to arrange tests for" "Could ensure that patients don't get "lost" to follow up"
I_2	"Putting pathways in place, I think, where it's really, really good….if you follow all these patients, and you record all their data and you record their staging and you record their follow-up, their blood levels, etc. and you have that all in a database, that becomes very, very useful information, for us and for patients, it tells us how we're performing, it tells us how we are underperforming perhaps, and it's also a very good database to say, turn around and say to patients we have very good results, or we don't have very good results. That's hugely important"
I_3	"If it could flag up appointments, provide drop down menus for care pathways and make documentation easy"
I_4	"…automatic capturing of patients who do not attend for appointments. No need to manually enter patient follow up times on a spread sheet"
I_5	"…Definitely if it could capture the MDT decisions in real-time and told me who was for follow-up next week or month that would be great"
I_6	"To be to analyse easy ... I think having an incorporating statistical type program to look at outcomes…I think the information should be more categorised." "well, I think that one should be individualised per site. I don't think there should be one generic letter…I think also, that Patient Leaflets should be individualised per site, because patients are going through the information Leaflets and they read everything and they don't and like most of them will understand it – what applies to them and what doesn't apply to them but others don't. So in this book, says that. What I think what will be good for them would be for them to record or to write what we are saying."

I_7	"The system would have to have a range of assessment forms inclusive of potential treatment symptoms and side effects – tailored to patients on chemo, or on hormones alone, or off treatment"
I_8	"I am not sure a computer program would help"
I_9	"Yes, definitely a good idea, would love tablets on ward rounds with all the bloods and xrays etc that are easy and quick 'to access"
I_{10}	"I would love to make a Patient Medical Record that they can actually hold in their hands because they always ask what their blood test is, what this is, that they can actually track themselves." "I would like a medical record for when I open up a patient's name I can see everything in a list down below that and what I mean by that is that I can see every note… ours, diagnostics, imaging, lab reports and then it would have all progress notes. You would pull them up and they would all be according to date – nurse, physiotherapist, social worker, doctor and then you could sort – I only want to see the doctor's notes."
I_{11}	"Oh, definitely is useful, cause you can look at scans and look at progression, if the treatment work, can look intermediately. For me it would be useful looking at the platelets and blood counts and compare the history" "It would be really good because everyone would be able to see everything in one place"

Perceived ease of use, in contrast, is the degree to which an individual believes that by using that particular information technology it would be free of effort (Davis 1989).

Table 6-2 Interview Theme 2: Perceived Ease of Use

Interview	Perceived Ease Of Use
I_1	"it [the system] would have to be easy to use"
I_3	"It would have to be easy to use! Appointment service/trigger interactive mode and needs to be easily adaptable"
I_4	"as long as there was no free text and there was drop downs and tick boxes it would be easy to use"
I_5	" It [the system] would have to be automated prompts, check boxes, linked with the hospital EPR"
I_6	"If they are user friendly. I think you are much more likely to have a mistake when you do it manually, and somebody comes and bugs you and then 3 x 2 means 10 already!"
I_7	"If the system could be handheld, and there was a good supply of them so that there would not be problems queuing to access the PCs"
I_8	"If the system made our day to day work more efficient"
I_9	"Easy to navigate through, easy to pull up different results such as scans, bloods and histology, confidential, easy to add notes etc "
I_{10}	"if there were a good system built I would use it."
I_{11}	"Most places are computer based now, if its laid out clearly and easy to use I'd use it"

Perceived self-efficacy is the degree to which an individual believes in one's own capability to organise and execute courses of action required to manage prospective situations (Bandura 1995)

Table 6-3 Interview Theme 3 - Perceived Self-Efficacy

Interview	Perceived Self-Efficacy
I_1	"I think I would need a lot more training from IT to use the system"
I_3	"Space, Time and analysis of benefit"
I_4	"…not possible to ascertain any challenges using the system as having used other systems previously I found them very robust and the data captured was reliable and accurate"
I_5	"If it was less time consuming"
I_7	"If it was simple, short, and the assessment tools were relevant"
I_9	"easy access (every clinic and ward) easy to navigate, quick to use"
I_{10}	"I'm much better if I'm organised and someone is organising me. I'm not always good at putting all that stuff in. So I'm a little at a loss there."
I_{11}	"If I was trained adequately it would improve patient care for sure"

Perceived benefits are defined as beliefs about the positive outcomes associated with behaviour in response to a real or perceived threat. The researcher attempted to delve into the perception of benefits in the anticipation of uncovering the benefits that would lead to functionality and to a better-designed program.

Table 6-4 Interview Theme 4: Perceived Benefits

Interview	Perceived Benefits
I_1	"…able to track patients follow up hospital wide, predict when patients due scopes and scans, gather stats on recurrences during follow up, able to access data from anywhere in the hospital" "can gather data hospital wide on recurrences, abnormalities on scans and so forth which could be good as further studies could be done into why "
I_2	"I also think that, that a database of patients can trigger alarms, for example, when say - patients slip through the network, and don't get followed up, or disappear off the network." "…the other thing is you can keep a database of patients who might be suitable for a new drug that's coming onto the market.." "Less administration from my practice point of view, which might reduce costs," " if you had the abilities to track complications, to track your results, track the outcomes, and then to turn around and compare yourself, or benchmark yourself to other institutions that to me would be one of the major things.
I_3	"Timelines, prompts and better information"
I_4	"Could track all patients attending the department, record the outcomes as per treatment regimes and highlight all the patients scheduled to attend clinics"
I_5	"I think the biggest thing would be to…to prompt you, like say for example, you know, if you had even where by you have your follow ups for say for example April of last year, if that was to send you a prompt"
I_6	"It would be good to have an electronic systems that would incorporate, you know, radiology, labs, chemotherapy all other treatments, we should be able to see, in case if a patient goes into emergency" "Better Communication"

I_7	“Generate solutions for need to intervene ”
I_8	“If there was a program, it would be great to be able to visualise all upcoming appointments, patient trials, scans, tests that are required”
I_9	“all the bloods filled neatly and in order, easy to access scans results, good correspondence letters, easier to read previous notes”
I_{10}	“Definitely needed, [one] could input the diagnosis, the ICD Code, the actual treatment, then [I_{10}] input the letter then we have the care plan - it would be brilliant it just has to accessible but everyone has to take responsibility.”
I_{11}	“Easier access to history, scans, bloods, would make things more efficient and getting things done quicker like decisions on treatment plans, if action needs to be taken, even getting referrals would be streamlined. I mean we’re meant to be going paperless and I think it’s a great idea for us as in a multidisciplinary environment everyone can see it”

Perceived challenges, is the degree to which an individual believes that by using that particular information technology would tests one's abilities, or have difficulty in carrying out a task. The researcher attempted to delve into the perception of challenges in the anticipation of uncovering the challenges that would need solutions and could draw on these challenges to design a better program.

Table 6-5 Interview Theme 5: Perceived Challenges

Interview	Perceived Challenges
I_1	"…may be time consuming and increase workload of staff…"could be difficult to track patients having scopes/scans in external institutions" "if system fails info may be lost" "Some patients may need scans more often, may not fit in program criteria"
I_2	"It's only as good as the data that's put into it." "Funding, or lack of it"
I_3	"Cost. Space. Lack of Knowledge"
I_4	"If it was linked actually with our computer system completely"
I_5	"...We'd a lot of resistance on previous attempts of developing a system"
I_6	"You know there has to be a shift in the parody in how you see the cancer."
I_7	"Time consuming or not enough terminals to be able to effectively use it"

I_8	“The only thing that would prevent me from using the system is that if it added to our daily work load”
I_9	“if there was going to be issues with confidentially, possible data missing, slow “ “might be difficult to add in notes that you would handwrite (such as patient tearful) would have to be able to see notes from the other specialities too like physio, speech and language etc”
I_{10}	“Nothing that would prevent me but what I would ask for a system like that is for equal opportunity access what drives me nuts here is that staff are inputting loads of data that nobody ever uses.”
I_{11}	“Limited information, like in the drop down menus, often there isn’t enough or even too much medical jargon that isn’t relevant even putting in diagnosis not always adequate for what you want to say”

Perceived Survivorship and Chronic Care Models Knowledge, is the degree to which an individual has prior knowledge, experience or through improved learning derives a perception of the models.

Table 6-6 Perceived Survivorship & Chronic Care Models Knowledge

Interview	Perceived Survivorship Care Plans & Chronic Care Models Knowledge
I_1	"No…"
I_2	"Not Really." "I think there is a big gap there that is worth exploring"
I_3	"No. if I was more familiar with Chronic care models and survivorship care plans I'd use them"
I_4	"I know about, I am familiar with survivorship, but we wouldn't use a specific survivorship or chronic care in the department" "I think we are kind of doing it anyway"
I_5	"It's a structured pathway."
I_6	"No." "This is how we should do it….I didn't think - It's a combination of them, because like this one [Flinders], I am using it every single day – 5As the plans and management and so on. This one [CMM], we are using it probably more than others, you know, in the system we have here in the department and we have multidisciplinary cooperation and Interaction with all the axillary services within the hospital."
I_7	"I have heard of them [Survivorship Programmes], but not seen them in practice. They definitely could help patients long-term. I am not familiar with chronic care models but do think they would be beneficial"
I_8	"Yes I am aware of survivorship plans. Yes I do think they would help patients" "No, I am not aware of any chronic care models. But I do think they would be beneficial when made available electronically"

I_9	“Unsure of what these are!”
I_{10}	“Yes and we have them but just haven’t used them. “ I would say I already do half of a Survivorship Plan” “Yes I know the Sanford ... and yah”
I_{11}	“No, I never knew about any of these, but they would be definitely beneficial. We use thinks like falls risk assessments, so if it served a purpose, and did what it says it does I can’t see why not”

Perceived Role of ICT, is the degree to which an individual perceives the role of ICT in Medicine, how ICT currently plays a role in their daily and how they perceive it will play a role in the future.

Table 6-7 Interview Theme 7: Perceived Role of ICT

Interview	Perceived Role Of ICT
I_1	"Communication, being able to read notes/assessments on EPR from other colleagues, scans, pathology results and outcomes" "I rely heavily on email as there is a paper trail as opposed to phones…I'd use phones for some follow-ups or to talk to patients families if they had concerns"
I_2	"I think, IT can help, but I think it means a change in mind-set, because, IT is only as good as what goes in, so if you have a clerk putting stuff into a computer, who doesn't really understand it, then, they don't necessarily put in the right things, or tick the right boxes, or whatever else."
I_3	"ICT currently widely used in Northern Europe in other areas of patients care, absolutely the way forward. However the contact with qualified and empathetic staff is essential"
I_4	"Could enhance communication between other departments"
I_5	"I'd say it would prevent backlogs if all the information was structured in the one place we would go paperless"
I_6	"I think the Internet is a very dangerous. Social networking is dangerous. It can spread inaccurate information quickly"
I_7	"There is definitely a role for ICT in managing patients with cancer as a chronic disease"

I_8	“Yes, I think there is a need for ICT”
I_9	“I think it's not being used nearly as much as it should be, we're always handwriting out notes, we've only started typing discharges in the last while”
I_{10}	“When I get up in the morning the first thing I do is to check my phone because a lot of the queries and consultations might actually go to America. I then check my calendar on my phone.”
I_{11}	“Frightening how reliant we have become on IT. We get results quicker, and as a results its improved outcomes because patients get the best treatment quicker, but I worry about what happens if they all go down. What if we email the wrong person, but I guess that can happen with paper too”

6.3 CONCLUSION SEMI-STRUCTURED INTERVIEW

Seven themes were identified from the transcripts – perceived usefulness, ease of use, self-efficacy, benefits, challenges, knowledge of survivorship care plans and chronic care models and, the role of ICT. The interviewees agreed that there was a use for such a system in the hospital, however one participant thought a computer program would not help solve existing problems. The area of communication breakdown was apparent across many departments and the use of ICT in many cases was perceived to be a solution to this problem. The system would need to be automated, with minimal effort for the user as to not increase workload, however interviewees were concerned about limiting information e.g. patient tearful, limited options of diagnosis. Challenges of the system included need for training, fear of loss of data, resistance to change and the need for change in mind-set. In addition to these challenges space, time, and increased workload were also deemed as non-technical challenges. Benefits ranged from trend analysis, easier access to information, better communication, and better coordination. A peculiar finding from the interviews was the lack of knowledge or awareness of chronic care models. While many interviewees had no prior knowledge of the usefulness, the benefits of the models, the research behind them, or how they could be applied to their day-to-day workings, participants expressed their wishes to learn more about the models and apply them to their practices.

Taking these valuable inputs in addition to literature findings, the researcher formulated a Software Requirements Specification (SRS) document.

6.4 SOFTWARE REQUIREMENT SPECIFICATION (SRS)

A Software Requirements Specification (SRS) establishes the basis of an agreement between the customer and the supplier on what the software product is to do (IEEE Computer Society 1998). The document can be used by a hospital to tender with an external organisation for development of a program. In addition, the SRS reduces the development effort, provides a basis for estimating costs and schedules, and facilitates in transfer the product to the users (IEEE Computer Society 1998). SRS is also used to prioritise work and during the validation process (IEEE Computer Society 1998). The SRS can be used at a later stage, when it can serve as a basis for enhancement for a later version of the product (IEEE Computer Society 1998). The following sections infer the Software Requirements Specification as set out by the IEEE standard (IEEE Computer Society 1998), formed based on analysis of interview transcripts and presented to the potential end users.

6.4.1 INTRODUCTION

The 'Hospital' offers a complete range of Oncology services including Diagnostics, Surgery, Medical, and Radiation Oncology, all delivered in one central location. Their mission statement states that they provide holistic oncology care in a safe, comfortable, calm environment that offers all of the benefits of their state of the art technology. The nursing model, relationship based care, enables nurses to establish caring relationships with patients and their families with an aim to prepare support and guide a patient through each stage of their cancer treatment. In light of the latest evidence in relation to the need for long-term follow up and survivorship plans, a proposed system to integrate all elements of cancer services has been advised. This system will help support clinicians develop patient pathways in an efficient and cost-effective approach, whilst delivering consistent care.

6.4.1.1 HOSPITAL ONCOLOGY PATIENTS' WORKFLOW

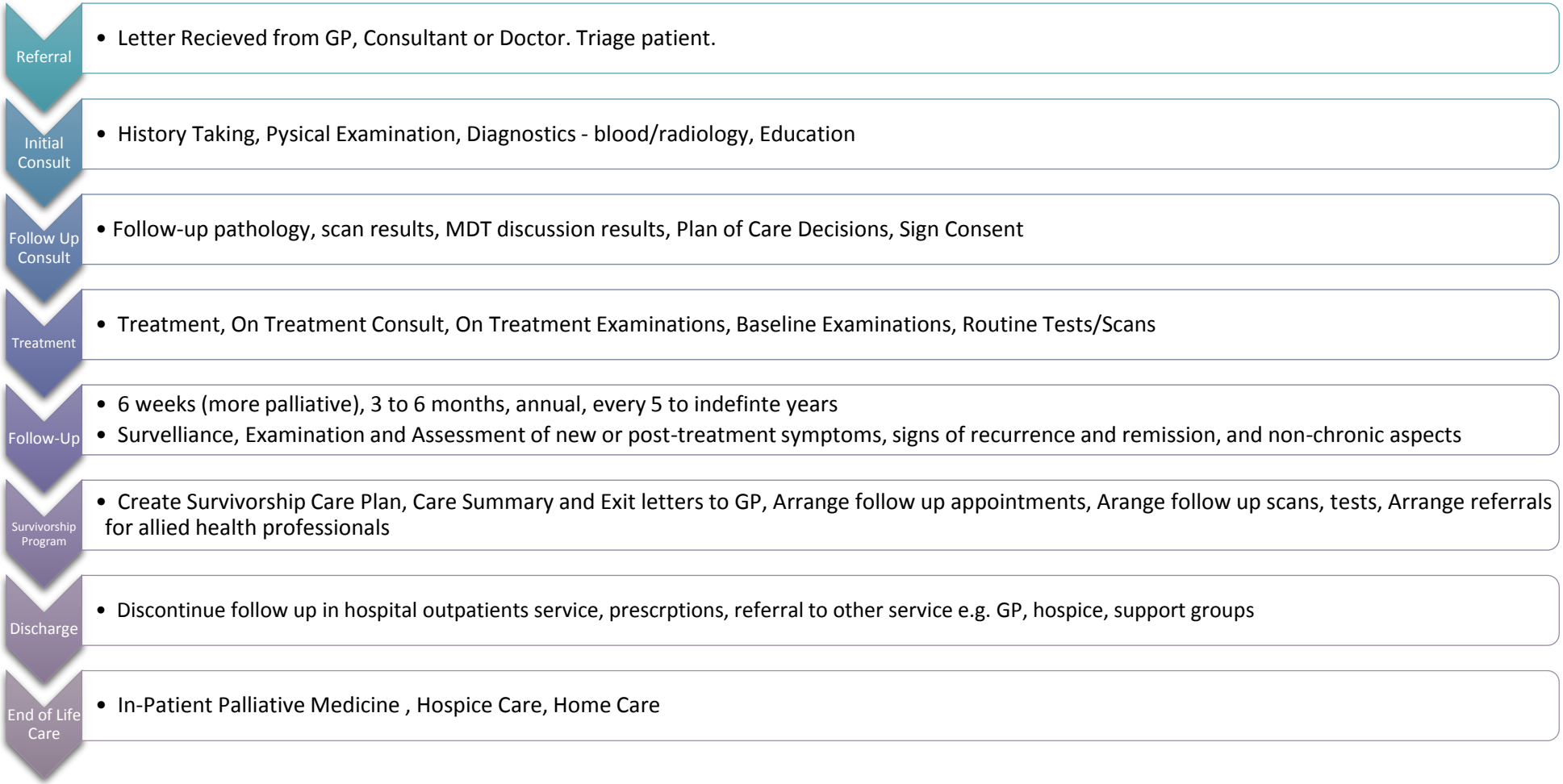

Figure 6.1 Workflow of Hospital Clinicians

6.4.2 OVERALL DESCRIPTION

This section will give an overview of the whole system. The independent self-contained system will be explained in its context to show how the system functions. This section will also describe the different type of stakeholders that will use the system, in addition to what functionality is available for each type. Concluding with, the presentation of constraints and assumptions associated with the system.

6.4.1.2 PRODUCT PERSPECTIVE

This self-contained system is intended to provide users with a computerised tool that allows clinicians to make a near optimal personalised treatment plan for a patient with cancer as a chronic disease. In addition, the system will monitor the long-term follow-up of this emerging cohort of patients. Allowing for extensive metrics to support evidence-based medicine, trends and ability to further the service, thus providing a better service for patients while maximising work efficiency. The scope of the project encompasses both server- and client-side functionalities. The details of various interfaces have been provided in Section 6.4.2 below.

6.4.1.2.1 SYSTEM INTERFACES

The Oncology System is a standalone software product. No external system interfaces are connected.

6.4.1.2.2 USER INTERFACES

The user interfaces shall require a standalone software environment. Provisions should be made that

6.4.1.2.3 HARDWARE INTERFACES

Provision for a Dictaphone and/or microphone and video recording should be integrated for upgrade of software.

6.4.1.2.4 SOFTWARE INTERFACES

The system is a standalone software product that does not have any external software interfaces.

6.4.1.2.5 COMMUNICATION INTERFACES

The systems will use the local network protocols managed by the IT department. The server and the knowledge-based databases will be located on the same host.

6.4.1.2.6 MEMORY CONSTRAINTS

No specific memory requirements have been specified.

6.4.1.2.7 OPERATIONS

The system documented herein will not affect the normal operation of any existing systems.

6.4.1.2.8 SITE ADAPTION REQUIREMENTS

There are no site adaption requirements for the changes specified herein this document

6.4.1.3 PRODUCT FUNCTIONS

The following list offers a brief outline and description of the main features and functionalities of the system. The features are split into two major categories: core features and additional features. Core features are essential to the applications operation, whereas additional features simply add new functionalities. The later will evolve over time and added at later points but are not essential for first release.

CORE FEATURES

1. USER SETUP
    - Register User
    - Allow User to customise profile/settings

2. GROUP CREATION & MANAGEMENT
    - Allocate user groups and access rights
    - Provide support for users

3. RECORD PATIENT HISTORY
    - Stores and monitors follow up appointments
    - Stores and monitors vital signs, comorbidities, blood counts and results, late-onset side-effects, new or post-treatment symptoms, recurrence, remission, no-chronic aspects
    - Stores demographics, treatment history, diagnosis

4. USER – TO – USER COMMUNICATION
    - Enables group members to view and add care notes, plans and findings
    - Overview of patients due for follow-up
    - Allows users to Alert fellow clinicians of issues or queries
    - Enables users to generate referral letters, exit letters etc.

5. GENERATION OF INDIVIDUALISED CARE PLANS
    - Allow creation and modification of Survivorship Care Plan
    - Allow creation and modification of Chronic Disease Management Plans
    - Allow creation and modification of patient pathways

- All creation and modification of education leaflets and referral letters

6. SHOW ALL PATIENTS
    - Provides easy access to relevant patient information
    - Overview of Oncology Services
    - Alert of patients due/over-due follow-up

7. ANALYSIS & MEASUREMENTS
    - Report generator on patient trends, treatments, side effects, recurrences, progressions, remissions, test and/or scan abnormalities, complications, decisions and outcomes
    - Analysis of service
    - Timelines
    - Trend lines

8. INTERVENTIONS
    - Assessment forms – Need to Intervene CDSS
    - Alert of patients due/over-due follow-up
    - Eligibility for clinical and drug trials

9. HELP MENU
    - Displays a list of topics covering the different components
    - Offers support on each feature, menus, settings etc.

10. AUDIT TRAIL
    - Auditable details of interactions with patient files, time and date stamped

ADDITIONAL FEATURES

11. SERVICE VISUALISATION
    - Presentation of visual representation of current patients, treatments, side effects and service volumes.
    - Allows users to identify due, overdue or missed follow-up's

12. SOCIAL MEDIA

- Allows clinicians ability to either audio or visually record and provide information to patients on treatment
- Create online forum monitored by a clinician

13. INTEGRATED VIDEO SUPPORT IN HELP MENU
    - Visually provide support to first-time users
    - Visually provide overview of all features

14. ADAPTABLE TO TABLET
    - Make all features available on tablet device

For more detailed information on these features, proceed to Section 3 of the document 'System Features'.

6.4.1.4 USER CHARACTERISTICS

The below table describes the actors of the system as well as a brief description of their roles

Table 6-8 List of Actors

Actor	*Synonym*	*Role*
Administrative Staff	Admin	Registers/updates patients records, managements appointments, prints
System Administrator	System Admin	Creates user groups & manages system
Patient		
Consultant		Performs exams, reviews, creates CCP, discharge
Clinical Nurse Specialist	CNS	Performs exams, reviews, creates appointments, Enters existing notes

6.4.1.5 CONSTRAINTS

The system should enforce user authentication by means of hospital login credentials and guarantee a timestamp and username for auditing facilities and reliability of data. The system will time out after 20 minutes of inactivity.

6.4.1.6 ASSUMPTIONS AND DEPENDENCIES

As previously mentioned, the features of this system are divided into two groups: core features and additional features. Core features are crucial to the basic functionality and must be implemented in order for the application to be of use. Optional additional features are not critical to the function of the application. These are usability or convenience enhancements that may be added after the application is released.

6.4.1.7 APPORTIONING OF REQUIREMENTS

Future versions of this system will be rolled out to incorporate the additional features 'Service Visualisation', 'Social Media', provision for tablet support and 'integrated video support in help menu' as discussed in the Section 6.4.1.3 Additional Feature.

6.4.3 SPECIFIC REQUIREMENTS

This section contains all of the functional and quality requirements of the system. It gives a detailed description of the system and all its features. As previously mentioned, the functionality of this software is divided into two main categories: core features and additional features. Core features form the body of the system and include any features essential to the functionality of the system. These features are critical in order to have a fully functioning application. Additional features, however, are not required for the software to function and will be added to enhance the system later.

6.4.1.8 EXTERNAL INTERFACES

No specific external interfaces.

6.4.1.9 FUNCTIONAL REQUIREMENTS

This section outlines the use cases for each of the active users separately. The functional requirements are subsequently grouped into different scopes as outlined below.

Access Management

Access management handles access control to the program including...

- Authentication
- Authorisation

Account Management

Account management handles the creation/editing/deleting of user accounts including other functions like password setting.

Patient Management

Patient management handles the creation or editing of patients record.

Statistical Data Management

The core platform will provide a database that - amongst other data - will contain statistical data related to patients, treatments, side-effects, service overviews, recurrence, progressions, remissions, abnormalities in tests and scans, complications, decisions, and outcomes. In addition to these statistical data, trend analysis and timeline analysis will be available.

Knowledge Management

Knowledge management handles the import/update/browsing/deleting of knowledge related to need to intervene alerts and clinical trial alerts in addition to loading of diagnosis, staging and medical related knowledge.

The following table, Table 6.9, provides an overview of the product use cases:

Table 6-9 Product Use Case Overview Table

Scope	Key	Description	Summary	Actors
Access Management	UC01-1	Login System	Log in as user to the Product	Admin, CNS, Clinician, System Admin
Access Management	UC01-2	Logout	Log out as user of the Product	Admin, CNS, Clinician, System Admin
Account Management	UC02-1	Create User Account	Create User Account	System Admin
Account Management	UC02-2	Edit User Account	Edit User Account	System Admin
Account Management	UC02-3	Lock User Account	Lock User Account	System Admin
Account Management	UC02-4	Unlock User Account	Unlock User Account	System Admin
Account Management	UC02-5	Delete User Account	Delete User Account	System Admin
Account Management	UC02-6	Reset Password	Reset Password	System Admin

Account Management	UC02-7	Change password	Change password	Admin, CNS, Clinician
Account Management	UC02-8	Activate account	Activate account	System Admin
Patient Management	UC03-1	Create Patient	Create Patient Medical Record	Admin
Patient Management	UC03-2	Edit Patient Record	Edit Patient Demographics of Patients Medical Record	Admin, CNS, Clinician
Patient Management	UC03-3	Discharge	Discharge patient base on cancer type (>1 year, 5, 10, 15 or end of life)	Clinician
Patient Management	UC03-4	Manage Appointments	Create/edit/cancel/View clinical follow-up appointments	CNS, Admin, Clinician
Patient Management	UC03-5	Record Findings	Record historical findings, clinical findings, patient vitals, Patient Symptoms (post op, post treat, signs of recurrence/remission/ progression), Non-Chronic Symptoms (fatigue, nausea etc.)	CNS, Clinician
Patient Management	UC03-6	Monitor Symptoms	Monitor Patient Symptoms (post op, post treat, signs of recurrence/remission/ progression), Non-Chronic Symptoms (fatigue, nausea etc.)	CNS, Clinician

Patient Management	UC03-7	View Record	View Patient Record	Admin, CNS, Clinician
Patient Management	UC03-8	Referral	Generate personalised referral as a result of findings	Clinician
Patient Management	UC03-9	Manage Care Plan	Generate /edit Care Plan Summary	CNS, Clinician
Patient Management	UC03-10	Manage SCP	Generate /edit/delete Survivorship Care Plan	CNS, Clinician
Patient Management	UC03-11	Manage CDMP	Generate/edit/delete Chronic Disease Management Plan (CDMP)	CNS, Clinician
Patient Management	UC03-12	Education	Generate personalised education as a result of clinician and clinical findings	CNS
Data Management	UC04-1	Statistical Analysis	Import and analyse statistical data	CNS, Clinician
Data Management	UC04-1	Visualise Data	Visualise statistical timeline data	CNS, Clinician
Knowledge Management	UC-05-1	Knowledge Management	Upload/Browse/Delete/Validate/ Link Knowledge	System Admin

6.4.1.9.1 INDIVIDUAL PRODUCT FUNCTION USE CASES

6.4.1.9.1.1 ACCESS MANAGEMENT

Access Management, handles access control (authentication and authorisation) to the product. Regarding access control, two major groups have to be considered – clinical, and non-clinical access.

- Clinical Access (Clinicians, CNS) includes the direct management, recording and editing of a patient record for clinical purposes.
- Non-Clinical Access (Data Administrator, System Administrator) includes view rights to the patient record in addition to the management of appointments.

In order to access the system, users are required to have a valid username (3-4 ID) and password. The following use case diagram, Figure 6.2, is an overview of the Access Management use cases:

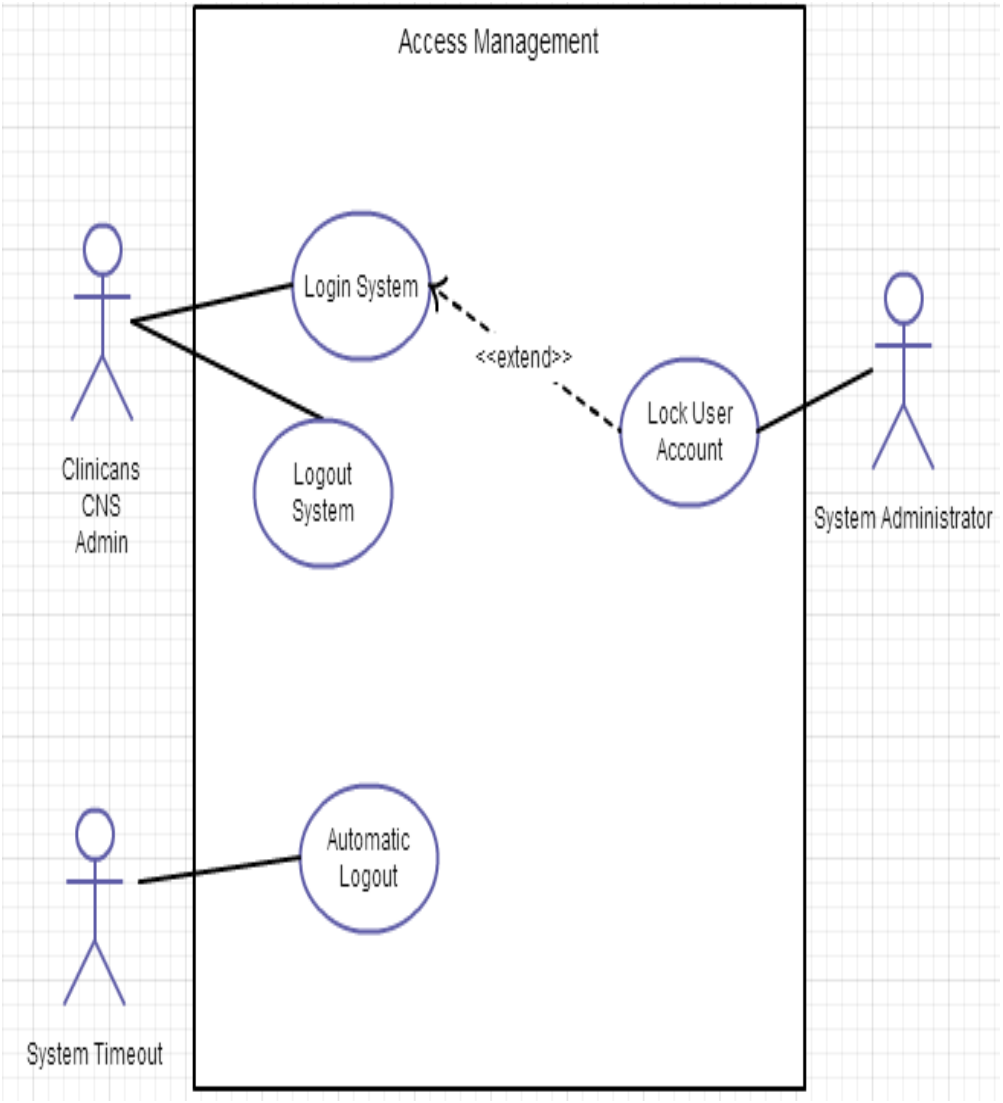

Figure 6.2 Access Management Use Case

6.4.1.9.1.1.1 USE CASE UC01-1: LOGIN TO SYSTEM

The user wishes to access the system. In order to prevent the unauthorised access and manipulation to patient records, all users of the product must be authenticated and authorised.

The following table contains a detailed description of this function

Table 6-10 Use Case #UC01-1: Login System' Description

Use Case Name	*Login System*	*Use Case ID*	*UC01-1*
Priority	High		
Scope	Access Management		
Description	The user wishes to access the system		
Primary Business Actor	System Administrator, CNS, Clinician, Admin		
Stakeholders	System Administrator, CNS, Clinician, Admin		
Trigger	The user wants to access		
Inputs	• Username (3-4ID login) • Password		
Precondition	• User-account is available, active and not locked • User has access to the login-page		
Typical Course of Events	1. User opens the login page 2. User enters the username (3-4 ID) 3. User enters the password 4. User clicks the login button 5. System validates username and password and creates a new session		
Alternative Courses	Automatic forwarding to the login page: • User-Session Time-Out • User logged out and returns to log-in screen		
Success Conclusion	the user has access to the system the page that the user wanted to access prior to authentication is displayed		
Failure Conclusion	Wrong Username/Password: • the failed-login-counter is being incremented • if the number of failed login-attempts exceeds a configurable threshold (3 Attempts) then the user account is being locked • Error Message identifying failure displayed • The user denied access to the system		
Assumptions	The user has been provided a 3-4 ID on gaining employment		

6.4.1.9.1.1.2 USE CASE UC01-2: LOGOUT OF SYSTEM

The user wishes to close the system and log out. The following table contains a detailed description of this function

Table 6-11 'Use Case #UC01-2: Logout System' Description

Use Case Name	*Logout System*	*Use Case ID*	*UC01-2*
Priority	High		
Scope	Access Management		
Description	The user wishes to close the system and log out		
Primary Business Actor	System Administrator, CNS, Clinician, Admin		
Stakeholders	System Administrator, CNS, Clinician, Admin		
Trigger	The user wants to end their session		
Inputs	None		
Precondition	The user is logged in		
Typical Course of Events	1. The user clicks the logout button 2. System closes and forwards user to Log-In Screen		
Alternative Courses	User logged out through automatic timeout		
Success Conclusion	The user is logged out		
Failure Conclusion	The user is still logged in An Error message displays detailing failure to log out		
Assumptions	User has already successfully logged in to the system		

The schematic workflow of authentication to the system is described in the following diagram (Figure 6.3):

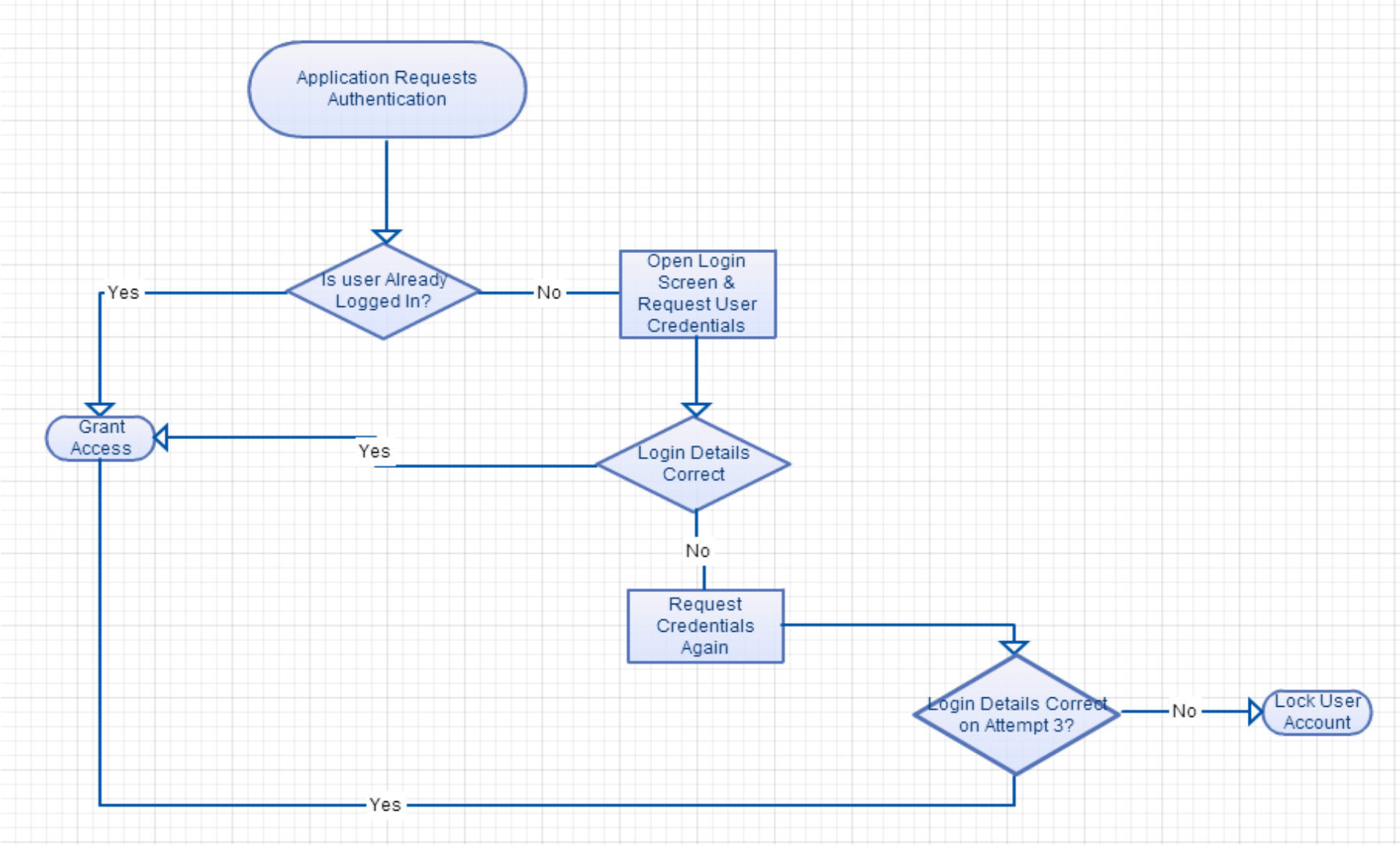

Figure 6.3 Flow Chart of Authentication

6.4.1.9.1.2 ACCOUNT MANAGEMENT

Account Management, covers the handling of user accounts, which falls under security and data protection. The Hospitals System Administrator manages users and user groups centrally. System Administrators can only create user accounts by request of departmental managers. User Accounts can be in one of the following states:

Table 6-12 User Account States

Inactive	User account that has been created, but no password attached to the account. This can be the initial state after creation, or if a system administrator has reset a password
Active	User accounts who have been created, password attached and ready to use
Locked	A system administrator, due to incorrect password attempt or misuse of system, has locked the account. Account is inaccessible by the user. System administrator must unlock account.
Delete	Termination of account on cessation of employment. Account is not physically deleted.

The following state diagram illustrates the lifecycle of an account (Figure 6.4):

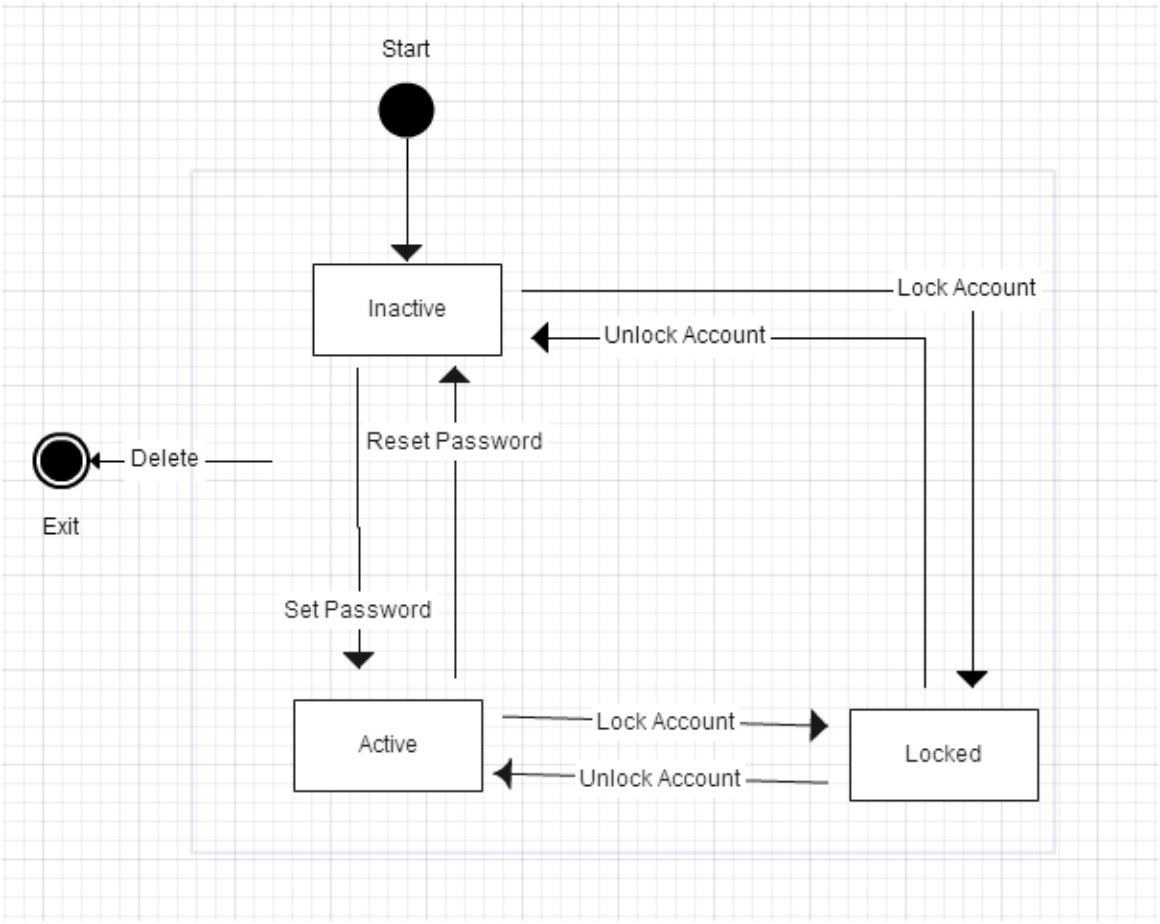

Figure 6.4 State Diagram of Account States

The following use case diagram, Figure 6.5, is an overview of the Access Management use cases:

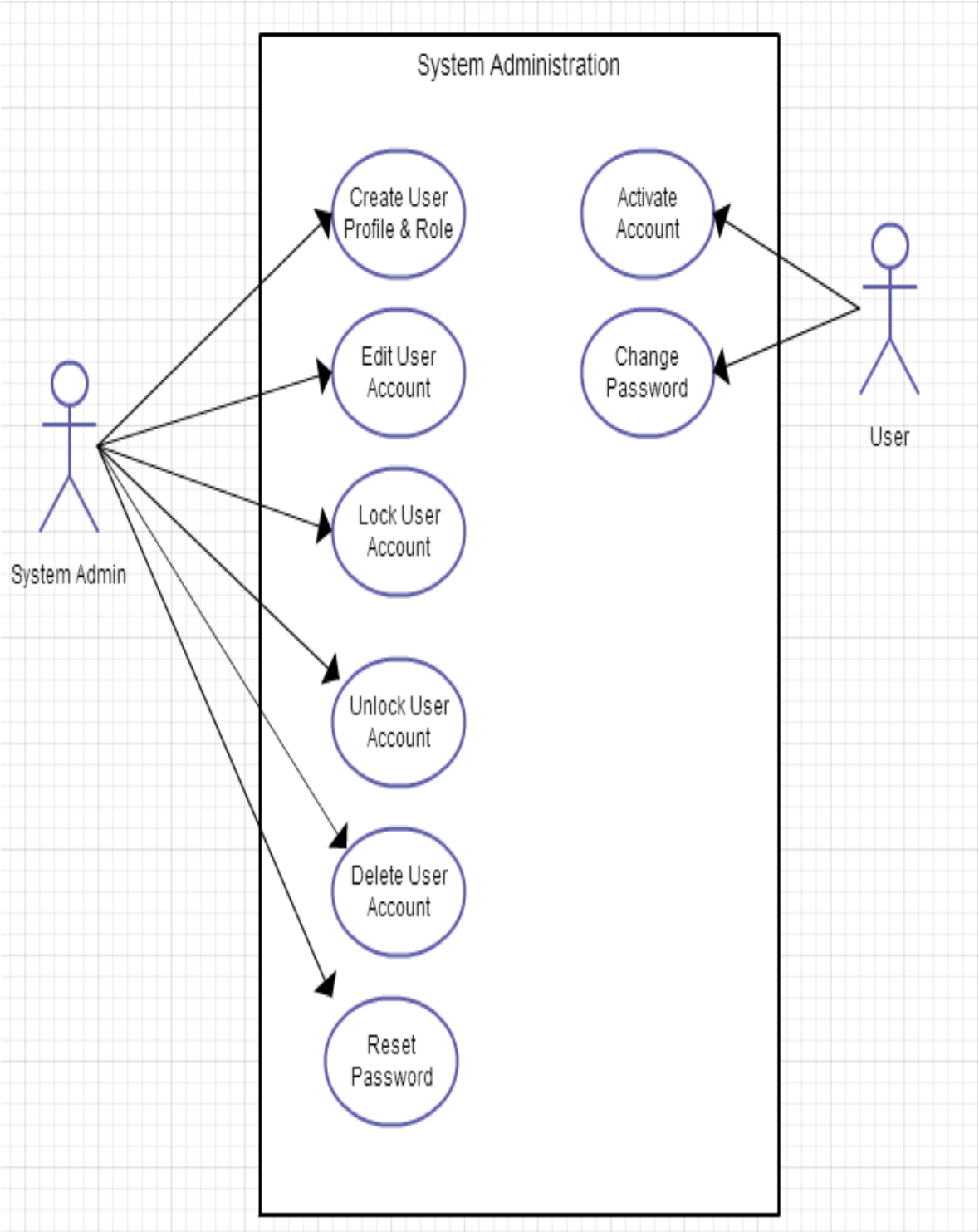

Figure 6.5 Account Management Use Case

6.4.1.9.1.2.1 USE CASE UC02-1: CREATE USER PROFILE

The creation of the user account is a part of the user administration and user management. Users are only able to use the system if they have a valid user 3-4 ID and user account.

Table 6-13 Use Case UC02-1 Create User Profile' Description

Use Case Name	*Create User Profile*	*Use Case ID*	*UC02-1*
Priority	High		
Scope	Account Management		
Description	The System Admin creates the user account on request of departmental manager based upon role and 3-4 ID. After this user has access to account.		
Primary Business Actor	System Administrator		
Stakeholders	System Administrator for setup; CNS, Clinician, Admin on activation		
Trigger	The system administrator wants to create a user		

Inputs	User Data:
	• Username:
	  ○ Hospital 3-4 ID e.g. ABC 1234
	• Full Name (Forename, Surname)
	  ○ allowed characters: a-Z, A-Z, , `, mutation characters, -, blank
	• Valid hospital email-address
	  ○ allowed characters: a-z, A-Z, ., _, -, 0-9, @
	• Role:
	  ○ Clinician, Clinical Nurse Specialist (CNS), Administrator (Data)		

Precondition	The system administrator is logged into the Account Management System		
Typical Course of Events	1. The System Admin clicks the 'Add User' button 2. System opens 'Add User' form 3. System Admin enters user data 4. System Admin selects and applies role 5. System Admin clicks 'Create User' button 6. System validates data entered 7. System creates user		
Success Conclusion	The user account is created, but still inactive.		
Failure Conclusion	The user account is not created An Error message displays detailing failure to create user		
Assumptions	Account is 'Inactive' until user sets new password. System Admin account is created by the System Operator. System Admin contact user of account creation.		

6.4.1.9.1.2.2 USE CASE UC02-2: EDIT USER ACCOUNT

Due to change in name (e.g. marriage, divorce), resulting change in email address, or change in role, the credentials of a user have to be edited.

Table 6-14 'Use Case UC02-2: Edit User Account' Description

Use Case Name	*Edit User Account*	*Use Case ID*	*UC02-2*
Priority	High		
Scope	Account Management		
Description	The System Admin updates the user's credentials.		
Primary Business Actor	System Administrator		
Stakeholders	System Administrator CNS, Clinician, Admin		
Trigger	The system administrator/user wishes to update user credentials		
Inputs	• Change User Credentials		
Precondition	• The system administrator is logged into the Account Management System • User has a valid Account • Change request has been approved by departmental manager		
Typical Course of Events	1. System Admin searches, locates and selects user profile 2. System Admin clicks 'edit profile' button 3. System renders user profile editable 4. System Admin makes required changes 5. System Admin clicks 'Update' button		
Alternative Courses	• Clicking the 'Cancel' button returns the System Admin to the user list		
Success Conclusion	The user account is updated		
Failure Conclusion	The user account is not updated An Error message displays detailing failure to update user		
Assumptions	System Operator can only edit System Admin Account		

6.4.1.9.1.2.3 USE CASE UC02-3: LOCK USER ACCOUNT

It may become necessary to lock a user from logging into the system (temporarily or permanently). The user account might be locked to avoid access for several reasons including abuse of position, security threat, or user not logged in within a threshold period e.g. 3 months. This use case is triggered automatically should a repeated incorrect attempt at logging in exceeds the set threshold.

Table 6-15 'Use Case UC02-3: Lock User Account' Description

Use Case Name	*Lock User Account*	*Use Case ID*	*UC02-3*
Priority	High		
Scope	Account Management		
Description	The System Admin or Access Management locks the user account.		
Primary Business Actor	System Administrator		
Stakeholders	System Administrator		
Trigger	User account is locked by the system administrator or incorrect login attempts		
Inputs	• Selected user from account list		
Precondition	• The system administrator is logged into the Account Management System • User has a valid Account – (created/active)		
Typical Course of Events	1. System Admin searches, locates and selects user profile 2. System Admin clicks 'edit profile' button 3. System renders user profile editable 4. System Admin clicks 'Lock Account' button 5. System Marks account as 'Locked'		
Alternative Courses	Automatic account locking upon failed login attempts: • The account management might lock a user account if the number of failed login attempts exceeds the configured threshold (3).		
Success Conclusion	The user account is locked The user does not have access to the account		
Failure Conclusion	The user account is not locked An Error message displays detailing failure to lock user		
Assumptions	System Operator can only lock System Admin Account. Failed Attempt lock out is an automatic process		

6.4.1.9.1.2.4 USE CASE UC02-4: UNLOCK USER ACCOUNT

It may become necessary to lock a user from logging into the system (temporarily or permanently). The user account might be locked to avoid access for several reasons including abuse of position, security threat, or user not logged in within a threshold period e.g. 3 months. This use case is triggered automatically should a repeated incorrect attempt at logging in exceeds the set threshold.

Table 6-16 'Use Case UC02-4: Unlock User Account' Description

Use Case Name	*Unlock User Account*	*Use Case ID*	*UC02-4*
Priority	High		
Scope	Account Management		
Description	The System Admin unlocks the user account to grant access once again		
Primary Business Actor	System Administrator		
Stakeholders	System Administrator CNS, Clinician, Admin		
Trigger	User account is locked and needs unlocking		
Inputs	• Username of Account		
Precondition	• The system administrator is logged into the Account Management System • User has a valid Account that is locked an not deleted • Request from departmental manager should account be locked for reason other than failed login attempt		
Typical Course of Events	1. System Admin searches, locates and selects user profile 2. System Admin clicks 'edit profile' button 3. System renders user profile editable 4. System Admin clicks 'Unlock Account' button 5. System Marks account as 'Unlocked' 6. 'Unlock Account' button changes to 'Lock Account' button.		
Alternative Courses	None.		
Success Conclusion	The user account is unlocked The user has access to their account		
Failure Conclusion	The user account is not unlocked An Error message displays detailing failure to unlock user User cannot access system		
Assumptions	System Operator can only unlock System Admin Account.		

6.4.1.9.1.2.5 USE CASE UC02-5: DELETE USER ACCOUNT

It may become necessary to delete a user from the system. Deleting means the account cannot be revived. A copy will be accessible at database level for audit purposes but cannot be reinstated or visible on the user list.

Table 6-17 'Use Case UC02-5: Delete User Account' Description

Use Case Name	*Delete User Account*	*Use Case ID*	*UC02-5*
Priority	Medium		
Scope	Account Management		
Description	The System Admin deletes the user account		
Primary Business Actor	System Administrator		
Stakeholders	System Administrator CNS, Clinician, Admin		
Trigger	User account to be deleted		
Inputs	• Username of Account		
Precondition	• The system administrator is logged into the Account Management System • User has a valid Account • Request from departmental manager for account to be deleted		
Typical Course of Events	1. System Admin searches, locates and selects user profile 2. System Admin clicks 'Delete Profile' button 3. System renders alert to validate decision 4. System Admin clicks 'Confirm' button 5. System Marks account as 'Deleted'		
Alternative Courses	None.		
Success Conclusion	The user account is deleted (logically) User account data remains on database, but marked 'deleted'		
Failure Conclusion	The user account is not deleted and remains active and unchanged An Error message displays detailing failure to delete user account		
Assumptions	System Operator can only unlock System Admin Account. Accounts cannot be 'undeleted'		

6.4.1.9.1.2.6 USE CASE UC02-6: RESET USER PASSWORD

A user requires access to product, but has forgotten password.

Table 6-18 Use Case UC02-6: Reset User Password' Description

Use Case Name	*Reset User Password*	*Use Case ID*	*UC02-6*
Priority	High		
Scope	Account Management		
Description	A user cannot access the system because of a forgotten password. The System Admin resets the account's password and thus inactivates the account. The user has to activate the account again by setting a new password.		
Primary Business Actor	System Administrator		
Stakeholders	System Administrator CNS, Clinician, Admin		
Trigger	User has forgotten their password, requests password reset from System Admin		
Inputs	• Notification from User of forgotten password		
Precondition	• The system administrator is logged into the Account Management System • User has a valid Account • Identity of user has been verified		
Typical Course of Events	1. System Admin searches, locates and selects user profile 2. System Admin clicks 'Reset Password' button 3. System renders alert to validate decision 4. System Admin clicks 'Confirm' button 5. System Marks account as 'Inactive' and resets the password		
Alternative Courses	None.		
Success Conclusion	The user account is inactive, and password reset		
Failure Conclusion	• The password is not reset • User account is 'active' and unchanged • User unable to access account • An Error message displays detailing failure to reset user password		
Assumptions	System Operator can only reset password of System Admin Account. In order to use the account the user must set a new Password (UC02-8)		

6.4.1.9.1.2.7 USE CASE UC02-7: CHANGE USER PASSWORD

A user requires a password change every three (3) months, in addition to users who may request to change password resulting from precautionary measures such as someone having knowledge of their password.

Table 6-19 'Use Case UC02-7: Change User Password' Description

Use Case Name	*Change User Password*	*Use Case ID*	*UC02-7*
Priority	High		
Scope	Account Management		
Description	The user is changing the password by entering the old one and the new one (twice)		
Primary Business Actor	System Administrator, CNS, Clinician, Admin		
Stakeholders	System Administrator CNS, Clinician, Admin		
Trigger	User wishes to change their password.Alternatively, the system has requested the user to do so at 3 months.		
Inputs	• The old password • The new password (twice)		
Precondition	• User has a valid Account • User is logged in		
Typical Course of Events	1. System renders alert to user on entering the correct password to change password 2. User enters new password twice 3. System validates password meets requirements		
Alternative Courses	1. User requests password to be 'Reset' (UC02-6) in order to change password 2. User is activating account (UC02-8)		
Success Conclusion	The user password has changed		
Failure Conclusion	• The password is not changed • An Error message displays detailing failure to change user password		
Assumptions	None.		

6.4.1.9.1.2.8 USE CASE UC02-8: ACTIVATE USER ACCOUNT

Accounts are 'Inactive' by default, and require a user to enter a password before their profile becomes 'Active'. This use-case is also applicable where a password has been reset.

Table 6-20 'Use Case UC02-8: Activate User Account' Description

Use Case Name	*Activate User Account*	*Use Case ID*	*UC02-8*
Priority	High		
Scope	Account Management		
Description	A user is prompted to enter a 'new' password on accessing the system for the first time.		
Primary Business Actor	CNS, Clinician, Admin (Referred to here as user)		
Stakeholders	CNS, Clinician, Admin		
Trigger	The account's owner wants to activate their account		
Inputs	• The new password		
Precondition	• User has a valid Account Username • Account has been created and is 'inactive'		
Typical Course of Events	1. Account holder accesses login screen 2. Account holder enters 'new' password twice and clicks activate 3. System validates password, 8 characters alpha-numeric and at least one special character 4. System stores encrypted password and activates account		
Alternative Courses	None.		
Success Conclusion	• The account is active • The password has been set		
Failure Conclusion	• The password is not set • User account remains 'inactive' • User unable to access account • An Error message displays detailing failure to set user password		
Assumptions	None.		

6.4.1.9.1.3 PATIENT MANAGEMENT

Patient Management is tasked with the generation of a patient's medical record, care plans, and follow-up regime. It is designed to support clinicians and clinical nurse specialists in the management of patients with cancer as a chronic disease.

The following state diagram, Figure 6.6, provides an additional overview to Figure 6.1 of a patient lifecycle.

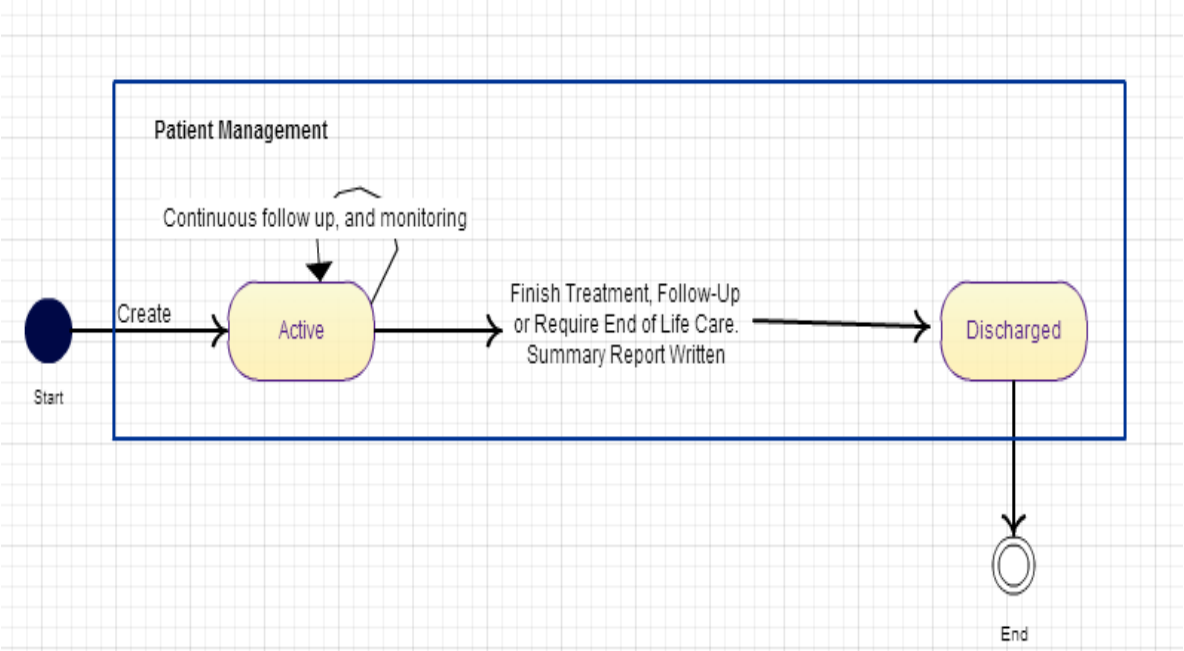

Figure 6.6 State Chart Diagram of Patient Management Overview Lifecycle

The following use case diagram, Figure 6.7, provides an overview of the patient management's use cases:

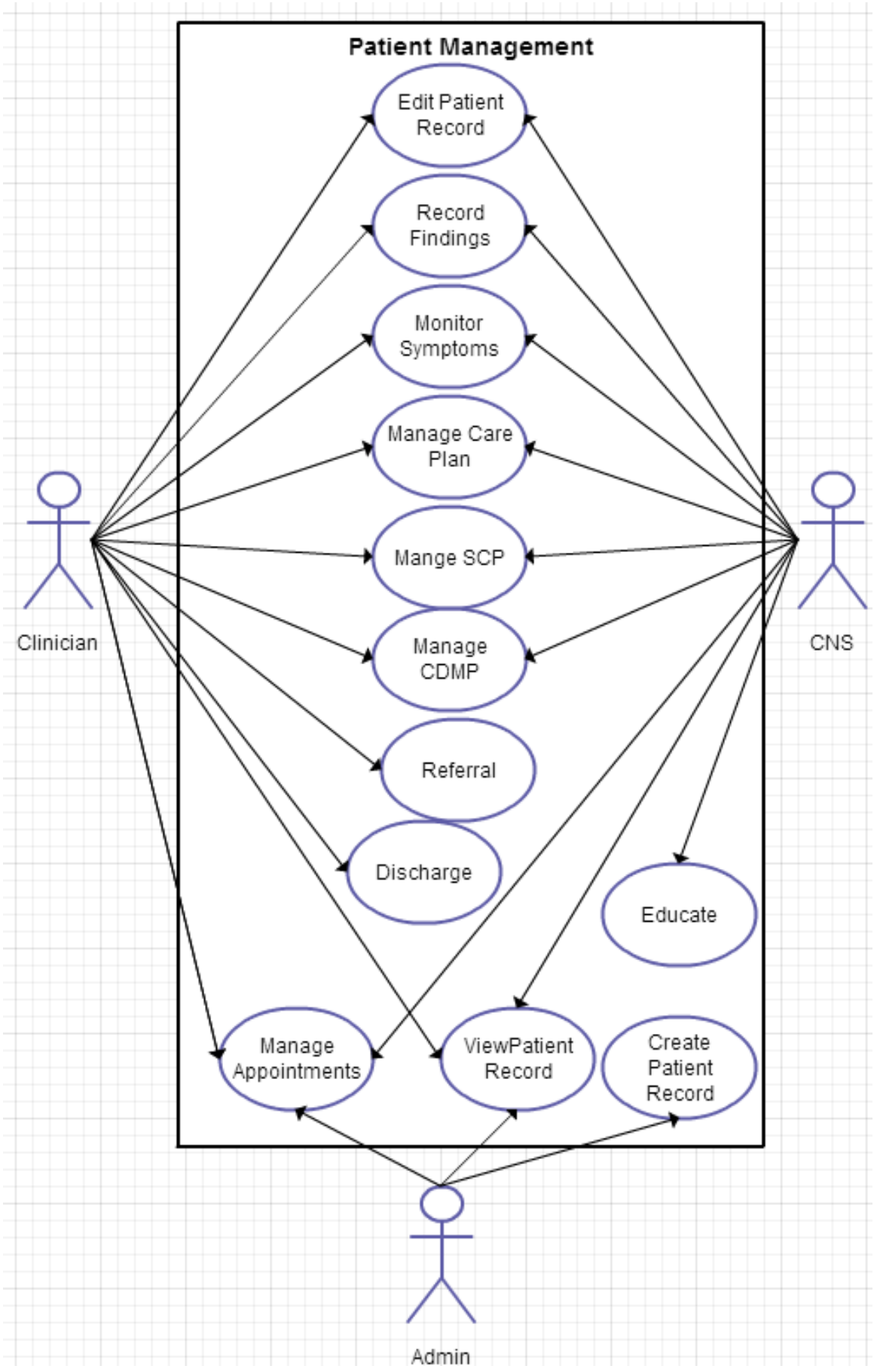

Figure 6.7 Use Case Diagram: Patient Management

6.4.1.9.1.3.1 USE CASE UC03-1: CREATE PATIENT RECORD

The creation of the patient record is a part of the patient management scope. Patients can only be registered on the system if they have an existing hospital Medical Record Number (MRN).

Table 6-21 Use Case UC03-1: Create Patient Record' Description

Use Case Name	*Create Patient Record*	*Use Case ID*	*UC03-1*
Priority	High		
Scope	Patient Management		
Description	Create Patient Medical Record		
Primary Business Actor	Admin		
Stakeholders	Admin, CNS, Clinician		
Trigger	The data administrator wants to create a patient record		
Inputs	User Data: • Patient Medical Record Number (MRN) • Full Name (Forename, Surname) ○ allowed characters: a-Z, A-Z, , `, mutation characters, -, blank • Demographics (DOB, Address, Occupation) • Assign primary clinician		
Precondition	• Patient is registered with an MRN and consented for treatment • Patient has no pre-existing record on the system • User is logged into system		
Typical Course of Events	1. The Data Admin clicks the 'New Patient' button 2. System opens 'Add Patient' form 3. Admin enters patient data 4. Admin clicks 'OK' button 5. System validates data entered 6. System creates Patient		
Alternative Courses	Clicking the 'Cancel' button returns the user to the search patient form		
Success Conclusion	• The patient record is created • Patient data has been stored		
Failure Conclusion	• The patient record is not created • The patient data is not saved • An Error message displays detailing failure to create patient record		
Assumptions	Patient has been registered with an MRN, a valid MRN is required to complete creation of patient record		

6.4.1.9.1.3.2 USE CASE UC03-2: EDIT PATIENT RECORD

Due to a change in a patient's demographical information, the data held on a patient may have to be edited.

Table 6-22 'Use Case UC03-2: Edit Patient Record' Description

Use Case Name	*Edit Patient Record*	*Use Case ID*	*UC03-2*
Priority	High		
Scope	Patient Management		
Description	Edit Patient Demographics of Patients Medical Record		
Primary Business Actor	CNS		
Stakeholders	Admin, CNS, Clinician (Referred to as 'user')		
Trigger	The user wishes to update patient demographics		
Inputs	Change Patients Demographics		
Precondition	• User is logged into system • Patient has a valid patient record		
Typical Course of Events	1. User searches, locates and selects patient record 2. User clicks 'Registration' tab 3. Patient Record is now editable 4. User makes required changes 5. User clicks 'Save Patient' button		
Alternative Courses	Clicking the 'Cancel' button returns the user to the patient summary		
Success Conclusion	The patient record is updated		
Failure Conclusion	• The patient record is not updated • An Error message displays detailing failure to update patient record		
Assumptions	Users cannot edit Patients MRN number, this is a unique identifier		

6.4.1.9.1.3.3 USE CASE UC03-3: DISCHARGE PATIENT

Discharge patient relates to the 'discharging' of a patient from the care and service of the hospital.

The patient record is marked as discharged, but can be reopened should the patient return.

Table 6-23 'Use Case UC03-3: Discharge Patient' Description

Use Case Name	*Discharge Patient Record*	*Use Case ID*	*UC03-3*
Priority	High		
Scope	Patient Management		
Description	Discharge patient base on cancer type (>1 year, 5, 10, 15 or end of life)		
Primary Business Actor	Clinician		
Stakeholders	Clinician		
Trigger	Patient is to be discharged from hospital care		
Inputs	Clinical note		
Precondition	• User is logged into system • Patient is registered on the system		
Typical Course of Events	1. The user enters the patient's name (first or last) or Medical Record Number in the search toolbar 2. System displays search results 3. Clinician selects patient from list 4. System renders patient summary page 5. Clinician clicks 'Patient Registration' 6. Clinician clicks 'Discharge' 7. Clinician enters date of discharge 8. Clinician enters reason for discharge 9. System generate discharge summary 10. System marks patient as 'Discharged' on search list		
Alternative Courses	None.		
Success Conclusion	• Patient successfully marked as discharged • Patient Discharge Summary generated		
Failure Conclusion	• Patient successfully marked as discharged • Patient Discharge Summary generated • Error message displays detailing failure to discharge patient		
Assumptions	Patient is no longer for follow-up All patients are marked 'Active' by default		

6.4.1.9.1.3.4 USE CASE UC03-4: MANAGE APPOINTMENTS

Manage Appointments refers to the creation, amendment, cancellation or viewing of clinical follow-up appointments.

Table 6-24 'Use Case UC03-4: Manage Patient Appointments' Description

Use Case Name	*Manage Appointments*	*Use Case ID*	*UC03-4*
Priority	High		
Scope	Patient Management		
Description	Create/Edit/Cancel/View clinical follow-up appointments		
Primary Business Actor	Admin		
Stakeholders	CNS, Clinician		
Trigger	Patient requires a new, amendment to or cancellation of follow-up appointment. User requires view of daily appointments		
Inputs	Patient, Time, date, physician, room number, appointment type		
Precondition	• User is logged into system • Patient is registered on the system		
Typical Course of Events	1. User selects "Appointments" tab 2. System renders Appointment Calendar Screen 3. User clicks "New Appointment" 4. System renders New Appointment Form 5. User searches patient and selects patient 6. User applies date and time 7. System checks available appointments notifying of double booking 8. User accepts date, and denotes appointment type 9. Appointment added to calendar and patient care pathway		
Alternative Courses	3. User selects appointment from calendar 4. System renders appointment 5. User updates time/date or status of appointment 6. Appointment updated 1. User Clicks "Notifications" 2. System renders list of appointments for the day, incomplete health records, pending tasks, patients who did not attend, patients overdue follow up 1. User opens patient record 2. User clicks 'care pathway' 3. System renders list of past, present and future appointments with summary note		
Success Conclusion	• Appointment successfully created/edited/cancelled/ viewed		
Failure Conclusion	• Appointment unsuccessfully created/edited/cancelled/ viewed • An Error message displays detailing failures		
Assumptions	External referrals are handled externally		

6.4.1.9.1.3.5 USE CASE UC03-5: RECORD FINDINGS

Record historical findings, clinical findings, patient vitals, Patient Symptoms (post op, post treat, signs of recurrence/remission/ progression), Non-Chronic Symptoms (fatigue, nausea etc.)

Table 6-25 'Use Case UC03-5: Record Findings' Description

Use Case Name	*Record Findings*	*Use Case ID*	*UC03-5*
Priority	High		
Scope	Patient Management		
Description	Record historical findings, clinical findings, patient vitals, Patient Symptoms (post op, post treat, signs of recurrence/remission/ progression), Non-Chronic Symptoms (fatigue, nausea etc.)		
Primary Business Actor	CNS, Clinician		
Stakeholders	CNS, Clinician		
Trigger	User adds/updates patient information, progress notes, and clinical findings.		
Inputs	Clinical information as appropriate		
Precondition	• User is logged into system • Patient is registered on the system		
Typical Course of Events	1. User clicks "Create Note" under the patient name at the main screen 2. The system displays a form named "Patient Findings". There are different tabs (Findings, Vitals, Symptoms, Diagnosis, Treatment, History) top of the window. User can switch those tabs to add/update different data. 3. User enters findings (e.g. weight, height, temperature, blood pressure and so forth) and clicks 'Save Patient' 4. System alerts of 'need-to-intervene' where necessary if findings entered are outside normal ranges 5. System displays 'Patient Summary' page 6. User works through tabs entering data as relevant 7. System automatically generates relevant summary note		
Alternative Courses	3. The patient information already exists in the system and doesn't need any update; user can skip forms and updates other notes as necessary 4. System displays updates and existing notes		
Success Conclusion	• The patient information is created/updated successfully • Summary note is generated		
Failure Conclusion	• The patient information is not created/updated successfully • Summary note is not generated • An Error message displays detailing failure to create patient findings note		
Assumptions	None.		

6.4.1.9.1.3.6 USE CASE UC03-6: MONITOR SYMPTOMS

Monitor Symptoms refers to the monitoring of patient Symptoms (post op, post treat, signs of recurrence/remission/ progression), Non-Chronic Symptoms (fatigue, nausea etc.) comparable to previous findings.

Table 6-26 'Use Case UC03-6: Monitor Patient Symptoms' Description

Use Case Name	*Monitor Symptoms*	*Use Case ID*	*UC03-6*
Priority	High		
Scope	Patient Management		
Description	Monitor Patient Symptoms (post op, post treat, signs of recurrence/remission/ progression), Non-Chronic Symptoms (fatigue, nausea etc.)		
Primary Business Actor	CNS, Clinician		
Stakeholders	CNS, Clinician		
Trigger	User wishes to monitor patient symptoms		
Inputs	• Patient's name (first or last) or Medical Record Number		
Precondition	• User is logged into system • Patient is registered on the system		
Typical Course of Events	1. The user enters the patient's name (first or last) or Medical Record Number in the search toolbar 2. System displays search results 3. User selects patient from list 4. System renders patient summary page 5. User clicks 'Patient History' 6. System renders information accordingly 7. User can compare existing records		
Alternative Courses	8. System alerts of 'need-to-intervene' where necessary if findings entered are outside normal ranges		
Success Conclusion	• Patient displayed on search list • Information renders successfully		
Failure Conclusion	• The patient did not show on search list • The patient history summary did not display • An Error message displays detailing failure to open/monitor patient history		
Assumptions	None.		

6.4.1.9.1.3.7 USE CASE UC03-7: VIEW PATIENT RECORD

The View Patient Record handles the search and viewing of a patient's medical record. The record displays as a summary of the patient with additional options for interventions depending on a user's role.

Table 6-27 'Use Case UC03-7: View Patient Records' Description

Use Case Name	*View Patient Record*	*Use Case ID*	*UC03-7*
Priority	High		
Scope	Patient Management		
Description	User can search for a patient's record and pull up a summarised view of the medical record.		
Primary Business Actor	Clinician		
Stakeholders	Admin, CNS, Clinician		
Trigger	User wishes to view patient record		
Inputs	• User enters MRN, or patient's name (first or last)		
Precondition	• User is logged into system • Patient is registered on the system		
Typical Course of Events	11. The user enters the patient's name (first or last) or Medical Record Number in the search toolbar 12. System displays search results 13. User selects patient from list 14. System renders patient summary page 15. User clicks 'Patient History' 16. System renders information accordingly		
Alternative Courses	5. User clicks 'Registration' tabs 6. System renders information accordingly		
Success Conclusion	• The search result was displayed based on the name or MRN entered • The patient summary was successfully displayed		
Failure Conclusion	• The patient did not show on search list • The patient summary did not display • An Error message displays detailing failure to open/view patient record		
Assumptions	Patient Record Exists, apply (UC03-1) to create		

6.4.1.9.1.3.8 USE CASE UC03-8: REFERRAL

Referral refers to the generation of a personalised clinical referral as a direct result of clinical findings, or at the discretion of the clinician.

Table 6-28 'Use Case UC03-8: Referral' Description

Use Case Name	*Referral*	*Use Case ID*	*UC03-8*
Priority	Medium		
Scope	Patient Management		
Description	Generate personalised referral as a result of findings		
Primary Business Actor	Clinician		
Stakeholders	Clinician		
Trigger	Clinician wants to generate a referral		
Inputs	Clinical information regarding reason for referral		
Precondition	• User is logged into system • Patient is registered on the system		
Typical Course of Events	1. Clinician clicks 'Documents' tab 2. Clinician clicks 'Generate Referral' button 3. System displays list of referral sources 4. Clinician selects referral source from list, 5. System Generate referral letter template including patients MRN, address, DOB, diagnosis and staging 6. Clinician enters reason referral and clicks 'Save' 7. System automatically saves to patients 'Documents' 8. System prompts clinician to print		
Alternative Courses	User selects "Cancel" and returns to Documents		
Success Conclusion	• 'Documents' tab successfully renders • List of referral sources displays • Letter is prepopulated with patient information • Letter is saved • Letter is printed		
Failure Conclusion	• 'Documents' tab does not successfully render • List of referral sources does not display • Letter does not prepopulate with patient information • Letter is not saved • Letter is not printed • An Error message displays detailing failures		
Assumptions	Internal referral appointments will be created using (UC03-4), external appointments will be managed externally.		

6.4.1.9.1.3.9 USE CASE UC03-9: MANAGE CARE PLAN

Manage Care Plan refers to the care summary; this provides clinical information for both the patient and the receiving care team. This summary helps ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care within the same location or as a reference to the patient. This summary improves transitions and discharges, communication among providers, and cross-setting relationships which can improve care quality and safety.

Table 6-29 'Use Case UC03-4: Manage Care Plan' Description

Use Case Name	*Manage Care Plan*	*Use Case ID*	*UC03-9*
Priority	High		
Scope	Patient Management		
Description	Generate/edit Care Plan Summary		
Primary Business Actor	Clinician		
Stakeholders	CNS, Clinician		
Trigger	Clinician wishes to create a new, or update an existing care plan summary		
Inputs	Clinical Information		
Precondition	• User is logged into system • Patient is registered on the system		
Typical Course of Events	1. Clinician clicks 'Documents' tab 2. Clinician clicks 'Generate Care Plan Summary' button 3. System Generate Care Plan Summary template including patients MRN, address, DOB, diagnosis and staging, 4. Clinician enters long term care plan, and any other relevant information and clicks 'Save' 5. System automatically saves to patients 'Documents' 6. System prompts clinician to print		
Alternative Courses	2. Clinician clicks on existing Care Plan Summary Document 3. Clinician makes required changes and clicks 'Save'		
Success Conclusion	• Care Plan Summary successfully created • Care Plan added to patients 'Documents' • Care Plan printed		
Failure Conclusion	• Care Plan Summary successfully created • Care Plan added to patients 'Documents' • Summary is not printed • An Error message displays detailing failures		
Assumptions	Existing documents can only be edited within an predetermined configurable timeframe e.g. 48hrs		

6.4.1.9.1.3.10 USE CASE UC03-10: MANAGE SURVIVORSHIP CARE PLAN (SCP)

The goal of the Survivorship Care Model is to optimise coordination and continuity of care between the patient and across all the multidisciplinary providers (Earle 2006). Survivorship Care Plan is an electronic record of a patient's history, diagnosis, treatment, and follow up plan is vital to obtain a full working knowledge of a patient's status, which in turn will help in decision-making. This document includes a diagnostic and treatment summary, information on lifestyle, nutrition and exercise resources, information relating to side effects, recovery, signs, and symptoms of recurrence, recommended follow-up schedules, knowledge of available support groups, knowledge of information sent to GPs. SCPs are a reference guide for both the patient and their physicians.

Table 6-30 Use Case UC03-4: Manage Survivorship Care Plan' Description

Use Case Name	*Manage Survivorship Care Plan*	*Use Case ID*	*UC03-10*
Priority	High		
Scope	Patient Management		
Description	Generate /edit/delete Survivorship Care Plan		
Primary Business Actor	Clinician		
Stakeholders	CNS, Clinician		
Trigger	Clinician wishes to generate /edit/delete Survivorship Care Plan		
Inputs	Clinical information		
Precondition	• User is logged into system • Patient is registered on the system		
Typical Course of Events	1. Clinician clicks 'Documents' tab 2. Clinician clicks 'Generate Survivorship Care Plan' button 3. System Generate Survivorship Care Plan template including patients MRN, address, DOB, diagnosis and staging, diagnostic and treatment summary, 4. System prompts Clinician to select additional information from predetermined lists 5. Clinician enters selects information from predetermined lists for long term care plan, information on lifestyle, nutrition and exercise resources, information relating to side effects, recovery, signs, and symptoms of recurrence, recommended follow-up schedules, and any other relevant information and clicks 'OK' 6. System Generates summary based on information gathered 7. Clinician verifies or amends documents clicks 'Save' 8. System automatically saves to patients 'Documents' 9. System prompts clinician to print		

Alternative Courses	10. Clinician presses ‘Cancel’ and returns to ‘Documents’ 2. Clinician clicks on existing ‘Survivorship Care Plan’ Document 3. Clinician makes required changes and clicks ‘Save’ 2. Clinician clicks on existing ‘Survivorship Care Plan’ Document 3. Clinician marks document as ‘deleted’ 4. System prompts user to enter reason for deletion 5. Record marked as ‘deleted’ (logically)
Success Conclusion	• Survivorship Care Plan is generated • Survivorship Care Plan is printed • Survivorship Care Plan is saved
Failure Conclusion	• SCP does not print • SCP is not saved • An Error message displays detailing failures
Assumptions	Existing documents can only be edited within an predetermined configurable timeframe e.g. 48hrs Deleted documents are not visible on the system, but are still stored in the database for audit purposes

6.4.1.9.1.3.11 USE CASE UC03-11: MANAGE CHRONIC DISEASE MANAGEMENT PLAN

Manage Chronic Disease Management Plan refers to the generation of a CDMP document. CDMP are a systematic approach to coordinated health care intervention and supporting communication between the physician and patient, plan of care, prevention, and complications by utilising evidence-based practice guidelines, empowerment strategies on an ongoing basis.

Table 6-31 'Use Case UC03-11: Manage Chronic Disease Management Plan' Description

Use Case Name	*Manage Chronic Disease Management Plan*	*Use Case ID*	*UC03-11*
Priority	High		
Scope	Patient Management		
Description	Generate/edit/delete Chronic Care Plan (CDMP)		
Primary Business Actor	Clinician		
Stakeholders	CNS, Clinician		
Trigger	Clinician wishes to generate/edit/delete Chronic Disease Management Plan		
Inputs	Clinical information		
Precondition	• User is logged into system • Patient is registered on the system		
Typical Course of Events	1. Clinician clicks 'Documents' tab 2. Clinician clicks 'Generate Chronic Disease Management Plan' button 3. System Generate Chronic Disease Management Plan template including patients MRN, address, DOB, diagnosis and staging, diagnostic and treatment summary, 4. System prompts Clinician to select additional information from predetermined lists based on evidence-based practice guidelines 5. Clinician enters selects information from predetermined lists for long term care plan, preventions, complications, empowerment strategies and recommended follow-up schedules, and any other relevant information and clicks 'OK' 6. System Generates CDM plan based on information gathered 7. Clinician verifies or amends documents clicks 'Save' 8. System automatically saves to patients 'Documents' 9. System prompts clinician to print		
Alternative Courses	10. Clinician presses 'Cancel' and returns to 'Documents' 4. Clinician clicks on existing 'Chronic Disease Management Plan' Document 5. Clinician makes required changes and clicks 'Save' 2. Clinician clicks on existing 'Chronic Disease Management Plan' Document 3. Clinician marks document as 'deleted' 4. System prompts user to enter reason for deletion 5. Record marked as 'deleted' (logically)		
Success Conclusion	• Chronic Disease Management Plan is generated • Chronic Disease Management Plan is printed • Chronic Disease Management Plan is saved		

Failure Conclusion	• CDMP is not generated • CDMP does not print • CDMP is not saved • An Error message displays detailing failures
Assumptions	Existing documents can only be edited within an predetermined configurable timeframe e.g. 48hrs Deleted documents are not visible on the system, but are still stored in the database for audit purposes

6.4.1.9.1.3.12 USE CASE UC03-12: EDUCATION

Education refers to the process of generating a personalised education leaflet for a patient based on clinical findings and outcomes. The CNS or Clinician can download the information for the patient. A copy will be saved to the patients' medical record.

Table 6-32 'Use case UC03-12: Education' Description

Use Case Name	*Education*	*Use Case ID*	*UC03-12*
Priority	Medium		
Scope	Patient Management		
Description	Generate personalised education as a result of clinician and clinical findings		
Primary Business Actor	CNS		
Stakeholders	CNS, Clinician		
Trigger	User wishes to provide educational information for patient.		
Inputs	• User enters MRN, or patient's name (first or last)		
Precondition	• User is logged into system • Patient is registered on the system		
Typical Course of Events	1. User selects "Educational Material" button 2. System renders Educational Material Information Screen 3. User selects diagnosis or diagnoses type from list 4. System renders Education Material based on selections 5. User makes personalised changes to tailor education towards patient 6. User clicks save and a record is kept on the patients summary under 'Documents' 7. System Prompts user to Print 8. User clicks "print"		
Alternative Courses	User selects "Cancel" and returns to edit education Document		
Success Conclusion	• The education material is saved to patients 'Documents' • The educational materials were printed out		
Failure Conclusion	• The education material is not saved to patients 'Documents' • The educational materials did not print out • An Error message displays detailing failures		
Assumptions	None.		

6.4.1.9.1.4 DATA MANAGEMENT

Data management covers the handling of patient data. Data in the system is considered to be a valuable resource, that can be processed and generated by the system's data analysis tools and must be distinguished from knowledge (which is stored in the knowledge base).

The database covers the following types of information; patient demographics, treatment types, side-effects, service overviews, recurrence, progressions, remissions, abnormalities in tests and scans, complications, decisions, and outcomes. In addition to these statistical data, trend analysis and timeline analysis will be available.

Information contained in the database is considered private and confidential; however, consent at time of treatment covers the use of secondary data in the hospital.

The following use case diagram, Figure 6.8, provides an overview of the patient management's use

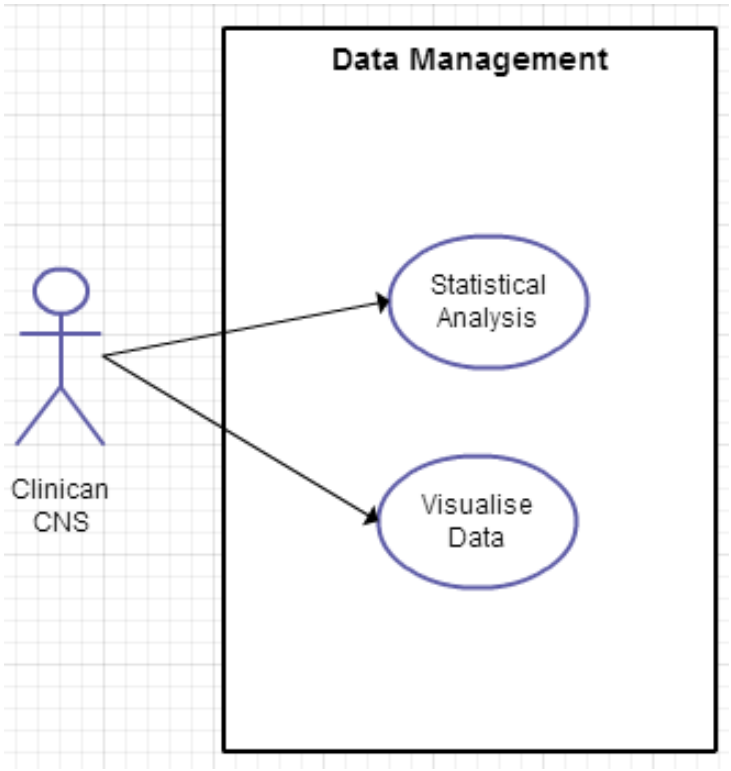

Figure 6.8 Use Case of Data Management

cases:

6.4.1.9.1.4.1 USE CASE UC04-1: STATISTICAL ANALYSIS

Statistical analysis relates to the analysis of clinical data based on information entered on the system. This giving users the ability to analyse progression, regression, recurrences and so forth in addition to giving a practice overview of patient volumes and to be used in furthering evidence based medicine and practice.

Table 6-33 'Use case UC04-1: Statistical Analysis' Description

Use Case Name	*Statistical Analysis*	*Use Case ID*	*UC04-1*
Priority	Low		
Scope	Data Management		
Description	Import and analyse statistical data to generate reports		
Primary Business Actor	Clinician		
Stakeholders	CNS, Clinician		
Trigger	The user imports statistical data for analysis to generate report		
Inputs	User enters date range		
Precondition	• User is logged into system		
Typical Course of Events	1. User clicks "Generate Report" 2. User selects criteria 3. User select time period and clicks 'generate' 4. System generates requested report		
Alternative Courses	Clicking the 'Cancel' button returns the user to the data management form		
Success Conclusion	• Reports are generated		
Failure Conclusion	• Reports are not generated • An Error message displays detailing failure to generate report		
Assumptions	Product has been populated with patient data, Statistical data is generated from findings entered in the system		

6.4.1.9.1.4.2 USE CASE UC04-2: VISUALISE DATA

Visualise Data relates to the visualisation of timelines and trend lines based on information entered on the system. This giving users the ability to visualise progression, regression, recurrences and so forth in addition to giving a practice overview of patient volumes.

Table 6-34 'Use case UC04-2: Visualise Data' Description

Use Case Name	*Visualise Data*	*Use Case ID*	*UC04-2*
Priority	Low		
Scope	Data Management		
Description	Visualise statistical timeline data		
Primary Business Actor	CNS		
Stakeholders	CNS, Clinician		
Trigger	The user wishes to visualise patient timelines or trend lines		
Inputs	• User inputs date range		
Precondition	• User is logged into system		
Typical Course of Events	1. User clicks "Generate Timeline/Trend line Report" 2. User selects criteria 3. User select time period and clicks 'generate' System generates requested report		
Alternative Courses	Clicking the 'Cancel' button returns the user to the data management form		
Success Conclusion	• Timeline/Trend line reports are generated		
Failure Conclusion	• Timeline/Trend line reports are not generated • An Error message displays, detailing failure to generate Timeline/Trend line report		
Assumptions	Product has been populated with patient data Timelines and Trend line data is generated from findings entered in the system		

6.4.1.9.1.5 KNOWLEDGE MANAGEMENT

Knowledge management covers the handling of knowledge data required to populate the system accurately. The following diagram illustrates the 'knowledge management' use case and description below:

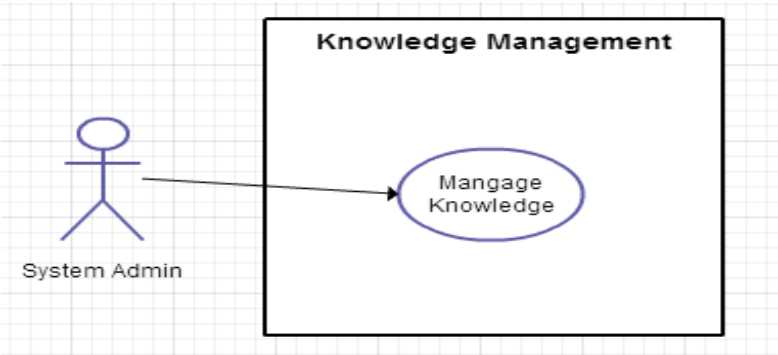

Figure 6.9 Knowledge Management Use Case

6.4.1.9.1.5.1 USE CASE UC05-1: MANAGE KNOWLEDGE

Table 6-35 Use case UC05-1: Manage Knowledge' Description

Use Case Name	*Manage Knowledge*	*Use Case ID*	*UC05-1*
Priority	Medium		
Scope	Knowledge Management		
Description	Upload/Browse/Delete/Validate/ Link Knowledge		
Primary Business Actor	System Admin		
Stakeholders	CNS, Clinician		
Trigger	User wishes to upload/Browse/Delete/Validate/ Link Knowledge		
Inputs	• Knowledge files include, but not limited to ○ Chronic Care Models ○ Survivorship Plan ○ ICD-10 codes or later versions ○ Staging criteria ○ Somatic Symptom Scales ○ Trial Requirements		
Precondition	• The user is logged into the system		
Typical Course of Events	1. The user opens the knowledge base and clicks the "Upload knowledge" button 2. The user opens the knowledge base and clicks the "Browse knowledge" button 3. The user opens the knowledge base and clicks the "Delete knowledge" button 4. The user opens the knowledge base and clicks the "Validate knowledge" button 5. The user opens the knowledge base and clicks the "Link Knowledge" button		
Success Conclusion	• The knowledge data has been uploaded and is available for the Browsing/Deletion/Validation/ Linking		
Failure Conclusion	• The knowledge representation has not been uploaded • An error message is shown		
Assumptions	Knowledge supplied is from a valid source		

6.4.1.10 PERFORMANCE REQUIREMENTS

No Specific requirements.

6.4.1.11 DESIGN CONSTRAINTS

The application shall be designed to run on Microsoft Windows 7.

6.4.1.12 SOFTWARE SYSTEM ATTRIBUTES

6.4.1.12.1 RELIABILITY

The system shall have no more than one failure per calendar week.

6.4.1.12.2 AVAILABILITY

This system shall be available 24-7-365.

6.4.1.12.3 SECURITY

Patient data must be securely maintained at all times. The system must support role-based access and be protected from unauthorised access. Methods of protection will include technological methods such as the use of passwords and encryption methods such as secure socket layer (SSL). Whilst other methods of encryption are available SSL is easy to implement and is proven to be secure. This will use a handshake protocol between client and the server. All communications between the client and server use the shared key to encrypt data. The system will reside on a virtual private network to enhance security. Stringent automatic data saving protocols are also in place. Using these methods will satisfy the users concerns around data hacking from external sites, loss of data due to power outage and change of hospital personnel.

6.4.1.12.4 MAINTAINABILITY

The system will be managed, maintained, and tested by 'Hospital' IT Group, in accordance with 'Hospital' Best Practices and Guidelines. The system should not require modifications, as provisions are in place for the extension of the project for future releases.

6.4.1.12.5 PORTABILITY

No specific requirements required.

CHAPTER 7: VALIDATION OF FINDINGS

7.1 EVALUATION & VALIDATION OF SRS

The trend for using Information Technology software for hospital systems and the fact that requirements for such system software are often complex and difficult to comprehend, it is therefore, a necessity to employ a method of understanding through the use of an SRS and verification. A documented Software Requirements Specification provides a baseline for both validation and verification (Department of Health and Human Services and Food and Drug Administration 2002).

Software verification provides objective evidence that the design outputs of a particular phase of the software development life cycle meet all of the specified requirements for that phase. Software Requirement verification is the process of checking the requirement document for consistency, ambiguity, reliability, correctness, completeness and accuracy (Kotonya and Sommerville 1996; Department of Health and Human Services and Food and Drug Administration 2002).

Software testing is one of many verification activities intended to confirm that software development output meets its input requirements. Other verification activities include various static and dynamic analyses, code and document inspections, walkthroughs, and other techniques. Software validation is a part of the design validation for a finished device. Validation of software typically includes evidence that all implemented software requirements have been correctly and completely and are traceable to system requirements.

For the purpose of this dissertation, validation of the software requirements document includes evidence that all outlined software requirements are true and accurately depicted. A conclusion that the software requirement specification is valid was highly dependent upon a comprehensive inspection by a member of the Hospital IT staff and the end users. An established software requirements specification is required for software validation process to be completed. The conduction of a software requirements traceability analysis is undertaken in order to trace software requirements back to system requirements and risk analysis results.

The IEEE Computer Society (1998) document states, “An SRS is *correct* if, and only if, every requirement stated therein is one that the software shall meet. An SRS is *unambiguous* if, and only if, every requirement stated therein has only one interpretation. An SRS is *complete* if, and only if, it includes all significant requirements, definition of the responses of the software to all realisable classes of input data in all realisable classes of situations and full labels and references to all figures, tables, and diagrams in the SRS and definition of all terms and units of measure. An SRS is *consistent* refers to internal consistency. An SRS is *ranked for importance and/or stability* if each requirement in it has an identifier to indicate either the importance or stability of that particular requirement. *Stability* can be expressed in terms of the number of expected changes to any requirement. An SRS is *verifiable* if, and only if, every requirement stated therein is verifiable. An SRS is *modifiable* if, and only if, its structure and style are such that any changes to the requirements can be made easily, completely, and consistently while retaining the structure and style. An SRS is *traceable* if the origin of each of its requirements is clear and if it facilitates the referencing of each requirement in future development or enhancement documentation.”

A member of the hospital IT team, a consultant, and a clinical nurse specialist evaluated the SRS document against requirements outlined in the interview transcripts and literature findings. The SRS document was validated against the IEEE SRS template and an iterative process was used to refine the document. The iterative process validated the SRS document against the IEEE template for accuracy, completeness, consistency, testability, correctness, and clarity. Suggestions to make descriptions less technical were expressed in addition to more in-depth explanations of the diagrams used and refinement of some of the functions.

CHAPTER 8: CONCLUSIONS

8.1 CONCLUSION

The burden of chronic diseases management is tremendous. Statistically chronic diseases are one of the biggest causes of death worldwide. However, while the rates of cancer are increasing, the population of cancer survivors are accordingly increasing globally due to advances in prevention, diagnosis and treatment. Subsequently this cohort of patients is now effectively considered a patient with cancer as a chronic disease. Even with these advancements, the challenge still lies in the management of late and long-term side effects of treatment including the psychological, psychosocial, and physical aspects of a cancer diagnosis. Cancer survivors require long-term follow-up appointments to monitor these side effects; signs of progression, recurrences, and secondary diagnoses, which for many can be vary from 5 years to life-long follow-up. While the literature has shown many models for the management of patients with chronic diseases, survivorship care plans, disease management plans, and patient pathways have been suggested to effectively manage these patients, while reducing costs, rehospitalisation, and emergency department visits.

The use of ICT can be successfully applied to enhance communication between provider and patient, provider and provider, and provider and system. ICT has shown, when adapted to these chronic care and survivorship models and guidelines, to improve population management, in addition to aiding in both shared multidisciplinary decision-making, and by use of decision support systems promoting guideline adherence and clinical trial criteria. ICT can facilitate in the improvement of coordination, and quality of care delivered.

Unfortunately, however, even with these benefits, barriers of implementation still prevail; Insurance companies refuse to reimburse clinicians for many aspects of survivorship care planning and tele-consultations, in addition, lack of funding makes it near difficult to implement new systems. Additionally, environmental changes and need for professional buy-in is essential to change long-standing cultural mind-sets. Furthermore, ICT systems are only as good as the information entered into them; if not all participants adopt new system approaches, the project

is likely to fail. Likewise if insufficient training is supplied the system is likely to be daunting and deemed too time consuming.

The literature identified some key findings surrounding ICTs roles in supporting clinicians in the management of patients with cancer as a chronic disease. These are as follows,

- ICT could be used for the assessment and surveillance of new or post-treatment symptoms, signs of recurrence and remission, and non-chronic aspects such as insomnia, failing to deal with emotional and psychosocial impact of a cancer diagnosis.
- ICT could be used in the monitoring of somatic symptoms with the integration of somatic symptom scales.
- ICT can open the lines of communication, between patient and physician, physician and physician, and physician and system optimising care coordination and continuity of care.
- ICT could be used to generate personalised, patient specific follow-up plans, Survivorship Care Plan (SCP), or Chronic Disease Management Plan (DMP) established from evidence-based information obtained during examinations.
    - SCPs are a reference guide for both the patient and their physicians, that includes educational material on long-term effect of their diagnosis, diagnostic and treatment summary, local support resources, guidance on follow-up care, rehabilitation, prevention and maintain their personal health
    - DMPs are a systematic approach to coordinated health care intervention and supporting communication between the physician and patient, plan of care, prevention, and complications by utilising evidence-based practice guidelines, empowerment strategies on an ongoing basis.
- Elements from Chronic Care Models such as Wagner's, 5As Model, Flinders Program and the Kaiser Permanente Pyramid can be concatenated and adapted to integrate ICT to effectively coordinate and manage patients, easing communication, shared decision-making, prompt and alert for guideline adherence and continuous care improvements
- ICT is critical in the areas of promoting compliance, tracking patients, obtaining information and measurement data while bridge the gaps in communication.
- ICT based self-management systems can provide a support for both monitoring chronic disease health status and delivering therapeutic interventions.

- ICT has changed how society can interact with health services, cancer centres can provide their own online support with information being managed and directed by clinicians.
- Personal Planning tools can aid forward planning of follow-up appointments, examinations and anticipating services.
- Health Portals could allow physicians to conduct remote virtual appointments providing physical and emotional support
- ICT can allow physicians to expand their knowledge of a patient's disease, detect trends, and determine the most effective course of treatment.
- ICT can be used throughout a patient cancer journey facilitating in the improvement of communication, transformation care coordination, and quality of care delivered, in addition to providing decision support.
- ICT can provide comprehensive rich patient data and support care standardisation and compliance. Thus playing a pivotal part in cancer research, clinical trials, collaborative research, and evidence based medicine subsequently improving cancer awareness promotion and prevention, early detection, treatment, long-term care and post diagnosis monitoring by facilitating in data sharing. ICT can aid in accrual of patients through alerts.
- ICT can be used to concurrently monitor symptoms, side effects, signs of recurrence or progression, while also facilitating in decision-making.
- ICT can be used to prevent a patient 'falling-through-the-cracks'.
- ICT can provide personalised treatment plans, bridging the gap between the multidisciplinary cancer care teams.
- ICT has improved both safety and efficiency of patient care.

The Semi-structured interviews identified seven theme - perceived usefulness, ease of use, self-efficacy, benefits, challenges, knowledge of survivorship care plans and chronic care models and, the role of ICT. Within these interviews, the researcher identified opinions and, key functional requirements that were necessary for the acceptance of the software including:

- The interviewees agreed that there was a use for such a system in the hospital, however one participant thought a computer program would not help solve existing problems.

- The area of communication breakdown was apparent across many departments and the use of ICT in many cases was perceived to be a solution to this problem.
- The system would need to be automated, with minimal effort for the user as to not increase workload, however interviewees were concerned about limiting information e.g. patient tearful, limited options of diagnosis.
- Challenges of the system included need for training, fear of loss of data, resistance to change and the need for change in mind-set. In addition to these challenges space, time, and increased workload were also deemed as non-technical challenges.
- Benefits ranged from trend analysis, easier access to information, better communication, and better coordination.
- The interviews showed a lack of knowledge or awareness of chronic care models. While many interviewees had no prior knowledge of the usefulness, the benefits of the models, the research behind them, or how they could be applied to their day-to-day workings, participants expressed their wishes to learn more about the models and apply them to their practices.

The evaluation and validation identified repetition and need to refine functionality. The iterative process validated the SRS document against the IEEE template for accuracy, completeness, consistency, testability, correctness, and clarity in addition to interview transcripts and literature findings.

8.2 RECOMMENDATIONS FOR FUTURE RESEARCH

This study focuses primarily on the clinical aspect of ICT roles in the potential management of patients with cancer as a chronic disease. Further research should be done to include patient groups and develop a system that integrates patients into the system. One study by McGrath, et al. (2008) outlines how often the most innovative solutions come from patients so engagement of patients through focus groups or surveys would be a good idea for future work. Staff were unaware of chronic care models and survivorship care plans, this is an area where education is needed to promote better practices.

Lack of communication was a recurring theme in interviews and merits a lot more research in how ICT can be used to enhance this fundamental issue. Finally, the implementation of the system is without the biggest area for future research. If such a system were rolled out it would be interesting to see if the perceived benefits and challenges transform into actual benefits and challenges. While the scope of this research did not involve implementation of an ICT system, changes resulting from items discussed during the interviews have begun to emerge and staff are keen to implement some improvements to current practices, which will be closely monitored going forward.

8.3 STUDY LIMITATIONS

As with many studies, this dissertation comes with its own limitations.

- The study focuses primarily on the clinical aspect of ICT roles.
- The study did not implement a working prototype and thus user acceptance testing could not be explored
- As outlined in Chapter 2 a number of interviewees withdrew from the study in addition to one interviewee not grasping the concept of the study, this resulted in a number of excluded studies and the need for further interviews, and focus groups to validate the study.

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APPENDICES

APPENDIX A-1 INTERVIEW GUIDE

Briefing: Thank him/her for participation, introduce myself (name and profession), define the situation for the interviewee (consent form, letter of invitation, confidentiality, recording, about 20 - 40 minutes, plus a short discussion afterwards), briefly state the purpose of the interview, and asking if the interviewee has any questions before the interview begins. The interviews were semi structure with the structured questions outlined below in Table A-0-1. Ad-hoc questions based on what the interviewee responded are depicted in Table A-0-2.

Table A-0-1 Semi-Structured Interview Questions

Main subjects/Researcher questions	*Interviewer questions*
Background Questions	Can you tell me a bit about yourself, What is your day-to-day routine?
User Requirements Building	How do you follow-up on patients after their treatment?
	For how long do you follow-up on these patients?
User Requirements Building	What do you monitor when following up these patients?
What can we fix	Are there any difficulties in doing this?
Can these be incorporated into the new system	What makes doing these tasks easier?
User Requirements Building	What do you think a computer program to manage patients with cancer with a chronic disease would need to do/have?
User Requirements Building	What would you like it to do?
	What do you think such a system could not replace?
ICT Role/Influence	Have you seen a change in the patients coming for treatment
Knowledge of Chronic Care Management	Do you know of Survivorship Care Plans?

Can these be incorporated into the new system	Do you think they could help the patients long-term?
	Do you know of any Chronic Care models? (Diagrams if no, and explain)
Can these be incorporated into the new system	Do you think they could be beneficial if were electronic and applied to your current practices?
ICT Role	Do you think there is a role for ICT in managing patients with cancer as a chronic disease
Barriers of ICT Adoption	What do you think would prevent you from using such a system
Adoption of ICT	What do you think would encourage you to use such a system
Debriefing	Are there any more things you would like to say before we end the interview?
	May I contact you, if further questions should arise?
	Thank you for your cooperation.

Table A-0-2 Ad-hoc Questions

Main subjects/Researcher questions	*Interviewer questions*
ICT Role	Opinion on teleoncology / telemedicine/ teleconsultations
ICT Role/Influence	Do you think that there's more literature now available to patients
User Requirements Building	Who looks after your follow-ups
Background	how long are you following these patients for after their treatment

APPENDIX B-1 – REQUIREMENTS GATHERING OVERVIEW DIAGRAM USED IN INTERVIEWS

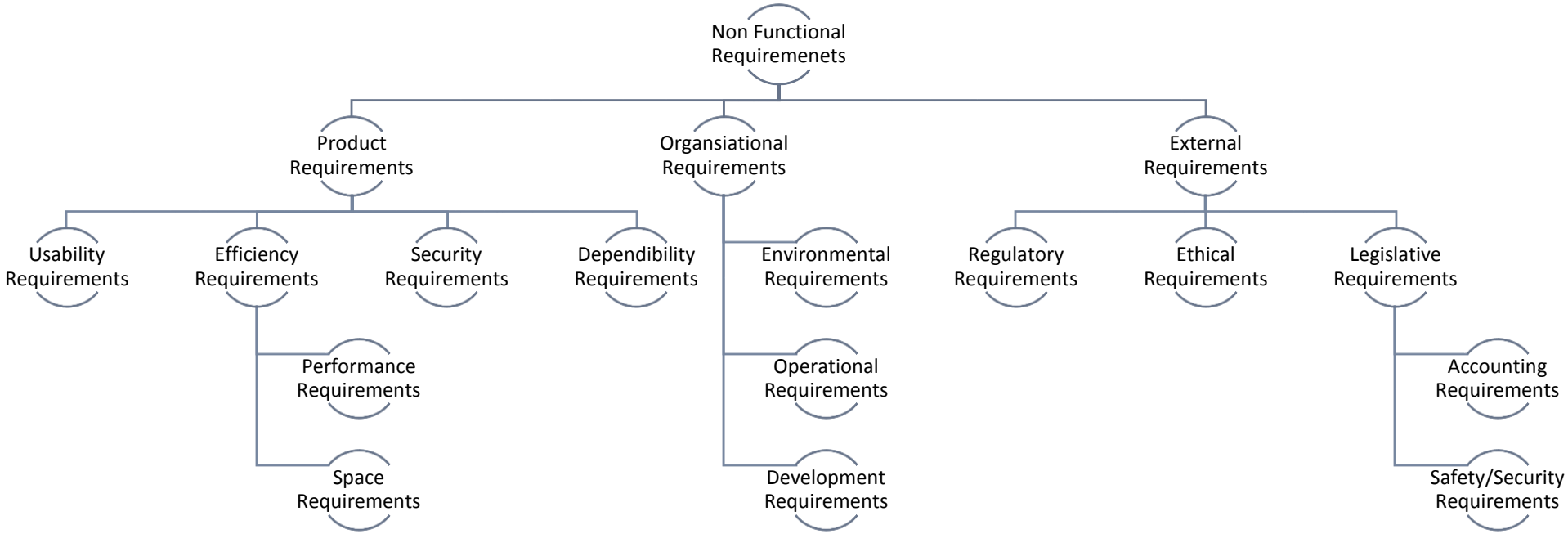
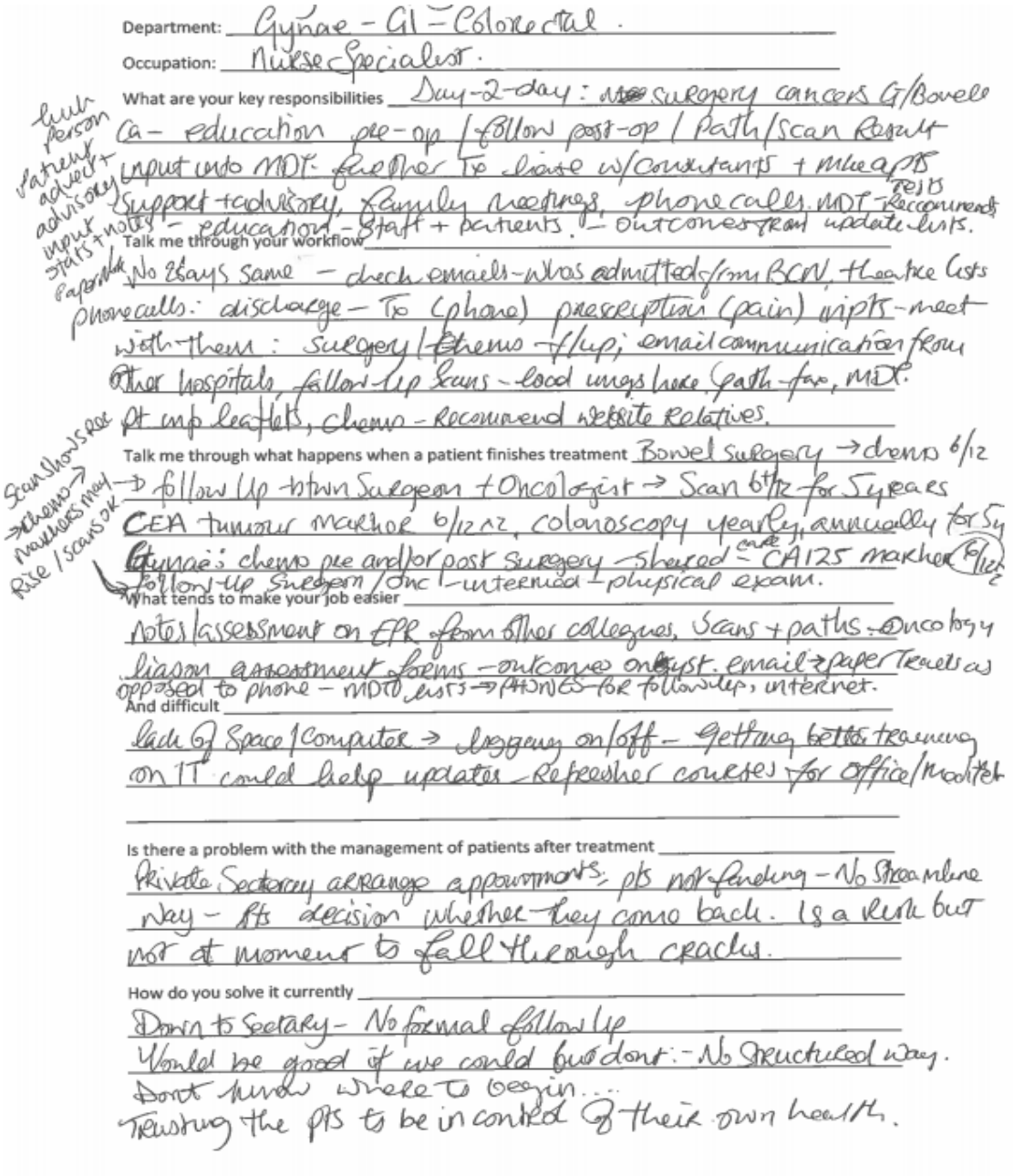


Figure B.0.1 Requirements Gathering Overview Diagram (adapted from (Sommerville, 2007))

APPENDIX C-1 – PILOT INTERVIEW TRANSCRIPT INTERVIEWEE

This was my pilot interview, my interviewee did not wish to be recorded which made it difficult to capture all that was said in the interview



Department: Gynae - GI - Colorectal.

Occupation: Nurse Specialist.

What are your key responsibilities Day-2-day: Surgery cancers G/Bowell Ca - education pre-op / follow post-op / Path/scan Result input into MDT. further To liaise w/consultants + MDT Support + advisory, family meetings, phone calls. MDT - Recommends - education - staff + patients. - outcomes from update lists.

Talk me through your workflow No 2 days same - check emails - who's admitted/from BCN, theatre lists phonecalls: discharge - To (phone) prescriptions (pain) wipts - meet with them: surgery / chemo - f/up; email communication from other hospitals, follow up scans - load imgs into Path - fax, MDT. pt info leaflets, chemo - Recommend website Relatives.

Talk me through what happens when a patient finishes treatment Bowel surgery → chemo 6/12 → follow up btwn Surgeon + Oncologist → Scan 6th/12 for 5yrs CEA tumour marker 6/12 x2, colonoscopy yearly, annually for 5y Gynae: chemo pre and/or post surgery - shared care CA125 marker 6/12 follow-up Surgeon / Onc - internal - physical exam.

What tends to make your job easier Notes/assessment on EPR from other colleagues, scans + paths - Oncology liason assessment forms - outcomes onlyst. email → paper Trackers as opposed to phone - MDT lists → PHONES for follow up, internet.

And difficult Lack of Space/computer → logging on/off - Getting better training on IT could help updates - Refresher courses for office/Meditech

Is there a problem with the management of patients after treatment Private Sectorary arrange appointments; pts not funding - No Streamline way - pts decision whether they come back. Is a risk but not at moment to fall through cracks.

How do you solve it currently Down to Secretary - No formal follow up Would be good if we could but don't - No structured way. Don't know where to begin.... Trusting the pts to be in control of their own health.

Figure C.0.2 Pilot Interview Transcript

How would you like to solve it Alerts - to say follow up → Put in Diary for MDT Scans — Day to due scan - every 6hr monthly scheduled. Faxing and going missing — clinic lists etc. Sent email to inform if docs are received - What is due. Scan paid externally cause of insurance → discrepancies going elsewhere.

Are there legal/environmental/regulatory requirements preventing change to workflow

No. Organise Ourselves - benefit to service if not IT Workspace. → organise yourself better called advance practice.

Are there any other questions?

No.

If I need to ask follow-up questions may I contact you? Would you be willing to participate in a requirements review? Yes.

yes.

APPENDIX D-1 – LETTER OF INVITATION

Ms. Aoife Riordan
Oncology Data Coordinator
Beacon Hospital
Sandyford
D18

10th April 2014

Beacon Hospital
Sandyford
D18

Re: Research Study: The Role of Information & Communication Technology (ICT) Towards The Management of Patients with Cancer As A Chronic Disease

Dear Sir/Madam,

I am currently undertaking a research study as part of my 2nd and final year in the MSc. Health Informatics, Master's Degree in Trinity College Dublin. In my professional work I am an Oncology Data Coordinator, with a keen interest in the use of Information & Communication Technologies in Health and hope to focus on the area of Cancer as a Chronic Disease.

The aim of the proposed study is to explore the role of information and communications technology (ICT) towards the management of patients with cancer as a chronic disease. In particular the study will focus on design and development of an ICT system to manage and support those living with cancer as a chronic disease from a clinician's perspective.

- What roles does ICT have in the management of cancer as a chronic disease
- What are, from a clinical perspective, the user requirements of an ICT system to support cancer as a chronic disease
-

I would like to invite all staff members with dealings with cancer patients to take part. Anyone who chooses to take part will be requested to sign a consent form to partake in requirements gathering interview and observation for potential prototype. The interview, which will be conducted in the vicinity of the hospital, will take an estimated duration of 45 minutes. Any information gathered during this study which is identifiable to you will remain fully confidential and anonymity will be maintained throughout the study. All participants have the right not to take part or to withdraw from the study at any stage without penalty.

Thank you for taking the time to read this letter. Should you wish to take part in the study or have any further questions you would like to ask before making a decision, please feel free to contact me at the above address or alternatively you can ring me on 0863692056 or email riordana@tcd.ie.

If you do decide that you would like to participate in this research study please sign the consent form attached, and return it to me in the pre-stamped envelope. Should I not hear from you I will assume that you do not wish to take part and I will not contact you again.

Yours sincerely,

Aoife Riordan

Signed: _____

APPENDIX E-1 – CONSENT FORM

INFORMED CONSENT FORM

Study Title: The Role of Information & Communication Technology (ICT) Towards The Management of Patients with Cancer As A Chronic Disease

Investigators: Ms. Aoife Riordan

Supervisor: Gaye Stephens

Please Initial box

1. I confirm that I have received a letter of invitation explaining the study and a Consent form. I have read the letter of invitation and consent form or it has been read to me. The information was explained to me and my questions were answered. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my legal rights being affected. ☐

3. I understand that data related to me collected during this study will be processed and analysed as is required by this clinical study and according to the Data Protection Act. ☐

4. I agree to take part in the user requirements gathering interview of a system prototype. ☐

_____	_____	_____
Name of Participant (Print)	Signature of Participant	Date

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent

_____	_____	_____
Name of Investigator (Print)	Signature of Investigator	Date

RESEARCHERS CONTACT DETAILS:

Aoife Riordan

Address: Oncology Data Coordinator, Radiotherapy Level -2, UPMC Beacon Hospital, Sandyford, D18

Tel: (xxx) xxxxxxx

Email: riordana@tcd.ie

APPENDIX F-1 – REQUIREMENTS GATHERING

Thinking about an ideal world. Please fill out these boxes with information you on what you think an ideal System would need to do, in order to make it easier to support/manage/coordinate patients with cancer as a chronic disease – long term.

STRENGTHS *(Benefits of such a system)*	WEAKNESS *(Disadvantages of such a system)*
OPPORTUNITIES *(What you'd like it to do/have – idealistic)*	THREATS *(limitations of the system – what could the system not do/replace)*

Figure F.1 Requirement Gathering Sample

APPENDIX F-2 – SAMPLE REQUIREMENTS GATHERING

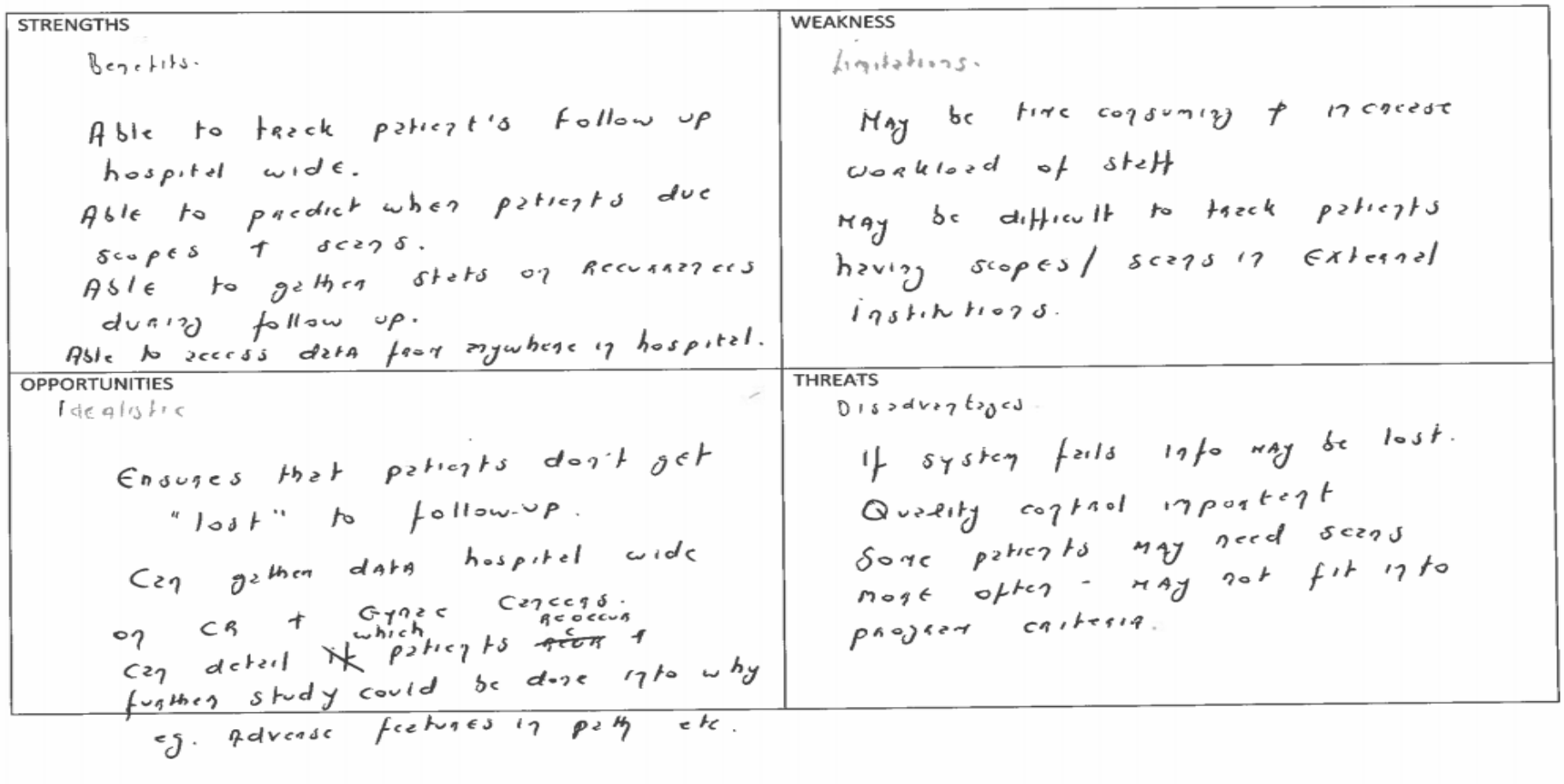


Figure F.0.3 Sample Completed Requirements Gathering

UPMC Beacon Hospital

Research Ethics Committee

Ms. Aoife Riordan
Oncology Data Coordinator
Radiotherapy Department
UPMC Beacon Hospital

6th January 2013

Study Title: The Role of Information & Communication Technology (ICT) Towards The Management of Patients with Cancer As A Chronic Disease.

Reference No: BEA0023

Dear Ms. Riordan,

The Healthcare, Research and Ethics Advisory Committee of UPMC Beacon Hospital received your ethics submission for the above study and reviewed and discussed the documents on the 5th December 2013.

I would like to advise you that this study has been approved with the following conditions:

1. You notify the committee of who your local supervisor is.
2. You submit a copy of your application prototype to the committee (once developed) to be included on your file.

If you have any queries please so not hesitate to contact me at ethics@beaconhospital.ie

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P.P. Teresa M

Mr. Maher Shuhaibar
Chairperson, UPMC Beacon Hospital REC

APPENDIX G-2 – BEACON ETHICS APPROVAL – ON SITE SUPERVISOR RESPONSE

Riordan, Aoife

From: Fagan, Gillian
Sent: 06 January 2014, 16:39
To: Riordan, Aoife
Subject: thesis

Dear,

Further to our conversation I wish to confirm that I am happy to be your supervisor here at UPMC Beacon for the following study;

Study Title: The Role of Information & Communication Technology (ICT) Towards the Management of Patients with Cancer As A Chronic Disease
Reference No: BEA0023

Kind Regards,
Gillian Fagan

Radiotherapy Services Manager
Beacon Cancer Centre
National Centre for Radiosurgery
UPMC Beacon Hospital
Sandyford
Dublin 18

Phone department: 01 2936691
Direct Line: 01 2936632
Mobile: 0876649260
Fax: 01 2936657

Email: fagang@upmc.edu

APPENDIX G-3 – BEACON ETHICS APPROVAL –RESPONSE

Riordan, Aoife

From: Riordan, Aoife
Sent: 06 January 2014 16:41
To: Nolan, Treasa; ethics@beaconhospital.ie
Cc: Fagan, Gillian
Subject: RE: Ethics Committee

Dear Beacon Research Ethics Committee,

Study Title: The Role of Information & Communication Technology (ICT) Towards the Management of Patients with Cancer As A Chronic Disease
Reference No: BEA0023

Thank you for your letter dated 6th January 2014.

As per your request please note Ms. Gillian Fagan will be my local supervisor.

Kindest Regards,
Aoife Riordan

Oncology Data Coordinator,
Radiotherapy -2
UPMC Beacon Hospital
Sandyford
D18

Tel: 01 293 8649

APPENDIX G-4 – TRINITY COLLEGE DUBLIN ETHICS APPROVAL

RE: Ethics Submission - 066/14 Inbox x

Tricia Fowler <Tricia.Fowler@scss.tcd.ie> 4 Feb
to me, Research

Hi Aoife

Thank you for your application. As it has received external ethical approval from UPMC Beacon Hospital, you may proceed with this study. We wish you success in your research.

Kind Regards
Tricia

Tricia Fowler
Executive Officer – Research Unit
School of Computer Science & Statistics
O'Reilly Institute
Trinity College
Dublin 2

Tel: + 353 1 896 1445

From: Aoife Riordan [mailto:riordana@tcd.ie]
Sent: 03 February 2014 10:24
To: research-ethics@scss.tcd.ie
Subject: Ethics Submission

Dear,

Re: Ethics Submission: Study: "The Role of Information & Communication Technology (ICT) Towards The Management of Patients with Cancer As A Chronic Disease"

Please find attached my submission to the TCD ethics committee for the above study.

I have been approved ethical permission from UPMC Beacon Hospital, all forms submitted to their ethical committee attached

Should you require any additional information please do not hesitate to contact me.

Kind Regards,
Aoife Riordan

APPENDIX H-1 – SECTION 1 OF SRS

H.1 PURPOSE

The purpose of this document is to present a detailed description of the requirements of functionalities for the 'patients with cancer as a chronic disease' system. It will illustrate the purpose and complete declaration of features of the system, the interfaces of the system, what the system will do, plus the constraints under which it must operate and how the system will react to external stimuli. The document will also offer a preliminary view of the software applications User Interface (UI). This document intended for both the stakeholders for its approval and as a reference for the IT change management department towards the development of the ICT software system.

H.1.1 INTENDED AUDIENCE AND READING SUGGESTIONS

This document is intended for all individual participating in and /or supervising the project. Readers who are interested in a brief overview of the project should focus on the remainder of Section 1, 'Introduction', in addition to Section 2, 'Overall Description', which provides a brief overview of each aspect of the project as a whole.

Readers who wish to explore the system features in more detail should continue reading to Section 3, 'Specific Requirements', which expands upon both the information laid out in Section 2 but also offers further technical details including user interfaces, hardware and software platforms, and so forth.

Readers interested in the non-technical aspects of the project should read Section 6.3.3.X, 'Software System Attributes', which are important to users. Readers who have not found the information they are looking for should consult Section 6.3.3.X, 'Other Requirements', which includes other additional information that has not fit logically into other sections.

H.2 SCOPE

The software system will provide Oncology Services within the 'Hospital' access to existing records; develop clinical patient pathways, decision support, survivorship programmes,

treatment summaries, and long-term follow up metrics. This software focuses on medical records and the associated diagnostics with cross functionality regarding the aforementioned. This system designed to maximise the Oncology Services productivity by providing tools to assist in the management of patients with cancer as a chronic disease, by maximising the services work efficiency and long-term evidence based medicine it will remain easy to understand, use and adaptable to needs.

H.3 DEFINITIONS, ACRONYMS & ABBREVIATIONS

This document features some terminology which readers may find unfamiliar. See the below table for a list of these terms and their definitions.

Table 0-3 Definitions, Acronyms & Abbreviations

Term	Description
Database	Collection information monitored by this system
System Administrator	Individual who is given specific permission for managing and controlling the system
Actor	Someone who interacts with the system in UML diagram
Software Requirements Specification	Documentation of the essential requirements (functions, performance, design constraints, and attributes) of the software and its external interfaces
Stakeholder	Any person who interacts with the system who is not a developer
User	Someone who interacts with the system
SCP	Survivorship Care Plan
CDMP	Chronic Disease Management Plan
MRN	Medical Record Number

H.4 REFERENCES

The following contains a list of references used by this document:

Software Engineering Standards Committee of the IEEE Computer Society, "IEEE Recommended Practice for Software Requirements Specifications", The Institute of Electrical and Electronics Engineers, New York, IEEE Std. 830-1998, 1998.

H.5 OVERVIEW

This document has been prepared in accordance with the IEEE Std 830-1998, IEEE Recommended Practice for Software Requirements Specifications. The remainder of this document contains an extensive description of the purposed system. The next section, 'Overall Description', of this document gives an overview of the functionality of this product. It describes the informal requirements and is used to establish a context for the technical requirements specification in the next section. This 'Overall Description' section also introduces different types of stakeholders and their interaction with the system. Towards the end of this section, the document will mention the system constraints and assumptions associated with the product. The third section, 'Specific Requirements', of this document is written primarily for the developers and describes in technical terms the details of the functionality of the product. The section provides the requirements specification in detailed terms and a description of the different system interfaces. Different specification techniques and languages are used in order to specify the requirements more precisely for different audiences.

APPENDIX I-1 - ADDITIONAL CHRONIC CARE MODELS

I.1 THE STANFORD COURSE MODEL

I.1.1 OVERVIEW

Developed during the 1990s, The Stanford Programme was developed by Stanford University, USA. The model often referred to as the Lorig Course or Lorig Model is accredited to Professor Kate Lorig. This model translated into over twenty languages has been adopted worldwide. Initially developed as the Arthritis Self-Management Program during the 1980s, the research recognised that the skills required for self-management were applicable across a range of chronic illnesses and subsequently developed the current model. The Stanford Chronic-Care Model enrols the use of peer educators to build self-efficacy amongst those who have similar concerns regarding the self-management of their disease. The model focuses on training methods to deal with these specific elements of anxiety over a 7-week period.

I.1.2 BENEFITS

The model is designed to incorporate a group environment that reduces the sense of isolation and facilities in self-efficacy and empowerment through the interaction of peer led education and sharing. The model also focuses on problem solving, decision-making and confidence building (Lorig et al. 2001) from the person's perspective not the health professional's perspective (Lawn and Schoo 2010). The use of scaling within the pre-and post-assessment and feedback tools means that the change/progress can be objectively measured over time. The course, developed and scientifically evaluated over multiple populations and contexts does not conflict with other interventions or medical treatment (Lawn and Schoo 2010).

I.1.3 LIMITATIONS

As the model is designed in a group situation, some patients find they are not suited to a group environment and do not participate or respond to a group setting. Others have concerns about privacy and confidentiality as not everyone wants to share publically their problems or concerns. The nature of this group setting means individual barriers are not addressed (Lawn and Schoo 2010). The limiting flexibility of the structured course content prevents the capacity for different learning abilities, styles, and speeds. Attendance has no direct impact on the behaviour of health care professionals (Lawn and Schoo 2010).

I.2 THE EXPERT PATIENT PROGRAMME (EPP) MODEL

I.2.1 OVERVIEW

The National Health Services (NHS) in the United Kingdom developed the Expert Patient Programme Model during the early 2000s. The EPP was strongly modelled on the Stanford Programme Model. Following a successful pilot study between 2002 and 2004 the course was rolled out to primary care trusts across England. As a direct result of a Labour Party manifesto that was issued by the UK Government in 2005, the government pledged to treble the investment in the EPP programme. As a result, in 2007 an increase of courses were made available and the formation of EPP Community Interest Company (CIC) was established. EPP CIC now successfully provides self-management courses for those living with any long-term chronic disease throughout England through the NHS and other organisations. The Expert Patient Programme Model promotes patient self-efficacy by setting weekly goals that they feel comfortable with undertaking (Wilson 2007; Lawn and Schoo 2010).

I.2.2 BENEFITS

The peer-based model designed to support people by increasing their confidence, improving their quality of life, and helping manage their condition more effectively. The model understands that with the correct support patients with chronic conditions can take the lead in managing their own condition. The model was found to be cost effective (Richardson et al. 2008), and improvements were noted in social, emotional, relaxation, and health distress in patients (Rogers 2009).

I.2.3 LIMITATIONS

Initially questions were raised regarding the ability to reach those most in need and the ethos of the programme (Rogers 2009). Rogers (2009) continued to express concerns regarding psychological assumptions made within the programme surrounding social needs and inequalities.

I.3 PATIENT NAVIGATOR PROGRAMME

I.3.1 OVERVIEW

First implemented during 1990, The Patient Navigator Programme was developed in partnership by Dr Harold P. Freeman and the American Cancer Society (ACS). The programme was developed as a direct result of a report written by the ACS entitled *Report to the Nation: Cancer in the Poor.* The report captured the hearings of low-income U.S. citizens during 1989 and found significant barriers for these people in accessing cancer care services. These barriers were due to financial barriers, logistical barriers and sociocultural barriers (Freeman 2006; Wells *et al.* 2008). In addition, the report found that poorer people suffered more pain, suffering and death due to late diagnosis and treatment, make significant sacrifices in order to obtain care, health education was irrelevant to them and turn to fatalism when in need of care (Freeman 2006). The Patient Navigator Programme offers an excellent example of effective care coordination