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FACULTY OF SCIENCE, ENGINEERING & TECHNOLOGY

School of Computing & Information Systems

An exploration of the pilot implementation of an online symptom monitoring diary to support people living with cystic fibrosis self-manage their condition.

By

Erin Roehrer

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Erin Roehrer

ABSTRACT

This thesis explores the pilot implementation of an online symptom monitoring diary (myCF pilot implementation) developed to support people living with cystic fibrosis (CF) through symptom monitoring. The research was conducted within a broader study, the myCF project, that was implementing an online symptom monitoring diary in Tasmania. The myCF pilot implementation was designed in conjunction with health care practitioners with the intention of increasing the patient's symptom awareness and in turn their CF self-management. This thesis presents findings on how the myCF pilot implementation was incorporated into the daily lives of people living with CF and how the myCF pilot implementation influenced people's ability to self-manage. More broadly, guided by the use of Normalisation Process Theory, this thesis contributes to improving understanding of the socio-technical factors and processes that arise during the integration of online symptom monitoring with supporting chronic disease self-management.

ICT tools have been proposed as a mechanism to contribute to improving people's self-efficacy for managing their condition, which in turn lead to improved health outcomes (Cummings et al., 2010, Ekberg et al., 2010). There is a need for more qualitative research to understand the requirements for ICT self-management tools (Ahern, 2007) and to improve the efficacy of these tools (Gomez and Pather, 2012, Cummings, 2008). This research explores the potential link between self-management tool efficacy and developing self-management 'knowledge'. ICT tools that are specifically designed to support individuals in symptom monitoring are still in their infancy and there is minimal evidence of the implementation of such tools (Gaikwad and Warren, 2009, Nijland et al., 2008, Solomon, 2008). Currently most self-management tools include a monitoring component with reporting back to health care professionals for decision making on the management of the patient's condition (Hardiker et al., 2013, McDermott and While, 2013). The monitoring of symptom data by health care professionals contradicts the foundations of self-management, aligning the self-management tool to a compliance model. CF has been identified as a chronic condition where patients could potentially benefit from ICT supported self-management. CF is one of the most common life-threatening genetic diseases, Tasmania has a high incidence of CF and much of the CF population is geographically dispersed and socially isolated. This thesis contributes to the current substantive and conceptual knowledge to the field of information systems by presenting findings on the interactions between the online symptom monitoring diary and CF in Tasmania.

The research methodology employed a qualitative approach that was underpinned by a subjective ontology and an interpretative epistemology. The research strategy consisted of a case study and a three-stage data collection over 6 months. Three groups of participants were involved in this research, for all three stages. These groups are:

1. Children (0-10 years) and a parent;

2. Teenagers (11 to 17 years) with CF, a parent may have been included; and

3. Adults (18 years plus) with CF.

The research design consisted of three research stages: Stage one explored participants' expectations and the initial introduction to the myCF pilot implementation by conducting semi-structured interviews, observations, and field notes. Stage two explored the participants' experiences of the myCF pilot implementation and utilised semi-structured interviews, observations, field notes and web-logs. Stage three used unstructured interviews to develop individual case studies and additionally used data collected from the first two research stages.

Data was analysed with an inductive thematic approach that developed abstracted themes, which generated insight and discussion from three different lenses for this research; the research stages, the individual cases, and at a holistic level. The themes were interpreted to gain insights for each research stage, resulting in the development of initial findings. Concept maps were used to identify clusters of the initial findings and to enhance the interpretation of the initial findings from all three stages of the research. The interpretation process resulted in research findings that represented both individual and group experiences. Further interpretation of the research findings, assisted by the use of Normalisation Process Theory, answered the research questions and research objectives, producing the final four key findings. In order to understand in detail the attitudes, insights, perceptions, and individual CF attributes over times as they interact with the myCF pilot implementation, a qualitative approach was adopted.

The key findings for the research are as follows:

- KF1: **Without a transition from self-management 'understanding' to self-management 'knowledge' it is not possible for an online symptom monitoring diary to provide self-management support.**

- KF2: **Symptom monitoring is a background activity for those with CF, and a focused activity for those who care for people with CF.**

- KF3: **Evaluation methods that focus on use of electronic tools for self-management support are not able to holistically capture all aspects of perception of helpfulness.**

- KF4: **Lack of consistency in user-interface design directly impacted on perceptions of satisfaction during interaction and overall evaluations of the entire online symptom monitoring diary.**

This research has made contributions to information systems knowledge at substantive, methodological and theoretical levels. At a substantive level it has provided a case study of how the myCF pilot implementation was incorporated into the lives of participants, and how self-management support was not evident from the pilot implementation. At a methodological level the design of this research has demonstrated the value of linking the analysis of the research stages through inductive thematic analysis. The thematic analysis moved the segmented data to abstracted themes that facilitated individual case development of the participants' experiences during the research. The interpretation of the

analysis through the use of a concept map developed the basic initial findings into comprehensive research findings that reflected both the individual and group perspectives present in this research. At a theoretical level, using the knowledge management hierarchy, the research has highlighted that the myCF pilot implementation does not support self-management without a transition from self-management 'understanding' to self-management 'knowledge'. The research has demonstrated that current evaluation techniques do not capture the intangible criteria that indicate whether the myCF pilot implementation was a success or a failure. Finally, this research has demonstrated that before technology is implemented to support people living with CF with symptom monitoring and self-management, we first need to be aware of what the participants understand self-management to consist of.

ACKNOWLEDGMENTS

ACRONYMS

BMI	Body Mass Index
CCM	Chronic Care Model
CDSM	Chronic Disease Self-Management
CF	Cystic Fibrosis
COPD	Chronic Obstructive Pulmonary Disease
CSCW	Computer-Supported Co-operative Work
EBM	Evidence-Based Medicine
FEV1	Forced Expiratory Volume in 1 second
FVC	Forced Vital Capacity
GDP	Gross Domestic Product
GP	General Practitioner
HCI	Human Computer Interaction
ICT	Information Communication Technology
IS	Information Systems
ISDM	Information Systems Development Methodologies
IT	Information Technology
PC	Personal Computer
PD	Participatory Design
NPT	Normalisation Process Theory
RCT	Randomised Controlled Trial
SDLC	Systems development life cycle
SLT	Social Learning Theory
SMS	Short Message Service
TCF	Tasmanian Community Fund
TPB	Theory of Planned Behaviour
TRA	Theory of Reasoned Action

TTMC   Trans-theoretical Model of Change

UCD   User Centred Design

UI   User-Interface

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CHAPTER 1 INTRODUCTION

1.1 INTRODUCTION

This thesis explores the pilot implementation of an online symptom monitoring diary developed to support people living with cystic fibrosis (CF) through symptom monitoring. The research was conducted within a broader study, the myCF project, that was implementing an ICT CF self-management support tool in Tasmania. This chapter provides an introduction to the research and presents the research problem and research questions. It introduces the contributions the research makes to information systems (IS) knowledge through the improved understanding of the integration of online symptom monitoring in a person's self-management of CF. The chapter is divided into the following sections:

- Section 1.2 outlines the research domain in which this research was conducted. The research is situated in the domains of ICT for symptom monitoring, self-management, and people with CF, their attitudes surrounding CF and their lifestyle.

- Section 1.3 introduces the research problem, the aims, questions and objectives. The use of ICT for chronic disease self-management is increasing and there is a need to understand how symptom monitoring tools may provide self-management support. This section additionally outlines the approach used in the research.

- Section 1.4 presents a summary of the contributions to information systems knowledge contributed by this research at substantive, methodological and theoretical levels.

- Section 1.5 provides an overview of the structure of the thesis, outlining the remaining chapters.

- Section 1.6 provides a summary of the chapter.

1.2 RESEARCH DOMAIN

The incorporation of ICT into chronic disease self-management is proposed to have the potential to provide an alternative means of information supply to individuals, health care professionals and other stakeholders (Celler et al., 2003). The range of ICT tools used in chronic disease self-management support is wide and varied, and includes telehealth (Akesson et al., 2007), telemonitoring (Gaikwad and Warren, 2009), telecare (Dale et al., 2009), information seeking support (Edgar et al., 2002), and symptom-monitoring systems (Warwick et al., 2010). For this research, ICT is associated with Internet delivered support. Previous research has identified that the understanding of individual engagement in, and benefit from, eHealth initiatives is important and currently this understanding appears to be limited (Cummings and Turner, 2010).

Traditionally the design of eHealth systems was focused primarily to meet the requirements of health care providers for healthcare delivery (Dawson et al., 2009). The focus is evolving to include patients in the system and this creates different ways of health service interaction and information gathering (Dawson et al., 2009). The inclusion of the patient in the system highlights the need for the design processes to address the requirements of both patient and health care provider. eHealth projects frequently commence due to a perceived need identified by those involved in the provision of health care services or researchers in the area.

In the chronic disease domain the potential benefits of using ICT to improve the information available, the communication methods and the individual's self-awareness of their own conditions have frequently been presented and discussed (Akesson et al., 2007, Cox et al., 2012, Paré et al., 2007). The role that ICTs can play in enabling and fostering chronic disease self-management has been encouraging in the areas of condition knowledge, self-efficacy levels, and health outcomes (Murray et al., 2005, Solomon, 2008). With the right functionality the ICT tool moves from being an information source to a tool that can promote self-management education (Bodenheimer et al., 2002).

ICT tools that encourage increased symptom awareness compliment self-management education (Battersby et al., 2003). Symptom monitoring can be beneficial, by highlighting symptom change, or detrimental by bringing focus onto the condition (Johnston et al., 2009), and therefore introduces a complexity of how ICTs can support symptom monitoring in a balanced manner. From the clinical point of view, regular monitoring of chronic disease symptoms significantly improves detection of symptom exacerbations (Turnock et al., 2005, Warwick et al., 2010).

There are many definitions of self-management and each differs slightly in the condition and life aspects they include. For this research, self-management is not centred on the disease and it is not a static process. Cameron-Tucker (2009) defines self-management as

> *"a dynamic process incorporating an individual's capability and confidence to be self-reliant in undertaking responsibilities and engaging in activities, such as adopting health-related behaviours, in a self-tailoring context to deal with the impact of living with a chronic condition on all aspects of their life: a sense of self and medical, emotional and social domains. In order to retain an acceptable and meaningful quality of life, such management involves the capability to undertake core tasks or responsibilities."(Cameron-Tucker, 2009: p 365).*

Once an individual demonstrates self-management behaviours self monitoring can allow for self-adjusting in order to achieve an acceptable quality of life (Coleman and Newton, 2005). When self-management develops into behaviours, the potential for an individual's level of self-management self-efficacy increases, boosting confidence and problem solving levels (Bodenheimer et al., 2002, Lorig et al., 2006, Newman et al., 2004).

The majority of ICT tools developed for chronic disease self-management include an automatic reporting component to health care professionals. Individuals are providing symptom monitoring data electronically through online symptom monitoring systems or interacting with health care practitioners to report upon that data, with few tools designed to be individually controlled. The development of ICT tools to support chronic disease self-management activities are developed with health care practitioners as 'drivers' and patients as 'testers'. The requirements for the ICT tools are developed on behalf of the individuals by the health care practitioners (Scandurra et al., 2008). Systems frequently experience a high level of attrition (Wangberg et al., 2008), potentially due to the lack of alignment with the individuals ICT tools requirements. ICT chronic disease self-management tools are designed to assist those with chronic diseases by improving confidence levels and self-management self-efficacy (Murray, 2012, Celler et al., 2003) however there is mixed evidence on the efficacy of these ICT tools (Cummings, 2009, Cummings and Turner, 2008, Wangberg et al., 2008, Warwick et al., 2010).

CF is the most common life-shortening genetic disease in the world (White et al., 2009, Staab et al., 1998) and affects multiple systems, particularly the respiratory and gastrointestinal systems. In Australia, 1 in 2500 people are diagnosed with CF (Bell et al., 2011). Tasmania has a birth incidence of 1 in 1800 people (Tasmanian Clinical Genetic Services, 2011), the second highest in the world. Children with CF rely on their parents for their condition management and treatment routines. Previous research has identified that teenagers experience difficulties with treatment compliance (Williams et al., 2007). This can often mean that parents have a high level of involvement with their children's CF condition management and treatment. CF was once a disease primarily located within the paediatric domain, this is no longer the case due to medical research and improved treatment techniques (Kulich et al., 2003). Life expectancy for individuals with CF has increased into their fifth or even sixth decade and therefore communication and self-management is of vital importance for the individual and their family. The management of CF includes

balancing daily medication, treatment, and management regimens. Medication has to be taken daily, some with different food types. Treatment includes daily physio that assist with breathing and airway clearance, and people living with CF need to find a balance between avoiding what makes them ill and participating in activities they find enjoyment in. The complex management regimen has the potential to be supported through the use of ICT and web technologies by assisting with symptom recording, monitoring and education.

Multi-disciplinary health practitioner teams located around Tasmania carry out CF clinical care. A challenge for CF clinical care in Tasmania is geographical barriers (Bradbury et al., 2008). Clinical care for individuals with CF includes regular clinic appointments with specialist doctors, CF nurses, nutritionists, physiotherapists and social workers. Care centres include paediatric and adult services, with the family heavily involved during the paediatric clinic attendance. Teenagers are transitioned into the adult clinic through parent, child and health care practitioner consultation. Health system interaction for individuals is frequent, with both formal methods (clinic and other formal care appointments) and informal methods (phone, email and drop in communication). Long-term relationships exist between individuals and health care practitioners, with individuals encouraged to be responsible for symptom management in the periods between clinic appointments. The time between clinic appointments varies depending on symptom status but is commonly scheduled for every three months at a maximum.

The diagnosis of CF usually occurs during childhood, almost always before the age of two (Gjengedal et al., 2003) and so the family is an integral part of early condition management. In most instances, the responsibility for condition management is with parents until adolescence, where the child is exposed to greater levels of responsibility (Webb et al., 2001, Zindani et al., 2006). Transition of care is challenging which can be attributed, in part, to the developmental changes the adolescent is facing (Fiese and Everhart, 2006). The impact of CF extends to the entire family, parents and siblings, with the potential for family functioning to be adversely affected (Herzer et al., 2010).

This research was conducted within a broader study, the myCF project, that was implementing an online symptom monitoring diary in Tasmania. The purpose of this research is to understand how the myCF pilot implementation was incorporated into the daily lives of people living with CF and how the myCF pilot implementation influenced people's ability to self-manage.

The research space is placed in the three areas of ICT for symptom monitoring, self-management, and people with CF, their attitudes surrounding CF and their lifestyle and contributes to each of the three areas. Figure 1.1 illustrates the three research domains.
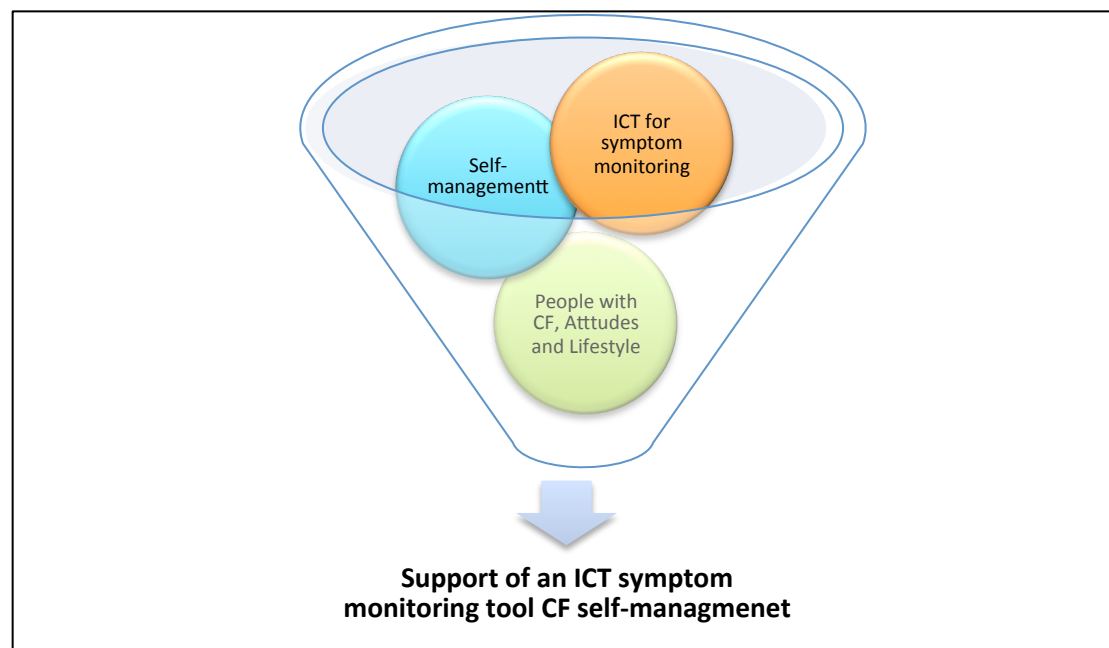
Figure 1-1 Location of research within broader research discourses

1.3 RESEARCH PROBLEM DEFINED

This research aims to explore the pilot implementation of an online symptom monitoring diary developed for the purpose of symptom monitoring to support individuals living with CF. There are concerns regarding the dominance of non-individually controlled ICT tools to assist in chronic disease self-management (Gaikwad and Warren, 2009, Nijland et al., 2008, Solomon, 2008), with minimal evidence available on the delivery and evaluation of individually control ICT tools.

The presence of ICT tools for supporting chronic disease care is steadily increasing in development and use (Akesson et al., 2007, Avison and Young, 2007, Cummings et al., 2009). The improved health outcomes and confidence associated with the use of ICT tools in chronic disease support has been acknowledged (Celler et al., 2003, Coleman and Newton, 2005, Cummings et al., 2010, Lindsay et al., 2009, Mirza et al., 2008), however the attrition of such tools casts doubt on the sustainability of these benefits (Ahern, 2007, Wangberg et al., 2008).

ICT symptom monitoring tools can form an effective part of self-management support programs however participants are providing symptom data electronically through the ICT tools or report to health care professionals on their data. The requirements for the ICT tools are developed on behalf of the individuals by the health care practitioners (Scandurra et al., 2008). ICT symptom monitoring tool's have demonstrated efficacy in selected settings (Davis et al., 2007, Warwick et al., 2010) however the participants are still guided by health care plans developed by their health care professional (Davis et al., 2007).

The management of CF requires the parents of children with the condition to manage the condition until they reach an age where condition management can be shared. The improving treatment, management and diagnosis of CF has resulted in a range of generations living with CF, as well as individuals managing the condition who do not experience CF symptoms themselves (Kulich et al., 2003). This introduces different stakeholders that need to be considered when developing an ICT tool for CF condition management support.

Health care service teams require objective evidence of not only the effectiveness, but also the safety of ICT platform design (Sanderson, 2007). This evidence must be collected whilst removing any burden to safety and confidentiality, essentially excluding the majority of individuals from participating in the development of tools that would support them in their chronic disease condition management. This, in turn, may create difficulties in the creation of a service platform for varying requirements when the overall requirements analysis has taken place through the health care practitioners. While individuals may have the same diagnosis, not all will have the same information needs in regard to managing their chronic condition (Bath, 2008). A clearer picture of the requirements for ICT support is needed to enhance current evaluations of ICT tools for chronic disease self-management. The development of such tools follow the increasing emphasis on promoting condition management and self-management of chronic conditions by those affected (Wanless, 2002). It has been identified that there is a need for more qualitative research in order to understand the various stakeholder requirements for ICT tools and chronic disease management support (Ahern, 2007).

Supplementing evaluation frameworks with behavioural theories is suggested by this thesis as one method of providing qualitative evaluation research. The use of these theories can further inform the definition of a successful implementation, currently an area lacking clear understanding (de Bont and Bal, 2008, Murray et al., 2011). One such theory developed to understand how new technologies can become a sustainable activity is Normalisation Process Theory (May and Finch, 2009). As a process theory, Normalisation Process Theory has the potential to increase the understanding of the implementation and interaction of new technologies that are developed to support people with chronic disease self-management. Previous studies have demonstrated a pure quantitative approach to chronic disease self-management ICT evaluation does not capture the qualitative improvements that the developed system may offer (Cummings, 2008). Additionally, there is a need to understand the requirements of the individuals, who will interact with such systems.

This research is exploring a pilot implementation of an online symptom monitoring diary, developed to support people living with CF through symptom monitoring, to address the following issues:

- The lack of individually monitored online symptom monitoring tools for chronic disease symptom monitoring and self-management
- The increasing trend of ICT tools developed for chronic disease symptom monitoring and self-management
- The different needs of a range of people involved in the care of people with CF

- The increasing need for more qualitative evaluation to understand the attrition and benefit of ICT tools.

1.3.1 RESEARCH AIMS

The research aims to explore the pilot implementation of an online symptom monitoring diary that was developed to support people living with CF through symptom monitoring. This includes examining why people elected to interact or not interact with the online symptom monitoring diary and the development of an understanding of the perceived role the online symptom monitoring diary has for self-management of CF.

1.3.2 RESEARCH QUESTIONS

The following research questions and research objectives have been designed to meet the aims and research problem of this study.

RQ1: How can an online symptom monitoring diary support an individual's self-management of cystic fibrosis?

RQ1 O1:   *To identify what individuals understand as cystic fibrosis self-management.*

RQ1 O2:   *To identify whether an online symptom monitoring diary can support an individual's self-management of cystic fibrosis.*

RQ1 O3:   *To explore the interaction between self-management knowledge and use of the online symptom monitoring diary.*

RQ2: How do people with cystic fibrosis incorporate symptom monitoring into their daily life?

RQ2 O1:   *To understand the nature of the choices that people living with cystic fibrosis make about their lifestyle.*

RQ2 O2:   *To understand the interaction between the lifestyle of people living with cystic fibrosis and symptom monitoring.*

1.3.3 RESEARCH APPROACH

Participants in the pilot study were randomised into three age based cohorts; paediatrics (ages 0 to 10 years), teenagers (ages 11 to 17 years) and adults (ages 18 years and greater). The myCF pilot implementation involved an online symptom monitoring diary developed to specifications given by clinicians for use by individuals living with CF (see section 2.4).

The research was conducted in three stages. The first stage involved conducting and analysing semi-structured interviews (fifteen interviews), observations and field notes. The focus of this stage was to explore the introduction and the participants expectations of the myCF pilot implementation.

The second stage involved conducting and analysing semi-structured interviews (fourteen interviews), observations, field notes, and web-logs. The focus of this stage was to explore the participants experience of the myCF pilot implementation during the six-week period.

The third stage involved conducting and analysing unstructured interviews, observations, field notes, and web-logs to develop the individual case studies. Data from the first two stages complimented this stage. From this stage 15 case studies were created, with 9 presented in this thesis. The focus was to develop a rich description of the myCF family participants, their lives and the impact of CF.

The data was analysed using inductive thematic analysis. The case study approach was applied at two levels. The first level was a single case study that followed the myCF pilot. The second level developed multiple individual case studies for each participant in the myCF pilot. The depth of analysis provided in the individual case studies resulted in saturation after the development of nine case studies. The nine cases selected to be included in this thesis provide a range of cases in each cohort.

The research approach enabled the researcher to fully explore the individual experiences of people with CF during the implementation of a web based symptom monitoring diary and to meaningfully identify and contribute to an improved understanding of the integration of online symptom monitoring tools in a person's self-management of CF.

1.4 SUMMARY OF CONTRIBUTION

This research has made a number of contributions to Information Systems knowledge at substantive, methodological and theoretical levels.

At a substantive level the research has provided a rich case study of how an ICT symptom monitoring tool, in the form of an online symptom monitoring diary, was actually used by participants. Gaining access to people with CF is difficult due to privacy and burden of care concerns, and the research has provided insight to participants living with CF, their 'understanding' and 'knowledge' of self-management and the role of symptom monitoring in their daily lives. The research has demonstrated that the regular use of an online symptom monitoring diary was not directly linked to perceived support. Self-management was not supported by the online symptom monitoring diary. However, the online symptom monitoring diary provided support during times of unstable symptoms. The online symptom monitoring diary clearly supported CF condition management despite its development as a CF self-management support tool.

The research commenced with an aim to explore the pilot implementation of an online symptom monitoring diary that was developed to support people living with CF through symptom monitoring. The initial focus was explored through technology however as the research progressed it became evident that technology currently did not support participants in the self-management of CF. The research shifted to understanding the factors that were required to support participants in their self-management. This research has demonstrated that before technology is implemented to support people living with CF with symptom monitoring and self-management, we first need to be aware of what the

participants understand self-management to consist of. This moves the outcomes of the research from a technological focus to a knowledge focus.

At a methodological level the research design has demonstrated the value of linking the analysis of the research stages through comprehensive inductive thematic analysis. The thematic analysis moved the segmented data to abstracted themes that facilitated individual case development of the participant's experiences during the research. The interpretation of the analysis through the use of concept mapping developed the basic initial findings into comprehensive research findings that reflected the individual and group perspectives present in this research.

The research design focused on a holistic approach to the research questions. The dual focus of 'the myCF pilot implementation experience' and 'the participant's life context' allowed each stage of the research to link and further enhanced the case study design. The research design reflected the moving priorities of CF symptom monitoring and life activities experience by people living with CF.

This research has provided a detailed demonstration of thematic analysis, providing guidance on the thematic analysis method. The process of thematic analysis raised the level of the data to themes, where the required abstraction was achieved. The theme abstraction enabled the capturing of insights by stakeholders, both as a collective group and the individual points of view. The iterative process was vital in producing the comprehensive and meaningful themes.

Finally, the interpretation of the research completes the methodological contribution of this thesis. After the creation of initial findings from the themes, the interpretation was continued with the use of a concept map. The concept map related the initial research findings to other initial findings across all the research stages (see Appendix E). The three phases of interpretation developed the basic initial findings into research findings that reflected the individual and group perspectives present in the research.

At a theoretical level this research has shown that participants have not yet demonstrated self-management 'knowledge' however they have demonstrated an understanding of the foundations of self-management. It was demonstrated that self-management 'knowledge' is the combination of self-management information and self-management action. This thesis has shown that the online symptom monitoring diary clearly supports condition management however people need to demonstrate self-management 'knowledge' before online symptom monitoring diary self-management support is possible. Without aligning self-management information to self-management action, the demonstration of self-management 'knowledge' is not possible. The use of Normalisation Process Theory to explore the research findings revealed that future ICT symptom monitoring tool implementations must focus on the participant's understanding of self-management. The role of technology for symptom monitoring activities cannot be clearly understood until this has been achieved.

It was found that symptom monitoring is focused work for those caring for people with CF, and background work for those who have CF. This research has provided evidence that

symptom monitoring is prioritised differently for those who are living with CF. The subtle differences between symptom monitoring requirements for care-givers and those with CF are required to be better understood to develop relevant ICT symptom monitoring tools that will assist with the development of self-management behaviours.

ICT symptom monitoring tools developed for self-management support need to consider participant understanding of self-management, as the health care professional understanding of self-management does not match the self-management 'understanding' held by the participants. The current tendency of performing condition management under a compliance model of care creates further difficulties in enabling the development of self-management 'knowledge'. This research has additionally demonstrated that current evaluation techniques do not capture the intangible benefits of emotional support that indicate whether the myCF pilot implementation was a success or a failure.

Finally it is evident that despite the nature of the platform that hosts the online symptom monitoring diary, participants expect consistency of the user-interface. Interaction with the myCF pilot implementation with mobile technology was perceived to enable greater flexibility for when and where they could enter symptoms. The expectation of user-interface consistency resulted in a participant evaluation that was formed from false expectations. Dissatisfaction with the consistency of the user-interface results in declining use of the online symptom monitoring diary.

The application of Normalisation Process Theory (see section 3.3.2) to an information systems case study has discovered unstable symptom patterns to be the main driver for interaction with the myCF pilot implementation. During times of unstable symptoms, symptom priorities are placed over life activities in order to adjust to the changing symptoms. Normalisation Process Theory enhances this explanation through the illustration of participants undergoing the four components of Coherence, Cognitive Participation, Collective Action, and Reflective Monitoring. Once symptoms are stable participants move through the components of Cognitive Participation, Collective Action and Reflective Monitoring to reach temporary attrition of the myCF pilot implementation.

Theoretical models of eHealth evaluation have been built upon in this research and continues on from the identification by Cummings (2009) that ICT symptom monitoring tools developed for chronic disease self-management have moved away from mandatory use and that there are a variety of factors influencing the interaction with ICT symptom monitoring tools. Evaluation of ICT symptom monitoring tools can no longer be assessed by pure interaction rates. A greater emphasis on the intangible benefits is required when evaluating participant controlled ICT symptom monitoring tools that take life, family and symptom priorities into consideration. The intangible benefits identified in this research consist of emotional support, parental and health care professional influence and the current interaction with symptom monitoring and daily life.

1.5 SUMMARY OF CHAPTERS

This section provides a summary overview of the remaining chapters in this thesis.

1.5.1 CHAPTER 2 BACKGROUND

Chapter 2 provides the background for the myCF project and the myCF pilot. The insights to the previous research that led to the development of the myCF project are described and the two previous projects, the Pathways Home for Respiratory Illness Project and the Enhancing Self-Efficacy for Self-Management in People with Cystic Fibrosis, are presented. The myCF project is introduced and the myCF pilot aims and objectives are outlined. The myCF project team membership, information relating to the team members professional backgrounds, the project milestones, and the researchers observations of the pilot milestones are provided. The chapter concludes with the description of the research project this thesis is concerned with, the myCF pilot implementation.

1.5.2 CHAPTER 3 LITERATURE REVIEW

Chapter 3 provides a review of the core literature in the three areas of ICT for symptom monitoring, self-management, and people with CF, their attitudes surrounding CF and their lifestyle. The review is supported by a critical review of the literature. The chapter commences by providing a background to the research area. ICT for symptom monitoring is explored and discussed in conjunction with ICT development and evaluation. Self-management for chronic disease is introduced and reviewed in terms of health seeking behaviour and partnership in health care. The chapter concludes with a review on CF literature, CF care in Tasmania, and the impact of CF to the individual and their family.

1.5.3 CHAPTER 4 RESEARCH METHODOLOGY

Chapter 4 provides the research methods used for this research. The chapter describes the philosophical stance adopted, the research strategy, the research design, and the tools and techniques used to carry out the research design. The chapter describes the method of data analysis used in this research, and presents the interpretation process that was facilitated by the use of concept maps. The chapter concludes by demonstrating how researcher bias was addressed.

1.5.4 CHAPTER 5 STAGE ONE: FOUNDATION BUILDING

Chapter 5 provides the in-depth data analysis of research stage one – **Foundation Building**. The focus of this stage was to explore the participants' expectations of the myCF pilot implementation, knowledge of computers, knowledge of self-management, system needs, and experiences of the participants as they were introduced to the myCF pilot implementation. The data analysis was conducted using inductive thematic analysis. Research stage one – **Foundation Building** data was obtained from interviews, observations and field notes. Seven themes have been identified and the axial codes are connected back to each theme and described with extracts from the interviews. The chapter concludes with an initial interpretation that produced eight initial findings.

1.5.5   CHAPTER 6 STAGE TWO: IMPLEMENTATION EXPERIENCE

Chapter 6 provides the in-depth data analysis of research stage two – **Implementation Experience**. The focus of this stage was to explore the participants' experience of the myCF pilot implementation. The data analysis was conducted using inductive thematic analysis. Research stage two – **Implementation Experience** data was obtained from interviews, observations, field notes, and web-logs. Eight themes have been identified and the axial codes are connected back to each theme and described with extracts from the interviews. The chapter concludes with an initial interpretation that produced nine initial findings.

1.5.6   CHAPTER 7 STAGE THREE: LIFE CONTEXT

Chapter 7 provides nine examples of the individual case studies developed to explore the individual experience of each participant and to provide extra context for the myCF pilot experience.   Research stage three – **Life Context** data was obtained from unstructured interviews, observations, field notes, and web-logs to develop the individual case studies. Data from the first two stages complimented this stage. 15 case studies were created in this stage, with saturation occurring after the development of 9 case studies. The chapter concludes with the combined analysis and interpretation through concept mapping that produced eight research findings.

1.5.7   CHAPTER 8 DISCUSSION OF FINDINGS

Chapter 8 provides a discussion of the findings. This chapter reintroduces the research questions. The discussion draws upon the analysis from all three stages, as presented in chapters 5, 6 and 7. The findings of this research are presented and discussed in relation to the surrounding literature. Finally the chapter answers the research questions in relation to the findings and presents the four key findings of the research.

1.5.8   CHAPTER 9 CONCLUSION

Chapter 9 provides a concise summary of the answers to the research questions presented in this thesis. The contributions of knowledge to Information Systems this research has made at substantive, methodological and theoretical level is presented. This chapter then discusses the limitations of the research followed by suggesting possible future research in this area.

1.6 CHAPTER SUMMARY

This chapter has provided an introduction to the background to this research. The research problem has been discussed together with the research aims, research questions and research objectives. Within this context, a set of research questions and research objectives were presented in this chapter to explore the implementation of an online symptom monitoring diary that was developed to support people living with CF through symptom monitoring.

The contribution to Information Systems knowledge has been presented at a substantive, methodological and theoretical level. This chapter has concluded with a summary review of the remaining chapters in the thesis.

The next chapter provides the context for the research that seeks to explore how an online symptom monitoring diary supports a person's self-management of CF. The chapter describes the background research that led to the myCF project and introduces the myCF pilot.

CHAPTER 2   BACKGROUND

2.1 INTRODUCTION

This chapter provides the background to the myCF project and introduces the myCF pilot. The chapter is divided into the following sections:

- Section 2.2 provides insights to the previous research that led to the development of the myCF project. The two previous projects were developed prior to this research and are included to provide the background understanding developed by the myCF project team and illustrate how this understanding informed the myCF project. These previous projects, the Pathways Home for Respiratory Illness Project and the Enhancing Self-Efficacy for Self-Management in People with Cystic Fibrosis, are presented.

- Section 2.3 introduces to the myCF project. The myCF pilot aims and objectives are outlined. The myCF project team membership, information relating to the team members professional backgrounds, the project milestones, and the researchers observations of the pilot milestones are provided.

- Section 2.4 describes the research project this thesis is concerned with, the pilot of myCF.

- Section 2.5 provides a summary of the chapter.

2.2 BACKGROUND TO THE MYCF PROJECT

The myCF project was initiated as a result of previous research conducted by a team of multidisciplinary researchers from the University of Tasmania. The multidisciplinary team drew upon the findings from each of the previous projects to refine and scope the next project, in order to develop relevant support for symptom monitoring and self-management for people living with CF. Tasmania has a CF birth incidence of 1 in 1800 people (Tasmanian Clinical Genetic Services, 2011), the second highest in the world. Many people with CF in Tasmania are geographically dispersed and isolated within the state. The two projects that informed the myCF project were the Pathways Home for Respiratory Illness Project (Pathways Home) CF arm and the Enhancing Self-Efficacy for Self-Management in People with Cystic Fibrosis (CFA) Project, each of these is described below.

2.2.1 PATHWAYS HOME

In Tasmania the burden of care due to CF and Chronic Obstructive Pulmonary Disorder (COPD) is the highest in Australia (Department of Health and Human Services, 2009). The potential of using ICT to support self monitoring and self-management behaviours (see sections 3.3 and 3.41) led researchers from the University of Tasmania, with funding from the Commonwealth Department of Health and Ageing, to commence an investigation into ICT supported self-monitoring (Cummings and Turner, 2005) under the Pathways Home for Respiratory Illness Project (Pathways Home). While the Pathways Home project enrolled patients from two distinct chronic disease cohorts, COPD and CF, the background to the current research project is based in the CF arm of Pathways Home. The overall aim of the CF arm of the Pathways Home project was to investigate interventions that would help with the development of self-efficacy for self-management and self-management skills in people with CF (Cummings et al., 2010). This project focussed on improving both clinical outcomes and patient reported quality of life.

The CF arm of the Pathways project was an investigation to see if an ICT tool, in this case a mobile phone application, could be developed for the use of daily symptom monitoring. The study hoped to discover if individuals with CF would use the tool and if the use of the ICT tool made a difference to the self-management behaviours and quality of life for individuals with CF.

Participants were recruited across Tasmania via a letter outlining the study and asking for volunteers. A total of 19 participants participated in the investigation. These 19 participants were randomised into 3 groups;

Control Group: Continued to receive normal level of care.

Intervention 1: Given access to a mentored self-efficacy for self-management program (face-to-face and via telephone).

Intervention 2:   Given access to a mentored self-efficacy for self-management program (face-to-face and via telephone).

Involvement in an ICT supported self-monitoring program (via mobile phone).

The project ran for 6 months with both qualitative and quantitative data collected. Assessments were taken at commencement; conclusion and 6 months post completion. These included the Stanford Self-Efficacy for Managing Chronic Disease 6-Item Scale questionnaire for adults, a CF specific Quality of Life questionnaire; SF36 version2 for subjective health status, Respiratory function tests FEV1, FVC; a Mentors questionnaire to determine mentees ability to self-manage and their degree of self-efficacy, along with recorded symptom patterns. A semi-structured interview was also completed with participants and mentors at completion. The initial assessment of the results indicated that there was sufficient evidence to undertake further evaluation of these intervention types.

A unique part of intervention arm of the Pathways Home project was the support of mentoring activity through ICT, feedback from participants also indicated that further research was needed (Cummings et al., 2011). Pathways Home demonstrated that mentoring assisted with developing self-efficacy for self- management behaviours, but the pilot study was too small to make definitive conclusions on the ICT arm (Cummings et al., 2011). The findings from Pathways Home demonstrated that that ICT interventions had the potential to improve self-efficacy for self-management however it was uncertain if the ICT tool used directly contributed to these findings. The findings warranted further investigation in a larger setting, leading to the development of the second project.

2.2.2   **CFA PROJECT**

The second project was funded by the Australian Cystic Fibrosis Foundation and extended the Pathways Home project to explore adolescents and older children with CF with particular emphasis on outreach areas. The project was based in Queensland, collaborating with the Royal Children's Hospital and the hospital's CF outreach service. The aim of the CFA project was to examine task-specific self-efficacy and self-monitoring and the project was designed to improve self-management behaviours and quality of life amongst CF patients (Roehrer et al., 2013).

Participants were recruited from the Royal Children's and Gold Coast Hospitals' outpatient and outreach clinics, and were between 12-19 years old. A total of 43 participants participated in the investigation. 15 participants received health-mentoring plus the ICT application. Participants were randomised to one of 3 groups:

Control Group: continued to receive normal level of care.

Intervention 1:	Involvement in the health-mentoring program. Given access to the ICT application, accessed either through a mobile phone provided by the trial or via a desktop PC and allowed the individual to record their symptoms via a daily electronic diary. The mobile phone was available to those who did not have desktop PC access.
Intervention 2:	Involvement in the self-efficacy program and allocated a mentor, without the daily diary or ICT application.

The project ran for six months, with a further six months of follow up. Data collection involved both quantitative and qualitative assessments collected at commencement, 3 months, 6 months and finally 6 months post completion.

The electronic diary consisted of a set of questions and an additional randomly generated question to improve data quality. Participants were able to view a summary of their clinical data as feedback on how their symptoms were tracking. The project mentors were also able to review their patients remotely.

The outcomes of the CFA Project provided sufficient positive response from the qualitative data and usage statistics to indicate that further investigation with a broader scope encompassing a more sophisticated suite of products, may be beneficial in supporting the CF community. Useful information was also obtained on aspects of self-monitoring that were not viewed favourably by these younger CF patients. For example the need to enter diary data on a daily basis was unsurprisingly, not an attractive option for young adolescents (Roehrer et al., 2013).

The CFA Project partially confirmed the findings from the Pathways Home project with the discovery that ICT supported self-monitoring could improve an individual's condition awareness. Additionally, the mixed feedback between adults and adolescents demonstrated there was a need to further explore the use of ICT supported symptom monitoring across the various age groups living with CF. These insights led to the development of a proposal for a project that included children, adolescents, and adults, the myCF project.

2.3 MYCF PROJECT

The small successes of the Pathways Home and CFA projects and the ongoing need to assist the Tasmanian CF community in raising levels of self-efficacy for self-management led to the myCF project. The myCF project utilised web based resources, building on from the previous two project platform experiences.

The myCF Project had three principal aims:

1. Improving access to educational material on CF.

   A web based information portal which contained expert reviewed health information sheets and links to other relevant sites, including the Australian Cystic Fibrosis (CFA) website. The creation of 'Talk to the expert' forums would provide a weekly live and pre-post information session on issues affecting individuals .

2. Increasing Community Support

   Increasing the availability of community support from peers and other families through a secure online chat room. The intention was for this element to eventually develop into a CF community support network for individuals, families, carers and health professionals. The secure chat room was not intended to be an alternative to medical advice, but to enhance it. This allowed individuals to see how other individuals dealt with the social and medical concerns and more importantly, how older people with CF can achieve many of the same life goals that their non CF-affected peers do.

3. Development of a Health Mentor System

   Introduction of a health mentor system of trained health professionals to encourage the development of self-monitoring and increase self-awareness about their condition. Health professionals that were already involved in CF care were trained to provide mentoring to individuals with the aim to improve levels of self-efficacy to self-manage their CF. The focus for the self-management behaviours and increased knowledge of the condition was not exclusively on the individuals but also on the families and immediate support groups, allowing the level of self-efficacy of the entire support unit to rise and hopefully address the challenges faced when transferring daily management from parent/carer to the individual.

The combined platform of a web-based delivery with mobile devices acting as additional input tools, integrated ICT in such a way that even when computer-based Internet access was not available, people could access the portal daily. The mobile devices allowed daily symptom input without potentially interrupting everyday routines, as a computer was not required. In addition a standalone mobile phone application for low-end phones was to be developed, similar to previous research. This was to ensure people without regular Internet access could still engage in online symptom monitoring. The reasons behind the myCF project was to provide a tool for individuals to improve their awareness of CF symptoms and access to educational material relevant to the CF Tasmanian context.

In the longer term, it was intended that the mentoring concepts and myCF web platform would be self-sustaining. It was anticipated the management and day to day running of the web platform would be undertaken by Cystic Fibrosis Australia. It was also anticipated that the developed mentoring frameworks and the myCF web platform concept would be applicable to other Chronic Diseases, particularly in rural or remote settings.

The myCF project team consisted of six people, four specialised CF health care professionals, and two ICT professionals. The specialised CF health care professionals included a respiratory physician, a paediatrician, a senior physiotherapist, and a dietician who provided health care to the majority of the CF community in Tasmania. The respiratory physician was the project team leader and the senior physiotherapist was the CF Tasmanian Associations board representative on the myCF project team. The two ICT professionals had experience in the design, development and implementation of ICT tools for health care delivery including chronic disease ICT tool experience. The role of project officer was held by one of the ICT professionals but moved to the physiotherapist during the development phase.

The myCF project was made possible through from the Tasmanian Community Fund. Six months after the project commencement, the first version of the myCF platform was developed. The myCF team hired an external research assistant to trial the myCF platform in the CF clinics. After the initial clinic trial, the myCF project team made the decision to change to an open source software platform in order to improve long term running costs of the myCF platform.

The specialised CF health care professional team used their knowledge of their patients and observations of clinic interactions to assist with the representation of the participants. The rapport built during care interaction and the conversations held during care interaction gave the specialised CF health care professional project team the confidence to speak on behalf of participants. From the researcher's[1] observation it was identified that the role of an individual's parent as a patient, or co-patient added complexities when the specialised CF health care professionals were speaking on behalf of participants for the requirements of the myCF web platform. The ICT professional project team viewed the identification of stakeholders from a consumer viewpoint as an enabler for building information to move myCF closer to pilot implementation. The specialised CF health care professionals were reluctant to involve participants before the release of the pilot. The question of when to involve participants caused tensions within the team and led to detailed discussions on how myCF would match anticipated individual requirements and predicted interaction preferences. The process of reaching accord for the myCF requirements was lengthy at times and during the end points of finalising decisions, the need for participant commentary became apparent.

The development of the independent mobile phone application for the ICT symptom monitoring tool was also addressed during the early stages of the myCF project. The development of the mobile phone application was a separate task to the myCF pilot. The application was developed so that it would eventually link into the ICT symptom monitoring tool allowing participants mobile symptom entry.

The repeated decision making and detailing of the myCF platform requirements created a belief in the final design of the ICT symptom monitoring tool requirements for the specialised CF health care professionals. Alternatively, the repeated revision of requirements was challenging for the ICT professionals. The challenges relate to the high

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[1] The researcher refers to the author of this thesis.

expectations of the specialised CF health care professional team regarding the use of ICT, combined with their expectation to be able to present a completely acceptable myCF platform at pilot stage. While the challenges presented the ICT professionals with frustrations, the uniqueness of the myCF project translated to a worthy pursuit. The specialised CF health care professionals perceived that the rationale behind the uniqueness draw card was in the use of technology and the new concept of online symptom monitoring.

The use of community links through specialised CF health care professional contacts and the endorsement of myCF by clinics were the main modes of involving participants. The role of the ICT professional team included participating in decision-making, and identifying and advocating the need for participant commentary on the myCF platform.

The myCF team meetings were an illustration of a productive work environment, with collaborative and consultative communication. Between meetings the atmosphere did not match the productive meeting experience, with emails highlighting negative aspects that were previously not present. The use of email to communicate negative aspects of myCF development was evident from the ICT professional team point of view. The communication breakdown appeared to impact the follow through for the myCF tasks that were communicated. The myCF team members made assumptions that governed the flow of communication and actions from the detailed myCF task descriptions. An incorrect assumption concerning what another myCF team member understood from the meeting communication had the potential to negatively influence the resulting decision making process for that item. The limited nature of the follow through from the meeting communication was an area that reduced each team members' understanding of the shared information and negatively impacted on the team communication.

The delays due to the difficulties in the myCF requirements sign off, the passive nature of participant involvement and communication breakdowns within the myCF team meant time was running out to implement the full myCF platform. The ICT symptom monitoring tool was one component of the myCF platform that was nearly complete. Due to time and budget constraints, the specialised CF health care professionals made the decision to focus on a pilot of the ICT symptom monitoring tool, in the form of an online symptom monitoring diary, known as the myCF pilot implementation.

2.4 MYCF PILOT

The focus moved to the design, development and pilot of the online symptom monitoring diary due to difficulties in signing off the questions for the online symptom monitoring diary, the passive participant involvement and the myCF pilot team communication breakdown. The online symptom monitoring diary (myCF pilot implementation) is the case study for this research. The researcher joined the research team at the commencement of the myCF pilot.

The myCF pilot implementation was planned to commence in December 2010 with post data collection to occur in February 2011. Due to delays in the sign off of the online symptom monitoring diary questions and uncontrollable complications with the hosting of the platform, the actual pilot period commenced in June 2011 and ceased in September 2011. The post pilot data collection occurred during November and December 2011.

During the re-scoping of the myCF project to the myCF pilot implementation, the researcher's role changed from a complete observer to a participant as observer (see section 4.5.3). The role change occurred as the researcher became active in the myCF pilot, moving from observing the team develop concepts to becoming involved in the myCF pilot implementation and data collection. This enabled the researcher to carry out the required tasks for the myCF pilot and to address the researchers own research aims, objectives and questions.

The purpose of the myCF pilot implementation was to allow participants to provide a review on the look, feel, navigation and the functionality of the online symptom monitoring diary. The tool was developed to allow participants to record symptoms and receive feedback in relation to baseline questions individuals had entered when symptoms reflected that participants were at their best health.

2.4.1   THE IMPLEMENTED SYSTEM

The myCF pilot implementation had a number of requirements. The participants entered data into the online symptom monitoring diary about how they were currently experiencing a range of symptoms. The functional requirements included the ability to enter a baseline of participant's symptoms. This baseline entry was to reflect the participant's best health in the last three months. The baseline online symptom monitoring diary included all the questions available in the daily online symptom monitoring diary (see Appendix B).

The daily online symptom monitoring diary format duplicated the baseline online symptom monitoring diary in layout and presentation. Instead of choosing their best health for each symptom, participants chose their current symptom status for the day (see Appendix B). Upon completion participants could chose to view reports comparing their daily entry with the baseline entry (see Appendix B).

The online symptom monitoring diary reports compared daily entries with the baseline entry and could be viewed across flexible date ranges. The reports were presented as either a tabular, ring graph or BMI format (see Appendix B). The reports used a traffic light system that displayed green for improved symptoms, amber for stable symptoms and red for worsening symptoms.

The myCF pilot implementation utilised desktop-based computers as a part of the participation criteria. However, as it was web-based it was possible to use mobile devices. The visual requirements for the myCF pilot implementation included an interface that required click through navigation, that was both quick and easy to interact with. A major visual requirement was for the online symptom monitoring content to be clearly presented.

The implementation was required to suit multiple Internet browsers and a range of Internet bandwidths. The myCF pilot implementation was required to appeal to a range of age groups and CF care combinations. The main CF care combinations include parent/caregiver to child and individuals.

An example of the questions used in the online symptom monitoring diary is illustrated in Figure 2.1.

Figure 2-1 Screenshot of online symptom monitoring diary - daily diary questions

Once the symptoms had been entered for the day, participants were able to view a comparison of the days entry to their previously entered baseline.

Figure 2.2 illustrated the tabular view using the traffic light feedback system.

Figure 2-2 daily diary entry summary - tabular traffic light feedback

Alternatively, participants could view their feedback in a ring or BMI (Body Mass Index) graph. Appendix B presents the online symptom monitoring diary user guide used as a part of the pre-implementation introduction session.

Whilst the use of the myCF pilot implementation was the focus of the six-week period, the web platform included an open blog page, a page containing outpatient clinic details, a "useful links" page and a "useful contacts" page. The participants were able to interact with these pages during the six-week period.

In addition to the data collection methods outlined in Chapter 4, section 4.5 other health outcome and surveys were collected as a part of the myCF pilot implementation. The results of the statistical analysis performed on the health outcome and survey data are separate from this research and not available for the analysis of this research.

2.5 CHAPTER SUMMARY

This chapter presented the background research for the myCF project and introduced the myCF pilot. The evolution from Pathways Home, through the CFA Project, culminating in myCF illustrates a natural progression of the linked projects, building on the findings from each previous project. The aims and objectives were outlined for the myCF project. The myCF project team was introduced and professional information relating to the myCF team

members was provided. The milestones for the myCF project were presented. This chapter showed the re-scoping to the myCF pilot from the myCF project due to difficulties in requirements sign off, project team communication breakdown and the reluctance to involve participants. The researcher became involved with the myCF project during the pilot stage. Observations of myCF lead the researcher to change their role in the myCF pilot implementation team, to that of an participant as observer. The role change enabled the researcher to carry out the required tasks for the myCF pilot implementation and to address the researcher's own research aims, research objectives and research questions. This chapter provides the context for the research that seeks to explore how an ICT tool for symptom monitoring can support individuals with self-management of CF.

The next chapter presents a review of the literature relevant to this thesis.

CHAPTER 3   LITERATURE REVIEW

3.1 INTRODUCTION

This chapter provides a review of the literature in the three domain areas of ICT for symptom monitoring, self-management, and people with CF, their attitudes surrounding CF and their lifestyle (see section 1.2). It is divided into the following sections:

- Section 3.2 provides a background to the research area of this thesis. The changing nature of health care demographics in Australia is explored and the use of ICT in health care is discussed. An introduction of eHealth concludes this section.

- Section 3.3 provides a review on the use of ICTs for symptom monitoring. ICT development and evaluation are presented in this section. The complexity of defining the user in ICT tools for chronic disease self–management is illustrated. Methods of ICT symptom feedback conclude this section.

- Section 3.4 reviews self-management concepts and the nature of health seeking behaviour is illustrated. The growing trend for partnership in health care in chronic disease is presented.

- Section 3.5 introduces the chronic condition of CF. CF care in Tasmania is described. The delivery of CF is illustrated and the impact of CF to the individual and their family concludes this section.

- Section 3.6 provides a summary of the chapter.

3.2 BACKGROUND

This section outlines some of the some of the broader influences acting on the three research domains of ICT for symptom monitoring; self-management; and CF, attitudes and life.

3.2.1 <u>CHANGING HEALTH CARE DEMOGRAPHICS</u>

Chronic disease is a high priority for any health care system due to the associated high costs, increased burden of care, and complex management (Young et al., 2007). Chronic disease in Australia accounts for over 80% of the health burden due to death, disability and a lower quality of life (AIHW, 2006). In addition, over $11 billion was spent on chronic disease care in 2001 (AIHW, 2006). More recent figures show chronic disease expenditure was $13 billion in 2005 (AIHW, 2012). The increasing cost of health care and the increasing rates of chronic disease place emphasis on ensuring the patient journey is efficient, proactive and planned (Coleman et al., 2009).

Chronic diseases are ongoing in nature and are rarely completely cured (AIHW, 2012). They are varied in terms of their impact, complexity and treatment; however, there are some common features, as identified by the Australian Institute of Health and Welfare. Chronic diseases include a complex causality, a long development period, a prolonged course of illness, and an associated functionality impairment or disability (AIHW, 2011).

The chronic care model (Wagner et al., 2001) was initially developed to improve patient care and health outcomes (Coleman et al., 2009). The chronic care model is shown in Figure 3.1. The six system changes involved in the chronic care model assist in creating evidence based, patient centred improvements in care (Coleman et al., 2009, Harris and Zwar, 2007). As well as improving patient care and outcomes, the use of the chronic care model is anticipated to improve health spending on chronic disease treatment and care (Coleman et al., 2009).
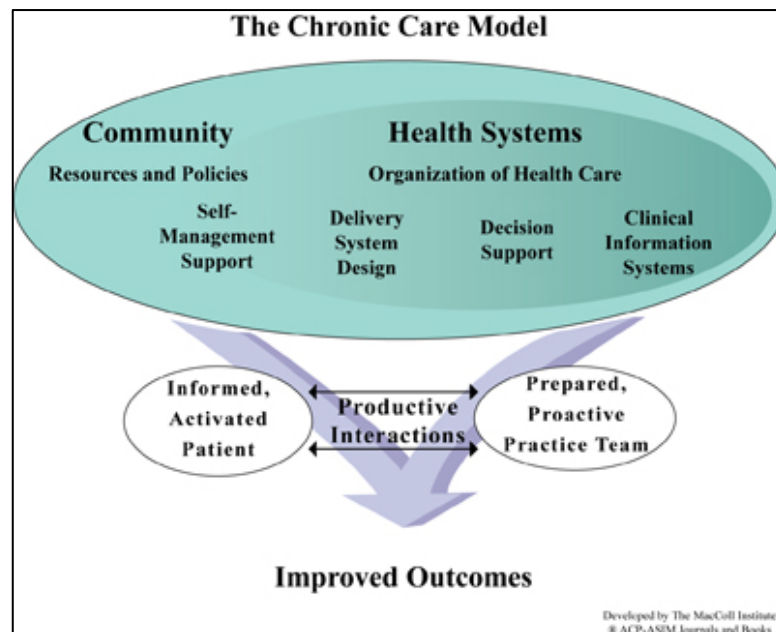
Figure 3-1 The Chronic Care Model (Wagner et al, 2001. p 72)

It is clear that chronic disease in Australia requires ongoing management and review, particularly as the majority of chronic disease onset can be prevented (AIHW, 2006). Improvements to how patients interact with the health care system are varied and include a focus for patient centred care, greater emphasis on self-management, and the use of ICT in both health care professional and patient management of the chronic condition.

Preventative condition management, and increased demonstration of self-management behaviours are linked to improving patient control of their condition (Cummings, 2009). The difficulties lie in understanding both the patient and health care perceptions on a more patient centred system of care (Simborg, 2010). There is evidence of patients both embracing greater condition and decision making (Pulman, 2010, Kawi, 2012), and moving away from a greater level of control (Asimakopoulou et al., 2012). There is a need for awareness of what may work for one patient does not necessarily work for another and this can create difficulties as the health care system moves forward to patient centred care (Novak et al., 2013).

3.2.2   INFORMATION AND COMMUNICATION TECHNOLOGY (ICT) IN HEALTH CARE

Research on system design in an organisational context has shown how several approaches, through involving a variety of users within the company's hierarchy structure, can assist with ICT design. There is a difference between the adoption and use of ICT tools in health organisations compared to business organisations due to the professional training of the health care professionals using the ICT tools (Chau and Hu, 2002). The driving need to reduce healthcare costs, and capitalise on the social, economical, and political benefits (Chau and Hu, 2002, Wu et al., 2006, Currell et al., 2000, Goldzweig et al., 2009) of ICT tools in health care continues the push of ICT tools despite these differences.

ICT tools have been integrated in health organisations to initially overcome limitations of information management, and provided a means to track information and produce accurate reports on quality, safety and effectiveness (Wu et al., 2006). The use of technology in the prevention of adverse events and reducing medical errors is additionally increasing in use and application, with research into decision support systems and prescription entry systems providing strong evidence of error reduction (Bates, 2000, Goldzweig et al., 2009). Over recent years the use of robot technology for surgical interventions has been introduced as the next stage of efficiency gains and improvements on patient outcomes (Barbash and Glied, 2010).

Electronic Health Records (EHR) is a more recent example of health system information integration in developed countries (Buntin et al., 2011). EHR is the electronic record of a health consumer's health related information that can be accessed by relevant health care professionals (Boonstra and Broekhuis, 2010). EHR has been integrated into the health care system at various levels. In Australia it is uncertain if the EHR is a direct replacement of paper health based records or something that can evolve to a clinician and patient accessible record (Showell, 2011).

Telemedicine is one of the early examples of the move from system support to illness diagnosis and management (Currell et al., 2000). Research into the use of telemedicine spans from the use of teleconsultation, the reliability of diagnosis through teleradiology and telepathology, the technical development, acceptability, standardisation, funding, and regulation of telemedicine, and accessing underserved populations via telemedicine (Currell et al., 2000, Darkins, 2012). The use of ICT to span distances between health care specialised and the patient is promising, enabling outreach services to improve accessibility to remote and underserved areas (Roine et al., 2001). However the promise of telemedicine is frequently hampered by Internet and resource availability (Darkins, 2012, Moffatt and Eley, 2011).

Chronic conditions and an ageing population are two factors that are placing an increased demand on the health care system (AIHW, 2010). The introduction of ICT in patient care and interaction has the potential of addressing the different levels of chronic disease confidence between the patient and health care professional team. Berge et al (2007) discuss the role of balancing out the internal vs external confidence levels an individual with a chronic condition may experience. The authors have noted that while the individual has high levels of confidence towards the health care team, the same level of confidence does not exist towards their own abilities to manage their condition and other areas of their life (Berge et al., 2007).

Research has shown the benefits of using ICT to improve the information available, the communication methods and the individual's self-awareness of their own conditions within the chronic disease domain (Paré et al., 2007). The role that ICTs can play in enabling and fostering self-management behaviours has been encouraging in that individuals not only increase their own knowledge and levels of self-efficacy but additionally have improvements in some clinical outcomes and enjoy greater levels of social support (Murray et al., 2005, Solomon, 2008). Health information is one of the most frequently sought topics on the

Internet (McMullan, 2006, Morahan-Martin, 2004) and is demonstrative of the shift from individuals as a passive participant in their health care to an active consumer of health information (Demiris et al., 2008). A subset of Internet base health information is health promotion, aimed towards health consumers in general, with the hope of disease prevention and wellness maintenance (Lintonen et al., 2008).

The use of ICT in chronic disease management has been the subject of various reviews (Dorr et al., 2007, Lorig et al., 2006, Nilsson et al., 2006). Through one of these reviews an improvement in adherence to guidelines, decreases in hospitalisation, organisational costs and access to information were recorded (Dorr et al., 2007). Zanaboni et al. (2009) have commented that ICT provides a solution that both health professionals and individuals accept and can draw benefits from. More recent reviews identify access to health promotion (Laakso et al., 2012), enhanced decision-making (Haddad and Chetty, 2012), and improved communication with health care providers (Stellefson et al., 2013) to be improved through ICT.[2]

Home-based telehealth enables connectivity between patients and health care professionals, allowing patients to monitoring their symptoms without leaving their home (Demiris et al., 2008, Wu et al., 2006). Long-term outcomes have not been reliably measured with home-based telehealth although studies have shown decreased health costs and improved access without impacting of the level of health care provided (Demiris et al., 2008, Wu et al., 2006). The secure transmission of health related data remains a concern in home-based telehealth however the use of secure Internet protocols has provided some relief for Internet based technology (Demiris et al., 2008).

The use of Internet applications to assist with accessing health information for health consumers is steadily increasing (Demiris et al., 2008). The use of the Internet additionally provides a common platform for patients to access disease management systems and to communication with peers and health care professionals (Demiris et al., 2008, Wu et al., 2006).

ICT has also been identified as a facilitator in developing self-management behaviours (Lorig et al., 2006, Cummings et al., 2010, Ekberg et al., 2010). As the provision of health care, in particular chronic disease, moves towards a partnership approach (see section 3.4.2) the use of ICT may be seen to supplement these activities, and in some areas, act as an enabler. Recent literature reflecting patient based eHealth includes some form of connectivity with their health care providers (Ahern et al., 2006, Atkinson and Gold, 2002, Bates and Bitton, 2010, Cox et al., 2012, Kreps and Neuhauser, 2010, Laakso et al., 2012, Oh et al., 2005, Pearce and Haikerwal, 2010, Westbrook and Braithwaite, 2010). Despite the ever-increasing connectivity through ICT, these tools are largely aimed towards patients linking with the health system in some fashion (Haddad and Chetty, 2012, Stellefson et al., 2013). ICT tools for patient driven care appear to be still in their infancy (Goldzweig et al., 2009). The users within the health field are now moving from an employee base to a patient base (Akesson et

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[2] Wellness monitoring through ICT quantified self-tracking is another element of the expansion of health care services (Demiris et al., 2008, Swan, 2009) however this application of ICT is outside the scope of this research.

al., 2007), it will be interesting to see how this involvement, if any and if desired, will impact of the ICTs development, usability, sustainability and portability.

Knowledge management includes the retrieval and organisation of data and information that will improve the capacity for making decisions and taking action (Heathfield and Louw, 1999, Gortzis, 2009). An essential criterion of knowledge management tools is the ability to accurately match an individual's information needs (Ilic, 2010). Knowledge management only enables when the information needs are accurately represented by the system (Heathfield and Louw, 1999). Individuals are required to be able to use the data available, to create information, understanding and hopefully knowledge. Data are facts or ideas that are used in the creation of information. When data is organised and in context, it becomes information. Data undergoes a change to become information that assists in developing understanding. Finally, knowledge is the understanding of information that can be converted into action (Jashapara, 2011).

3.2.3   <u>WHAT IS EHEALTH?</u>

eHealth, or rather the term eHealth, is widely used by many across the information systems, health and other associated disciplines. Despite this wide use, the actual meaning of eHealth may be seen as ambiguous (Kim and Park, 2012, Showell and Nohr, 2012). Oh et al. (2005), in their systematic literature review, revealed 51 unique definitions for eHealth. Within the 51 definitions there is a single common thread of technology and health as a process.

The definitions the review included ranged from JHITA (2000) simplistic

> "*Internet-related healthcare activities*" (Oh et al., 2005), Table 3;

to Eysenbach's (2001) more substantial

> "*e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology*"(Oh et al., 2005), Table 3.

Complexity or length of definitions aside, a further dimension exists for each of the perceived stakeholder groups in each definition. eHealth Technologies (2003) encompass a range of stakeholders within their definition;

> "*The use of emerging information and communication technology, especially the Internet, to improve or enable health and healthcare thereby enabling stronger and more effective connections among patients, doctors, hospitals, payors, laboratories, pharmacies, and suppliers*"(Oh et al., 2005), Table 3.

As a comparison Blake (2001) provides a definition with a more business orientated, health provider focus;

> *"The combined use of electronic communication and information technology in the health sector. It is important to note that e-health is much more than business transactions. It encompasses everything from digital data transmission to purchase orders, lab reports, patient histories and insurance claims."*(Oh et al., 2005), Table 3.

It is worth noting that each of the 51 different definitions in the systematic review defined eHealth in a positive frame using adjectives such as benefits, improvement, enhancing, efficiency and enabling (Oh et al, 2005). Additionally, other themes identified in the definitions included activities, stakeholders, outcomes, place and perspectives (Oh et al, 2005). These four themes have the capacity to represent a varying range of points of view, or perspectives, and is illustrative of the many lenses that eHealth can be viewed through. Ahern et al (2006) claim that the multiple stakeholders, including patients as users, each bring an unique view towards what eHealth's potential is. They also suggest that these views are not always similar. It would seem that as long as clear and direct communication exists between those working within the eHealth field; with predetermined guidelines and definitions agreed upon, the diversity of the definition of eHealth can only represent the rich application and potential that eHealth may bring to an individual, a community or a nation.

However, Ahern et al. (2006) argue against the common application of the term eHealth, as the various definitions only cloud the term and its application. They state the lax in clear definition may bring those who use the term to cross purposes, with each individual unclear on the other party's true intent. Pagliari et al (2005), a self-confessed complementary work to Oh et al, in response to a call from the UK National Health Service (NHS) Research and Development Programme, provide additional resources to define eHealth and to assess its scope and value for the future of health care (Pagliari et al., 2005). It is essential, in light of Oh et al's (2005) review, and Pagliari et al's (2005) additional definition categorisation, that the term eHealth is clearly defined. For the purposes of this research, eHealth is;

> *"e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterises not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology."*(Eysenbach, 2001). Accessed 24/10/2010.

Eysenbach's definition not only encompasses the two themes of health and technology but additionally includes the five themes of activities, stakeholders, outcomes, place and perspectives (Oh et al., 2005). This holistic inclusion allows for the application of eHealth being associated with a range of users, environments and methods of use, demonstrating flexibility and accessibility.

As described in section 3.2.1 the management of chronic disease requires constant review and monitoring thus increasing the demands on the health care system. ICT has been introduced to chronic disease self-management as a means to assist both patients and care providers, however most systems require the patients to link into the health care system in some fashion, as shown in section 3.2.2. A lack of availability of ICT for individual monitoring of chronic diseases is evident, and the wide range of stakeholders creates a need for the anticipated data and information to be meaningful and applicable for all stakeholders in chronic disease self-management.

3.3 ICT FOR SYMPTOM MONITORING

ICT use within the health domain is varied and offers a number of benefits and pitfalls (Schiavo, 2007, Celler et al., 2003, Roehrer et al., 2013). Benefits such as improved health outcomes and quality of life, decrease in fiscal costs, connections of dispersed networks, non-traditional methods of treatment and means of information supply to various stakeholders have been identified. ICT may also act as an enabler within non-traditional methods of treatment for care-givers(Celler et al., 2003). The use of information systems within chronic disease management and treatment, in particular ICT, allows for an alternative means of information supply to individuals, families, health care practitioners and other stakeholders(Celler et al., 2003).

Recognising and identifying symptom patterns has long been associated with the prevention of chronic disease exacerbations (Warwick et al., 2010). There is a need to understand the factors that support symptom monitoring (Warwick et al., 2010). These are both internal factors (positive attitudes and confidence in capacity to manage) and external factors that include family support (Warwick et al., 2010). A number of authors (Mammes, 2004, Slater, 2005, Hidi and Harackiewicz, 2000) have identified that the interest may align with either the activity of health monitoring, the use of the technology on which the health monitoring takes place or an external interest that can tie health monitoring and technology together.

Higher levels of self-efficacy have been attributed to lower levels of ICT symptom monitoring tool use (van der Meer et al., 2007), providing evidence of the influence of internal factors that influence an individual's state of symptom monitoring (Warwick et al., 2010). Symptom monitoring is seen to be both beneficial, highlighting symptom change, and detrimental, bringing focus onto the condition (Johnston et al., 2009). The technologies used to support symptom monitoring contribute to barriers of ICT symptom monitoring tool use, as priority is placed on the availability of the technology in order to improve the accessibility (Peirce et al., 2011). Studies of ICT supported symptom monitoring have rarely made it past piloting, creating difficulties in sustainability (Peirce et al., 2011). This creates questions around the accuracy of requirements for ICT symptom monitoring tools and the role of symptom monitoring in the daily lives of those living with chronic disease.

A number of authors (Mammes, 2004, Slater, 2005, Hidi and Harackiewicz, 2000) have identified that the interest of symptom monitoring may align with either the activity of health monitoring, the use of the technology on which the health monitoring takes place or an external interest that can tie health monitoring and technology together. Warwick et al.

(2010) highlight a need to understand the factors that support symptom monitoring, going beyond assuming and speaking on behalf of different user groups. These include both internal factors such as, positive attitudes and confidence in capacity to manage, and external factors such as family support (Warwick et al., 2010). The adherence to treatment rests on a combination of beliefs and behaviours of both the parent and the child for young families (Williams et al., 2007). Family function and dysfunction have shown to influence adherence to CF treatment in the home setting for teenagers and their parents (Cepuch et al., 2012).

More recent literature has identified ICT self-management support programs to be beneficial for health behaviours and health outcomes (McDermott and While, 2013, Hardiker et al., 2013) however these are linked to clinical practice rather than individually driven systems. Individuals are providing symptom data electronically through the ICT tools or report to health care professionals on their data. The requirements for the ICT tools are developed on behalf of the individuals by the health care practitioners (Scandurra et al., 2008). Systems frequently experience a high level of attrition (Wangberg et al., 2008), potentially due to the lack of alignment with the individual's symptom monitoring requirements. The ICT tools are designed to assist those with chronic disease by improving confidence levels and self-management self-efficacy (Murray, 2012, Celler et al., 2003).

The high level of system attrition draws in the concern of system sustainability. Previous research has noted a tendency for the implementation of ICT tools to be largely approached from the technical perspective, with less regard for the people-related perspective (Juciute, 2009). Common causes of ICT project failure include the lack of clear links between the project and agreed measures of success, and lack of effective engagement with stakeholders (Juciute, 2009). Individual attitudes, alignment with current resources, and alignment with the actual problem are all important factors that must be considered when developing ICT symptom monitoring tools, in order to ensure the greatest chance of sustainability (Wootton et al., 2009, Wickramasinghe and Misra, 2008). A shift from the technical to the human and societal implications is required for relevant ICT symptom monitoring tool sustainability (Fuchs, 2008). This includes the integration of the foundations of chronic disease self-management.

The monitoring of symptom data by health care professionals contradicts the foundations self-management, aligning behaviours to a compliance model. Self-management requires the use of skills and knowledge that will enable a person to make independent judgements and take independent actions when managing their condition (Hibbard et al., 2010). ICT symptom monitoring tools that require reporting to health care professionals re-enforces the traditional relationships of care (see section 3.4.2) and lacks the partnership required to assist in the transition to demonstrating self-management 'knowledge' through independent behaviours. This is further expanded on in section 3.4.

3.3.1   ICT DEVELOPMENT

Corbett (1987), Gill (1991), Scarbrough & Corbett (1991) and Zuboff (1988) have all given claim that the traditional approach to Information Systems design has resulted in systems

that were associated with a high level of stress and low motivation amongst users. Additionally Gasson (2003) and Pang and Schauder (2007) describe the Information Systems design journey from the techno-centric design approaches that lead to the traditional 'waterfall' approach, focusing on the use of technologies to manage functional tasks by specific users to more user focused methods.

The success of an ICT development has traditionally been measured from an organisational context – usability, profitability, sustainability (Kujala and Väänänen-Vainio-Mattila, 2009) and this is attributed to the tendency to improve effectiveness and efficiencies. Harris et al (2009) has also identified user satisfaction, system outputs, data quality and perceived system design ownership as additional success factors. Harris et al (2009) conducted a review on the relationship between system success and users involvement, as a response to conflicting, earlier reviews. The review concluded that user involvement and user satisfaction have a strong relationship with the potential success of a system, yet the additional measures of system success must also be taken into account. Additionally, Harris (2009) makes the important distinction that while user satisfaction with a particular system may be high, when all success measures are taken into account the system is in fact, a failure.

As the development of ICT in health increasingly includes patient based systems, improvement in efficiencies and effectiveness is no longer sufficient. ICT development in health is required to balance the health system requirement for improved care, and to offer individuals the opportunity to take responsibility of their own health care (Pfeiffer, 2009, Brownsell et al., 2012). More recently, studies are focusing on the development of ICT tools that assist in personalising health care (Salvi et al., 2012) and frameworks for involving patients are not well developed, or used (Salvi et al., 2012). The move to patient centred care requires a move to the inclusion of individuals in ICT development (Brownsell et al., 2012, Kanstrup and Bertelsen, 2011).

USER CENTRED DESIGN

User Centred Design (UCD) may assist with the complication of defining the individual user and their requirements in eHealth projects. The concept of UCD was first developed in 1986 and stresses the importance of ensuring that systems development occurred through an improved understanding of the user's system requirements (Gulliksen et al., 2003). Through focusing on the user, and their requirements, an iterative development cycle is encouraged and prototypes are continuously refined after review by the users (Massanari, 2010). Criticisms of UCD include that users don't actually defined the problem rather they describe desired features and solutions (Tidwell, 2006). The length of time required involving users in the design and development process is also seen as a drain of resources (Massanari, 2010). A response to these criticisms is that without allocating additional time and resource to understand the user, the requirements of patient based eHealth projects may be based on assumptions, with the resulting systems meeting health system needs but not the patient needs (Cummings and Turner, 2010). For health system eHealth projects UCD is not a new concept. Despite this, the use of UCD with the use of patient groups is still in it's infancy (Searl et al., 2010).

For the majority of eHealth projects, the concept of a user centred approach does not involve all of the stakeholders until the final phase of the system development lifecycle (Powell and Armstrong, 2009). This is partially apparent for eHealth project that include patients as a beneficiary or end user (Cummings and Turner, 2010). Additionally, the use of the term 'user' may contain an implicit assumption that the developed system is required to be used by a participant, in order for them to be considered for involvement in the eHealth project development. For some systems, the use or non-use may be irrelevant – the mere existence of the system may be of benefit. Perhaps it is time to widen the scope by the removal of the term 'user' and replacing with a more generalisable term.

3.3.2   ICT EVALUATION

Evaluation is the act of assessing the properties of an information system, in any stage of the systems development life cycle (SDLC), in order to assist with decision-making (Ammenwerth et al., 2004). Evaluation of ICT is conducted with varying approaches and methodologies, each addressing their own criteria (Lagsten and Karlsson, 2006). Alkin and Christie (2004) organise the field of evaluation into three areas of use, methods and values. Use based evaluation is focused on designing evaluations that will assist stakeholders in program decision-making (Alkin and Christie, 2004). King and Stevahn (2012) hold a participatory view on use based evaluation, in order to increase the applicability of the system for the end users. The authors acknowledge that involving stakeholders has the potential to improve the utilisation of a system however you cannot force people to participate in the evaluation process. Evaluation based in methods is focused on the construction of new knowledge and how evaluation can be undertaken so that the results are a true reflection of the evaluation process (Alkin and Christie, 2004). Until recently, experimental design was linked with rigorous evaluation outcomes and was the gold standard to which other methods were judged (Alkin and Christie, 2004). Methods based evaluation rarely includes stakeholders in developing the questions and criteria for assessment (Alkin and Christie, 2004). Value based evaluation is concerned with the judgements evaluators place on their findings, leading to the where the outcomes of evaluation should be focused (Alkin and Christie, 2004). Evaluation based in values extends from the provision of information to decision-makers, to the evaluators creating judgement on the data they are presenting, along with recommendations (Alkin and Christie, 2004). It is the evaluators responsibility to represent the multiple perspectives held by different stakeholders (Alkin and Christie, 2004). Michael Scriven, a leading author in this area of evaluation (Alkin and Christie, 2004) emphasises that it is not necessary to understand why a program works to determine the value, and therefore research is this area is not restricted to experimental design (Scriven, 1991). This goes against the current trend in evaluation through metrics.

System usability, system performance, tool effectiveness, cost-benefit, and user satisfaction are just some of the methods by how a project is evaluated (Ammenwerth et al., 2003, Rahimi and Vimarlund, 2007). These methods all require interaction with the ICT, and for some evaluations, low or no interaction with the ICT tool is an indicator that the project may have failed (Eng, 2002). The use of the randomised controlled trials (RCT) as the 'gold standard' of medical interventions (Currie, 2005) have been criticised as they miss the more

nuanced qualitative aspects of the evaluation. Cummings (2008) illustrate where RCT results showed no apparent benefit from the ICT intervention yet the qualitative analysis highlighted non-quantifiable benefits received by the RCT participants. Catwell and Sheikh (2009) observed the lack of contextual considerations in eHealth evaluations through the use of RCT. Evidence exists that the evaluation of eHealth needs to move from web logs and testimonials of benefits (Gustafson and Wyatt, 2004) to include qualitative evaluation approaches (Cummings et al., 2010).

EVALUATION OF EHEALTH SYSTEMS

Throughout the literature and this chapter, the potential benefits of eHealth to patients, practitioners, families and surrounding professions have been presented for discussion (Murray et al., 2005, Celler et al., 2003, Schiavo, 2007). Ahern (2007) agrees with the purported benefits yet acknowledges the many challenges associated with the implementation and evaluation of eHealth. Ahern additionally acknowledges there is a need for more qualitative research in order to understand the various requirements of stakeholders for eHealth (Ahern, 2007, Bath, 2008). While the call for qualitative research is promising, and will enable each stakeholder to register their subjective viewpoint on the issues, the traditional domain of the medical sciences is quantitative in nature (Cummings and Turner, 2010, Currie, 2005). By nature, quantitative research places random controlled trials as the gold standard of objectivity and rigour (Ahern, 2007) yet Eysenbach (2002) discusses the challenges in achieving a rigorous random controlled trial. Others have seemly dismissed qualitative research due to the perceived impact of group dynamics, interactions and research involvement may have on the results (Timmermans and Berg, 2003). The answer lies in the complementing of both quantitative and qualitative research to explore and evaluate eHealth. Qualitative evaluation captures the complexity of the socially constructed relationship individuals have with eHealth, and the benefits that are not easily quantifiable (Robertson et al., 2010, Greenhalgh and Russell, 2010). More recently, the inability of ICT to provide the anticipated value, and the need to capture the complex processes of ICT interaction, is attributed to a call for more qualitative evaluations (Hedman and Borell, 2012). Evaluation, in the context of this research, is the process of understanding how a system meets the requirements of the people interacting with the system and how the system is incorporated into daily lives.

Summative evaluation occurs at the end of the implementation and determines how the system meets the agreed performance criteria (Rigby, 2006). The evaluation focuses on the outcomes and results on the information system (Goodman, 1998). This type of evaluation typically uses quantitative measures that provide tangible outcomes however they are unable to capture data that may benefit research in the process of system implementation (Rigby, 2006). A large number of studies focus on summative evaluation (Yusof et al., 2008), with several presented below.

Formative evaluation occurs during the development process and continues as the system is developed and implemented (Rigby, 2006). The evaluation focuses on the development of the information system and the processes of development (Goodman, 1998). Formative evaluation enables continuous and early evaluation however the evaluation criteria are

continuously adjusted and this creates difficulties for evaluation research (Rigby, 2006). Evaluation is focused on the many perspectives of the different stakeholders and involves iterative, user-focused assessment (Kanstrup and Bertelsen, 2011, Kushniruk and Turner, 2011, Kushniruk et al., 2008). There is a call for greater utilisation of formative ICT evaluation (Irani and Love, 2013, Ammenwerth et al., 2003, Gomez and Pather, 2012) to respond to the increasing dynamic nature of ICT development (Kusunoki and Sarcevic, 2013).

The use of formative evaluation is time and task intensive, and can require greater stakeholder involvement in the development process. The outcomes of a system developed with formative evaluation may be considered 'user-centred' however there are difficulties in accessing the appropriate stakeholders, at the right time, in an eHealth environment. The trade off in abandoning formative evaluation is ironically, stakeholder focused. Without formative evaluation, system issues may be missed that result in stakeholder requirement mismatch and increased spending during development (Kusunoki and Sarcevic, 2013). The information requirements for the different stakeholders in eHealth ICT developments are different, depending on their role (health care professional or health care consumer) and if they are a carer or a person with the health need. Chronic diseases that span from childhood to adulthood are a prime example of the different information needs and flows between the healthcare professional, the parent, and the child (Conway, 1998, Gjengedal et al., 2003, Hafetz, 2010, Lowton, 2002, Masterson et al., 2011, Williams et al., 2007). User centred design emphasises usability with methods such as task analysis, prototyping, and usability evaluations. The goal of user centred design is the development of usable systems (Kujala, 2003) as tailored information is more likely to be perceived to be relevant than non-tailored information (Ahern, 2007).

Formative evaluation is typically user focused and includes participatory design (PD), human computer interaction (HCI), and useability studies (Kusunoki and Sarcevic, 2013, Ahern, 2007, Harris and Weistroffer, 2009, Kushniruk and Turner, 2011, Kushniruk et al., 2008, Kanstrup and Bertelsen, 2011).

PD emphasizes democratic participation through workshops or prototyping. It is of Scandinavian origin where designers and workers have collaborated on understanding users and their tasks when planning and designing (Harris and Weistroffer, 2009). Future users are directly involved in the design process and often takes place through mutual learning (Simonsen, 2010). Users are equal partners in the design process (Waller et al., 2006). The inclusion of users within the PD processes places emphasis on accurate requirements, in order to prevent systems developed that are not appropriate for the users (Høstgaard et al., 2011, Kusunoki and Sarcevic, 2013).

HCI is concerned with designing, developing and implementing interactive computer systems (Sears and Jacko, 2008). It often includes simulation and usability methods to reduce the number of technology induced errors and improve the fit of the system to the users requirements (Kushniruk et al., 2008, Kushniruk et al., 2005). Frequent user evaluation occurs at every stage of the design process, reflecting the flexible developmental lifecycle of HCI approaches (Waller et al., 2006).

Useability is a measure of how efficient, effective and enjoyable a system is to use (Preece et al., 2002). For eHealth systems this is of particular importance due to the many stakeholders involved and the nature of the supported decision-making. Throughout formative evaluation, the focused is placed on the user and the needs of the user. As the system develops, the user's needs may alter due to changes in process or protocols. There is a flexibility to react to these changes when following formative evaluation however eHealth has the added complexity of multiple user perspectives (Petersen et al., 2010).

THEORIES ALIGNED TO THE EVALUATION OF EHEALTH SYSTEMS

"Normalisation Process Theory is concerned with the social organisation of the work (implementation, of making practices routine elements of everyday life (embedding), and of sustaining embedded practices in their social contexts (integration)." (May and Finch, 2009, p538)

Normalisation Process Theory is concerned with what is required for individuals to implement the new practice or technology into a routine and is used to assist with eHealth implementations (Murray, 2012, May and Finch, 2009). Developed during the period of 1998 to 2008, Normalisation Process Theory has a brief history of application to eHealth implementations yet the focus of these previous applications appear to be at a organisational level, for the implementation of health informatics supporting clinical work (Mair et al., 2008, Murray et al., 2011). Regardless of this, Normalisation Process Theory is founded in sociology and does not appear to be limited in its intended application (May and Finch, 2009). Normalisation Process Theory organises the implementation of work into four components; coherence, cognitive participation, collective action, and reflexive monitoring (May and Finch, 2009). Coherence is sense making work, Cognitive participant is reflective work, Collective Action is operational work, and reflective monitoring is appraisal work (May and Finch, 2009). The theory is not in a particular sequential order and is considered an action theory, it explains what people do rather than what are people's attitude or what they believe when in action (May et al., 2009). Normalisation Process Theory does not require the application of all four components in order to implement a new practice (May et al., 2010).

Normalisation Process Theory was developed when seemingly successful telemedicine systems failed to become widely adapted and used, despite widespread user support (May et al., 2009). The strength of Normalisation Process Theory is that is assists in understanding why some processes lead to an embedded practice and others do not (May and Finch, 2009). In using Normalisation Process Theory the focus in on what people actually do when approached with technology implementation (May et al., 2009).

Figure 3.2 represents the four components of Normalisation Process Theory, adapted from May and Finch (2000).

Coherence (sense making work)	Cognitive Participation (relational work)
▪ Differentiation ▪ Individual Specification ▪ Communal ▪ Specification Internalisation Investments: *Meaning*	▪ Initiation ▪ Legitimation ▪ Enrolment ▪ Activation Investments: *Commitment*
Collective Action (operational work)	**Reflective Monitoring (appraisal work)**
▪ Interactional Workability ▪ Relational Integration ▪ Contextual Integration ▪ Skill Set Workability Investments: *Effort*	▪ Systematisation ▪ Individual Appraisal ▪ Communal Appraisal ▪ Reconfiguration Investments: *Comprehension*

Figure 3-2 Components of Normalisation Process Theory

Several theories have been drawn upon in the creation of the Stages of Use framework. Chiu and Eysenbach (2010) draw upon several theories to model a 'Stages of Use' framework that assists to explore the adoption of ICT in chronic disease care and the associated factors influencing that adoption and interaction behaviour. The Stages of Use framework revealed a number of factors that impact on usage behaviour and attrition yet the authors caution that a limitation of their study was that not every possible factor that could be an influence on each stage was discovered in their exploratory research (Chiu and Eysenbach, 2010).

The application of an organisational-based theory, such at Normalisation Process Theory, provides an additional lens to the evaluation of eHealth systems. The role of such theories is to expand on the current frameworks for evaluating eHealth systems and can potentially identify where existing theories are limited in their application. Exploring the adoption of ICT in chronic disease care through the Stages of Use framework aligns with Normalisation Process Theory however a limitation of the Stages of Use framework is that adoption is linked with the use and non-use is regarded as system attrition (Chiu and Eysenbach, 2010).

Applying Normalisation Process Theory to the evaluation of eHealth systems has the potential to highlight the needs based interaction of those living with a chronic disease, such as CF. This is due to the periods of stable symptoms where symptom monitoring and condition management are background activities.

3.3.3   <u>DEFINING THE USER</u>

Health consumers, including patients, are not easily identified as stakeholders in eHealth projects and there appears to be a larger focus on health care practitioners, health administrations and designers of ICT for health projects (van Gemert-Pijnen et al., 2011, Kushniruk and Turner, 2011). The difficulty increases when ICT is developed for individuals to use independently with no mandatory clinical reporting. The literature appears to demonstrate very little evidence of such projects being undertaken and evaluated (Cox et al., 2012, Nijland et al., 2008, Gaikwad and Warren, 2009, Solomon, 2008, Bolton et al., 2011). More recent studies on symptom monitoring for individuals with CF and chronic obstructive pulmonary disease (COPD) appear to have reduced the automatic reporting however the symptoms entered into the online diaries were still remotely accessed by health professionals acting as mentors (Cummings et al., 2010, Lindberg et al., 2013).

Within the Information Systems and Health Informatics literature there is ongoing discussion of ICT providing means to connect, educate and enable a greater spread of health service delivery. These discussions are typically approached from the point of view of one stakeholder group – i.e., health professionals, health service recipients, organisations etc. Within each of these discussions, not all of the stakeholders are given a firsthand representation, or are in fact identified clearly at all (Kushniruk and Turner, 2011). This highlights a need to focus on the individual stakeholders in order to initially define the user or users and then use this definition to create an accurate representation of the user needs and potential of involvement within the systems development process. Participants in eHealth projects can have multiple roles, that is they can be general health care consumers or patients with a specific condition relating to the project target group. This results in further complication of how the individual user is defined.

There are claims to include health care consumers, and in particular, patients within the stakeholder groups of eHealth, and that patients as users have unique perspectives to add to the potential improvement of eHealth (Ahern et al., 2006). Though this inclusion is stated in theory, the author's do not transfer to practice when opinions are sought on the future of eHealth and eHealth research (Ahern et al., 2006). While all patients may not have the knowledge base to participate in such an interview, the claim that all stakeholder groups were able to offer an opinion is a falsehood in this case. The irony is that patients are referred to as users in the previous section of the paper (Ahern et al., 2006).

3.3.4   <u>THE DIGITAL DIVIDE</u>

While the benefits of eHealth are numerous and may hold the potential for enhanced health care delivery and interaction (Nijland et al., 2008), those who cannot or will not access the internet are still at a disadvantage. If anything the gap between the 'have's' and 'don't have's' has the potential to increase further. The 'digital divide' is the subject of wide ranging research, with multiple definitions and impact levels (Eysenbach, 2000, Bath, 2008). At the simplest level, the digital divide is the unequal spread of Internet availability, access and use between different socio-demographic groups (Willis and Tranter, 2006).

Internet availability does not always result in hassle free access (Wyatt et al., 2005, Dewan and Riggins, 2005). Up until 2005 Tasmania had the lowest percentage of Internet use, but between 2005 – 2007 this had grown from 49% to 70%, which is the greatest increase in Australia (Australian Bureau of Statistics, 2011a).

In addition to the digital divide, not all patients are interested in managing their own health (Asimakopoulou et al., 2012). This is problematic when health care providers and ICT professionals make the assumption that the patients will buy into eHealth. Not only is there a mismatch in the patient user needs to eHealth, but the change management practices to ensure the patient utilises eHealth may not be effective.

3.3.5 ICT SYMPTOM FEEDBACK

The traditional use of the traffic light system is to use green feedback indicators as normal or improved systems, orange feedback indicators as slight drop in systems and red indicators as significant decline (Rothe, 1997, Steurer-Stey et al., 2010, Taylor et al., 2009, Cummings et al., 2009). Simply put, green is normal, orange is caution and red is stop! In project management, the red, amber, green method is used to indicate project risk and time line tracking (Harper-Smith and Derry, 2012). Green is indicative of useful activity that is on track, orange (amber) is indicative of concerns and risks that should be monitored closely and red is indicative of major concerns where corrective action should be taken immediately.

Davis et al. (2007) utilised a traffic light report in conjunction with a 5 point grading system. The use of the green feedback indicator was for symptoms improvement. The use of the orange feedback indicator was to indicate a 1-point worsening symptom. A returned red indicator meant that symptoms were 2 or more points worse. In using either a 5 point grading system or a traffic light system, there is a consistency for symptom feedback.

As shown in section 3.3 identifying and responding to symptom patterns is associated with the prevention of chronic disease exacerbations. There is a high level of system attrition associated with the use of ICT symptom monitoring tools (see section 3.3.), questioning the fit of the ICT symptom monitoring tool to the needs of those who the system is aimed. The linking of these ICT tools to health care professionals for monitoring is illustrative of a compliance model of care, and this conflicts with the foundations of self–management (see section 3.4).

Formative, user focused evaluation ensures on-going development to meet the participant's requirements. In this research, the participants had no input to the system that was developed for their individual use, with the requirements determined by the specialised CF health care professionals, on behalf of the participants (see section 2.3). In the care of CF, the specialised CF health care professionals have close contact with the patients and their families, potentially allowing for an increased understanding of their patients requirements for an ICT symptom monitoring tool that traditionally would be possible. Additionally, Internet access is required for ICT symptom monitoring, and this can be difficult when dealing with a chronic disease such as CF (see section 3.5.3).

3.4 SELF-MANAGEMENT

Barlow, Wright et al (2002) have characterised self-management as the ability to deal with chronic illness symptoms and treatment and additionally to be able to adjust to the lifestyle challenges and social consequences connected with that chronic illness. Similarly, Gruman and Von Korff define self-management as;

> "engaging in activities that protect and promote health, monitoring and managing symptoms and signs of illness, managing the impacts of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes" (Gruman and Von Korff, 1996), p1.

Gruman and Von Korff (1996) provide a definition that describes the planning, management and prevention of illness however self-management is a dynamic process that enables individuals to be in a partnership of their own health care, and creates an acceptable balance between their condition responsibilities and their life activities (Cameron-Tucker, 2008). Self-management is not performed in isolation, the condition does not define the individual and their life should not be framed by their condition. In their exploration of self-management education and behaviour programs, Cameron-Tucker (2008) developed the following comprehensive definition:

> "Self-management is a dynamic process incorporating an individual's capability and confidence to be self-reliant in undertaking responsibilities and engaging in activities, such as adopting health-related behaviours, in a self-tailoring context to deal with the impact of living with a chronic condition on all aspects of their life: a sense of self and medical, emotional and social domains. In order to retain an acceptable and meaningful quality of life, such management involves the capability to undertake core tasks or responsibilities." (Cameron-Tucker, 2008), p365.

Once an individual demonstrates self-management behaviours, self monitoring can allow for self-adjusting in order to achieve an acceptable quality of life (Coleman and Newton, 2005). Once self-management becomes a learned behaviour, the potential for an individual's level of self-efficacy increases, potentially creating a rise in confidence and problem solving levels (Lorig et al., 2006, Newman et al., 2004, Bodenheimer et al., 2002). Lorig and Holman (2003) make the distinction that every individual self manages, one cannot simply decide not to manage their condition as that in itself is a management decision. There appears to be a conflict in Lorig and Holman (2003) observation as that every decision can therefore be allocated as self-management, however self-management is a deliberate and dynamic process. Self-management cannot be simplified to the simple choice of managing or not managing one's condition. Such decisions would form the foundation for developing self-management 'knowledge'. Self-management 'knowledge' has the tendency to be measured in the ability to demonstrate condition education and improvement in health outcomes (Norris et al., 2001, Eland-de Kok et al., 2011), and the effectiveness of ICT tools supporting the development of self-management 'knowledge' is judged on this two dimensional definition (Norris et al., 2001, Gallant, 2003).

Self-management behaviours, whilst giving similar health outcomes for many within a similar chronic disease group, should still be as individualised as each different person in order to remain beneficial to each different individual (Muir Gray, 2004). Individualised care however, has the potential to increase health costs on the health system and individuals, an outcome that neither party will benefit from (Linden et al., 2010). The role of ICT in addressing this gap has evolved to that of providing a platform enabling mentoring and health care practitioner interaction in addition to the traditional face to face delivery (Celler et al., 2003, Newman et al., 2004). ICT has the potential of increasing exposure to educational information of the chronic condition, and depending on the functionality of the platform, increasing awareness of symptoms, moving from reactive to proactive participation in treatment. This moves the platform from an educational source to a tool that can promote self-management education (Bodenheimer et al., 2002).

The integration of ICT tools into chronic disease self-management takes advantage of the increasing accessibility and cost-effectiveness of the Internet, and the increasing exposure individuals have with technology (Murray, 2012). These very same benefits are also challenges for the integration of self-management with ICT as Internet access is still subject to the digital divide (Murray, 2012, Lorig et al., 2013). The continued development of ICT tools for chronic disease self-management using health care professional requirements (Scandurra et al., 2008) challenges the foundations of self-management that requires partnership and independent decision making. The empowerment of patients for self-management is additionally proving to be problematic, as both the patients and the health care systems struggle with the move to patient centred care (Asimakopoulou et al., 2012, Hibbard et al., 2010).

3.4.1 HEALTH INFORMATION SEEKING BEHAVIOUR

Weaver et al. (2010) identify health information seeking behaviour as a number of factors that may predict an individual is more inclined to seek and build upon information about a diagnosis. A recent diagnosis of a chronic illness is a main contributor for health seeking behaviour and is supported by other authors attempting to understand the incentives in seeking out health related behaviour through social circles, formal networks and the Internet (Rice, 2006).

The role of ICT in health seeking behaviour is dependent on the individual's current technology use. If the individual does not typically use the Internet to search for health information then they more likely to seek condition information in a face to face or written format (Miller and Bell, 2012). The development of ICTs for chronic disease support is based on the assumption that individuals use technology and view it as a trusted source of health information. Health information is sought out via trusted sources, and the development of ICTs that support health seeking behaviour are required to be perceived as a trusted information source (Khoo et al., 2008).

The Internet is a valuable tool in accessing and distributing health related information (Lee et al., 2010). It is important to note that health seeking behaviour leads to accessing information, which can then be turned to knowledge. One does not stumble upon

knowledge on the Internet, regardless of the tendency to use information and knowledge interchangeably (Lee et al., 2010, Davenport and Pruzak, 2000). Health seeking behaviour is simply the first step of developing self-management 'knowledge'.

3.4.2   PARTNERSHIP IN HEALTH CARE

Health care delivery is moving towards a health care practitioner-patient partnership, particularly in the area of chronic disease management (Kaplan and Harris-Salamone, 2009, Aarts et al., 2004). This partnership in health has been seen to be a part of the 'patients at the centre' movement – driven in part by the WHO highlighting the need to involve patients in their own treatment (Bødker et al., 2004, Heeks, 2006). Whilst the concept of shared health care decision-making is not new, it has become a point of policy in many countries (Kaplan and Harris-Salamone, 2009).

The table below is adapted from Joosten et al (2004) and illustrates the differences between the traditional model of health care delivery, the extreme of the informed medical model and the middle ground of shared decision making. This middle ground represents the partnership in health approach.

Table 3-1 Models of health care delivery

	Paternalistic model ('traditional medical model')	Shared decision-making	'Informed medical model'
Role of the health care practitioner	Completely Active – Reports only selected information to the patient, after choosing what the health care practitioner views as best for the patient.	Active – reports all information and potential treatment to the patient. The choice of therapy to be used is decided with the patient.	Completely Passive – Reports all information and potential treatment to the patient. Does not make any recommendations or decisions on the choice of therapy.
Role of the patient	Completely Passive – Accepts the health care practitioner's plan and obliges with all requests.	Active – From the information given the patient forms their own opinions on the treatment options. This is discussed with the health care practitioner and a treatment plan is formed together.	Completely Active – From the information given the patients forms their own opinions, with no input from the health care practitioner. The patients decide on the choice of therapy by themselves.
Information flow	One way Health care practitioner to patient	Two way Health care practitioner and patient	One way Health care practitioner to patient
Decision Making	Health care practitioner based	Health care practitioner and patient, in conjunction with other necessary individuals.	Patient based
'The final say'	Health care practitioner	Health care practitioner and patient	Patient

Table adapted from Joosten et al, 2008. pp220.

Studies have shown that through a partnership, or shared decision making, approach in health care leads to an improvement in patient satisfaction, treatment adherence, depression, level of knowledge and long term health planning (Aarts et al., 2004). The authors of a systematic review carried out in 2008 make the comment that;

> " SDM (shared decision making) has been proposed as an important advance in modern clinical practice, and clinicians have been urged to adopt it in order to foster relationships with their patients that are more appropriate to the modern age." Joosten el al, 2008. p 224

The dilemma in the move towards participation in a partnership for health care delivery is that terms such as 'participation' and 'involvement' are often used to describe the roles of the patient and health care practitioner. Many models and definition of 'patient involvement' and 'patient participation' have been developed – some of these with very different perspectives on the true meaning of these terms (Kaplan and Harris-Salamone, 2009). Guadagnoli and Ward (2009) suggest that;

> "…participation should be defined by whatever level the patient is most comfortable with." p 337

Thompson (2009) additionally discusses that patient's do support greater involvement in decision making, yet also require the health care practitioners to understand the involvement should be optional, and the requirement for involvement may change with context and the passing of time. This could be seen as an illustration of potential complications in the successful delivery of a health care practitioner-patient partnered health care as the roles of both the patient and health care practitioner are constantly evolving. Ingadottir and Jonsdottir (2010) propose that the essential component in a successful partnership of health care delivery is dialogue and the use of this dialogue may enhance the presence of trust and the ability to be responsive to the changing patient needs in a chronic disease setting.

The need for a responsive and partnered approach to CF treatment in Tasmania is not unheard of in a chronic disease setting yet the added difficultly of geographical disbursement and increasing adult populations means health care practitioners may need to look beyond the traditional methods of health care delivery.

As shown in section 3.4 self-management is a dynamic process that includes a partnership with the individual's health care professional, moving away from the traditional, or compliance, model of care. Self-management includes accessing condition and treatment information, understanding the information, and utilising the information to create and change behaviours. Health seeking behaviour is indicative of developing self-management 'knowledge', and in conjunction with a partnership with their health care professional, individuals can effectively use ICT tools developed for self-management. The use of ICT tools for symptom monitoring has the potential to overcome some of the barriers to traditional methods of care, as shown in section 3.4.2.

3.5 CYSTIC FIBROSIS, ATTITUDES AND LIFE

CF is one of the most common life threatening genetic diseases (Marciel et al., 2010). It affects the respiratory and gastrointestinal tracts through the faulty transport of salt that causes thick mucus build up (Cystic Fibrosis Foundation, 2005, Bell et al., 2011, Wahl et al., 2005). CF was first identified as a specific condition by Dorothy in 1938 (Talmon et al., 2009). Symptoms of CF can include a persistent cough, frequent chest infections, abnormal bowel motions and poor weight gain (Talmon et al., 2009). CF can additionally affect the pancreas, the digestive system, the liver disease, the skeletal system, and the reproductive system in males (Talmon et al., 2009). Historically, individuals diagnosed with CF survived to early childhood or teenage years (Talmon et al., 2009).

CF was once primarily a paediatric disease. Due to medical research and improved treatment techniques this is no longer the case (Kulich et al., 2003). Children born with CF can now expect to live into their 40s or longer (Bell et al., 2011), with some predicted to reach their 50s (Webb et al., 2001). The latest estimation of the average life span for those with CF has increased from 12.2 years in 1979 to 27.9 years in 2005 for males, and from 14.8 years to 25.3 years for females (Reid et al., 2011). With the increasing life expectancy the number of people transitioning from paediatric to adult care is also increasing. Communication between the paediatric and adult care centres is of vital importance to improve the transition of care from the paediatric team to the adult team (Rapley and Davidson, 2009). Dependency on the health care system is also found to increase as those with CF reach adulthood with an increase in condition complications (Bell et al., 2011).

A factor which has contributed to the increased life expectancy of CF individuals is the existence of dedicated CF specific multi-disciplinary teams (Cummings and Turner, 2010). Specialised CF centres are to be established when 50 adult cases are present within a treatment area (WHO, 1999). Tasmania's number of CF adult cases reached 50 in 2006. A collaborative approach was adopted to determine the best way to provide multi-disciplinary adult care. In 2006 a dedicated CF clinic with outreach services was established. The clinic is based in Hobart with outreach centres in Launceston and Burnie. The clinic offers paediatric and adult specialised CF care.

3.5.1 <u>CYSTIC FIBROSIS - A TASMANIAN CONTEXT</u>

Tasmania has a high birth rate of CF of 1:1,600, compared with that of the Australian mainland (approximately 1:2500) (Bradbury et al., 2008). In Tasmania approximately 45% of individuals living with CF are adults (18 years and over). The population of Tasmania is geographically dispersed. This creates logistical challenges for some CF families in accessing specialised services and leads to a reactive approach to care, rather than a proactive, preventative approach (Wagner et al., 2001). Avoiding the cross of bacteria further complicates regular contact between families. The minimal contact between different families prevents the development of a supportive network (Bradbury et al., 2008).

3.5.2 <u>DELIVERY OF CYSTIC FIBROSIS CARE</u>

Before 2006, general paediatricians or adult respiratory physicians at one of the three regional hospitals managed individuals with CF, with additional paediatric services to the North and Northwest provided on a six monthly basis by an outreach team from the Royal Children's Hospital in Melbourne (Bradbury et al., 2008). Since 2006 a paediatric outreach clinic has been operating.

The challenge presented to individuals with CF in Tasmania is that even with an adult centralised CF Unit operating in the state, the geographical spread of the CF population can make it difficult for all to participate in regular, physical visits. Additionally, as CF emerges from its once paediatric domain, individuals are faced with a lack of self-management behaviours, and low levels of self-efficacy for their self-management of CF.

Participants under the age of 18 visit clinic appointments with their parent or guardian, with the parent acting as the condition manager. As the child ages, the parent and child may share some condition management responsibility however the parent still oversees the child's treatment. The parent role moves from completely managing the child's treatment, to eventual non-involvement once they have reached adulthood.

During stable symptom periods, clinic appointments are usually three to six months apart. A multidisciplinary team of health care practitioners that include a clinician, a CF nurse, a dietician, a physical therapist and a social worker meet with individuals and their families during these clinic visits.

3.5.3   IMPACT OF CYSTIC FIBROSIS ON INDIVIDUAL AND FAMILY

As the diagnosis of CF commonly occurs during childhood (Gjengedal et al., 2003) family involvement forms a large part of early condition management. Intensive daily condition management is undertaken by the parents of young children, who are also processing the new information about their child's diagnosis and future health needs (Gjengedal et al., 2003). The management of CF includes balancing daily medication, treatment, and management regimens. Medication has to be taken daily, some with different food types, treatment includes daily physio to assist with breathing and airway clearance, and people living with CF need to find a balance between avoiding what makes them ill and participating in activities they find enjoyment in. Parents hold the responsibility of condition management until adolescence, where the child is exposed to greater levels of responsibility (Cepuch et al., 2012, Webb et al., 2001, Zindani et al., 2006).

The transition of care can be a challenging period, as the adolescent deals with their need for autonomy (Fiese and Everhart, 2006). The time of care transition needs to be considered from not only the individual perspective, but also the family perspective (Towns and Bell, 2011). The influence of the family as a support base during the time of transition is mixed, providing assistance to the individual (who may not wish it) and causing concern to the parents, who are worried over their child's role in condition management (Tuchman et al., 2008).

The impact of CF extends to the entire family, parents and siblings, with the potential for family functioning to be adversely affected (Herzer et al., 2010). The two areas highlighted to be at greatest risk is communication and involvement with other family members (Herzer et al., 2010).

As shown in section 3.5 CF is no longer a paediatric chronic disease, individuals born with CF can live into their fifth decade. Tasmania has the second highest incidence of CF in the world, and the care of CF includes overcoming the logistical challenges across the geographically dispersed state. The delivery of CF health care is provided through clinics (usually planned for every three months), with the individuals and their families undertaking treatment between clinic appointments (see section 3.5.2). The multidisciplinary care of children with CF usually includes considerable parental involvement. Section 3.5.3 highlighted how the impact of CF affects the entire family, regardless of the age of the individual. The parents of children undertake symptom monitoring and this transitions, with

varying success, to the individual as they reach teenage years. ICT symptom monitoring tools for CF therefore needs to be applicable to individuals with CF, and their parents.

3.6 CHAPTER SUMMARY

This chapter has provided a review of selected literature in the three key domain areas of ICT for symptom monitoring, self-management, and people with CF, their attitudes surrounding CF and their lifestyle.

The chapter commences by providing a background to the research area. The management of chronic disease requires constant review and monitoring, increasing the demands of the health care system. ICT has been introduced to chronic disease self-management as a means to assist both patients and care providers, however most systems require the patients to link into the health care system. A lack of availability of ICT for individual monitoring of chronic diseases is evident, and the wide range of stakeholders creates a need for the anticipated data and information to be relevant for all stakeholders in chronic disease self-management.

The literature indicates that identifying and responding to symptom patterns is associated with the prevention of chronic disease exacerbations, and can be clinic or individually based. There is a high level of system attrition associated with the use of ICT symptom monitoring tools and this questions the fit of ICT symptom monitoring tools to the needs of those who interact with the system. The linking of these ICT tools to health care professionals for monitoring is illustrative of a compliance model of care, and this conflicts with the foundations of self–management.

The evaluation of ICT can is both summative and formative, and includes a variety of methods and philosophies. Formative, user focused evaluation ensures on-going development to meet the participants requirements. The development of ICT tools for symptom monitoring has the potential to address health care system and individual needs however such tools require Internet access.

This chapter has shown that self-management is a dynamic process that includes a partnership with the individual's health care professional. Self-management knowledge includes accessing condition and treatment information, understanding the information, and utilising the information to create and change behaviours. Health seeking behaviour is indicative of developing self-management knowledge, and in conjunction with a partnership with their health care professional, individuals can effectively use ICT tools developed for self-management.

Finally, the literature has illustrated that CF is no longer a paediatric chronic disease. Tasmania has the second highest incidence of CF in the world, and the care of CF includes overcoming the logistical challenges across the geographically dispersed island state. The delivery of CF health care is provided through three monthly clinics, and individuals and their families manage treatment and medication between clinic appointments. The multidisciplinary care of children with CF usually includes considerable parental involvement. The impact of CF affects the entire family, regardless of the age of the

individual. The parents of children undertake symptom monitoring and this transitions, with varying success, to the individual as they reach teenage years. ICT symptom monitoring tools for CF therefore needs to be applicable to individuals with CF, and their parents.

This chapter identified the current challenges present in the core literature of ICT for symptom monitoring, self-management and people with CF, their attitudes and their lifestyle. As identified in section 1.3, this research addressed the following issues:

- The lack of individually monitored online symptom monitoring tools for chronic disease symptom monitoring and self-management
- The increasing trend of ICT tools developed for chronic disease symptom monitoring and self-management
- The different needs of a range of people involved in the care of people with CF
- The increasing need for more qualitative evaluation to understand the attrition and benefit of ICT tools.

The core literature has provided guidance on the concepts that were required as a part of the research design for data collection. Section 3.2.2 highlighted a need to ensure the usability of ICT tools developed for chronic disease symptom monitoring and self-management complement a person's confidence levels in managing their condition. The use of usability (see section 3.3.2) concepts as a discussion topic for the semi-structured interviews in the first two research stages (see section 4.5.2) enabled the researcher to explore what the participant expectations, requirements and barriers to use were in the myCF pilot implementation.

Section 3.2.2 illustrated a requirement for ICT tools to be designed with the health consumer in mind. Section 3.3 expanded on this by describing the complexity of identifying and involving all stakeholders, and for the tendency for ICT tools developed for chronic disease symptom monitoring and self-management to be automatically linked to the health care system. The use of Participant Centred Design (see section 3.3.1) concepts as a discussion topic for the semi-structured interviews in the first two research stages (see section 4.5.2) created a participant definition for the myCF pilot implementation and explored the perceptions participants had with the required level of involvement in the design and implementation of the myCF pilot implementation.

Section 3.2.2 introduced the wide range of stakeholders in ICT tools developed for chronic disease symptom monitoring and self-management and illustrated the need for anticipated ICT tools to contain meaningful and applicable for stakeholders that will interact with the ICT tool. Additionally, the evaluation of such tools (see section 3.3.2) lacks the qualitative application to separate periods of non-use and complete ICT tool attrition. The use of sustainability (see section 3.3) concepts as a discussion topic for the semi-structured interviews in the first two research stages (see section 4.5.2) enabled the researcher to explore the acceptance of the myCF pilot implementation and participant perceptions of future use.

Section 3.5 highlighted that the management of CF can be both an individual and family activity and there are various influences to the successful management of CF, in particular

family communication and involvement. The increasing life span of people with CF places additional pressure on the health care system and people living with CF are required to undertake intensive daily treatment. The use of self-management (see section 3.4) concepts as a discussion topic for the semi-structured interviews in the first two research stages (see section 4.5.2) developed an understanding of participants' current self-management behaviours and explored the perceptions participants of self-management during the myCF pilot implementation.

The next chapter provides a detailed description of the methodology adopted for this research to address the research questions identified in Chapter 1, section 1.3.2.

CHAPTER 4   RESEARCH METHODOLOGY

4.1 INTRODUCTION

This chapter describes the methodology used in this research. The chapter is divided into the following sections:

- Section 4.2 presents the research philosophy and the underpinning subjective ontological and interpretivist epistemological approach that supported the research philosophy.

- Section 4.3 describes the research strategy. There were two keys elements to the research strategy: the first element was the case study as location, including access to the myCF pilot implementation project team and building rapport, and the second element was the three-stage approach to the data collection.

- Section 4.4 presents the three stage research design. The research aims and research are re-introduced. Research stage one – **Foundation Building** involved exploring the participant's experience of the myCF pilot implementation introduction and the participant's expectations of the myCF pilot implementation. Research stage two - **Implementation Experience** involved exploring the participant's experience of the myCF pilot implementation. Research stage three – **Life Context** involved the development of rich case studies using all the research design stages data.

- Section 4.5 presents the tools and techniques used in the three stages of the data collection that supported the research strategy of this study. Research stage one used semi-structured interviews, observation, and field notes. Research stage two utilised the tools and techniques from research stage one and in addition used web-logs. Research stage three used unstructured interviews, observation, field notes and web-logs, and additionally used data collected from the first two research stages. The section concludes with the ethics approval for this research.

- Section 4.6 describes the data analysis approach for each of the research stages. To achieve the objectives of the research, thematic analysis with an inductive iterative approach was used to ensure the results were grounded in the data.

- Section 4.7 describes the approach taken for the interpretation and discussion of this research.

- Section 4.8 presents the method used to address researcher bias for this research. The evaluation used for this research draws on Lincoln and Guba's (1985) 'trustworthiness criteria'.

- Section 4.9 provides a summary of the chapter.

4.2 RESEARCH PHILOSOPHY

This section presents the research philosophy and introduces the ontological and epistemological positions taken by the researcher. The research aims to explore the pilot implementation of an online symptom monitoring diary that was developed to support people living with CF through symptom monitoring. This includes the exploration of why people elected to interact or not to interact with the myCF pilot implementation and the development of an understanding of the perceived role the myCF pilot implementation has for self-management of CF. The research scope is limited to the cystic fibrosis community of Tasmania and the myCF pilot implementation.

The required data to illuminate the research problem is non-numeric and so the ontological and epistemological needs of the research is of a qualitative nature. The ontological and epistemological position of this research is discussed in the following sections.

4.2.1   ONTOLOGY

Ontological beliefs are concerned with the "world view" of the researcher and the phenomena under study (Orlilzowski & Baroudi, 1991). Ontology is concerned with 'what is' the nature of all things (Mason 1996). The basic question to be asked in an ontological context is; can the phenomena occur in an objective setting – without the interactions of humans, or does the phenomenon occur only through the actions of humans in creating, acting and interpreting it? (Burrell & Morgan, 1985). An objective ontology is the former world view, and the latter is a subjective ontological position.

Subjective ontologists follow the belief that the researcher is not separate from the subject of inquiry and frequently undergoes the same experiences of the research participants (Garcia and Quek 1997). Reality is created through the interactions and beliefs of people (Neuman 2003). The experience under study is not assumed to be value free and unproblematic, therefore the researcher must interpret the interactions and meanings within that experience (Orlikowski & Baroudi 1991).

This research is exploratory in nature. In order to answer the research questions posed, a subjective ontology offers the opportunity to discover the different meanings and interpretations that each participant gives to their environment. In order to understand how different participants define perceived requirements and interaction with eHealth initiatives, it is the individual's perceptions, actions and meanings behind those actions that the researcher is concerned with.

The subjective ontological position additionally allows the interpretive use of the web-log data that will form part of the research data collection. The numeric information has the ability to add valuable insights to the subjective perspective each participant will offer to the researcher, creating a richer case study in the process. Thus the most appropriate ontology for this research is of a subjective nature.

4.2.2   <u>EPISTEMOLOGY</u>

Whilst the ontological and epistemological positions of a researcher are two separate entities, they may sometimes illustrate inter-linkages when certain ontological positions will automatically lead to a predetermined epistemology (Walsham, 1995). Walsham (1995) notes the usual ontological stance for an interpretive researcher would be of a subjective nature, with particular emphasis on that relationship when the research phenomena is concerned with human interpretations and meanings associated with information systems. An interpretive epistemology recognises that unlike innate objects, humans operate in part due to the conditions of their environment and in part due to their own perceptions of that environment. It is straight forward to predict what happens to a pot of water when placed over direct heat however the predication is not as forthcoming when trying to understand how different people will react when placed in similar situations. How people will react is dependent on their current circumstance; a combination of environmental, physical, economical, emotional and social conditions. While each individual offers a unique perspective, these views can be combined to offer a shared interpretation of how the phenomenon behaves in the research conditions. To capture these conditions, an interpretive epistemology will enable the researcher to bring together these perspectives and discover the meanings behind these perspectives (Willis, 2007).

Klein and Myer (1999) also noted the increased value of the interpretivist approach in information systems research, defining it as:

> *"Interpretive methods of research in Information Systems are "aimed at producing an understanding of the context of the information system, and the process whereby the information system influences and is influenced by the context"(Walsham 1993, p4-5)… it attempts to understand phenomena through the meanings that people assign to them." (Klein and Myer, 1999, p69)*

The nature of the phenomena under study involves processes of communication, interaction between human and technology and the interactions between the participants themselves. In order to understand these processes, many which will have differing meanings for each participant, an interpretive epistemology allows these individual understandings to be combined whilst still representing each participant (Orlikowski and Baroudi, 1991). The interpretive nature of the research also allowed for the quantified data drawn in from the use of the myCF pilot implementation to be combined with the qualitative interviews. This approach further enhanced each data type and increase the meaning it represents for the researcher. Explanations of the interactions are not meaningful enough by themselves to ensure that each of the participant's perceptions can be truly represented. The meaning behind that explanation, and how one interaction may or may not be linked to another will assist in providing the researcher with the intricacies in the research problem area.

Interpretivism consists of two essential elements, rationalism and relativism (Willis, 2007). Rationalism can be described as reality is understanding by thinking about that reality. Relativism can be described by the idea that the reality we experience is underpinned by our culture and experiences. The combination of these two elements leads to a world view

which allows reality to be created not only through the physical sense, but also within the intellectual sense, through the groupings of the unique perspectives on the research area. Willis (2007) succinctly describes an interpretive research as indicated in table 4.1;

Table 4-1 Interpretive research characteristics

Nature of reality	Socially constructed
Purpose of research	Reflection and understanding
Acceptable methods and data	Subjective and objective research methods are acceptable
Meaning of data	Understanding is contextual, universals are de-emphasised
Relationship of research to practice	Integrated activities, both guide and becoming the other

Table adapted from Willis (2007: 95-117)

As the above table illustrates, research and practice may evolve and interchange with each other in interpretivist research (Willis, 2007). Interpretive research is emergent, the true meaning of the situation or the data collected is not apparent until all the puzzle pieces have been placed together and a holistic understanding can be achieved. Through the nature of this epistemology nothing is dismissed and through the guidelines of the chosen methodology the research phenomena can be understood. Through the chosen epistemological viewpoint the definition of reality is the interactions we have with each other, with our environments and the combination of the two.

4.2.3   QUALITATIVE METHODOLOGY

This is an exploratory research in the three domains of ICT for symptom monitoring, self-management, and people with CF, their attitudes surrounding CF and their lifestyle. Language, behaviour and experiences are essential to provide meaning to the research phenomena. An explanation or presentation of objective events does not allow for the researcher to be exposed to the detailed understandings between the intersections of ICT for symptom monitoring, self-management, and people with CF, their attitudes surrounding CF and their lifestyle - nor will activity logs or other standalone numeric data sets. Therefore a subjective interpretive paradigm is deemed the most appropriate for this research.

At a higher conceptual level Willis (2007) argues that qualitative and quantitative research approaches are more than simple research methodology. The different data types have traditionally separated the two but it is possible to use numbers and statistics in qualitative research (Green and Thorogood, 2009). The use of either qualitative or quantitative

methods can stem from a deeper underlying paradigm of the researcher towards not only types of data but also, how the world is viewed by the researcher (Willis, 2007).

Green & Britten (1998) present the argument that whilst quantitative methods is considered the norm for medical science research, it has also been noted by Naylor (1995) that there is more to medicine than just scientific rules. The authors highlight that in addition to these rules, clinical experience is also needed to make sense of different medical situations. Qualitative research can widen the scope of evidence based medicine using experience mixed with science (Green and Britten, 1998). A health practitioner has the rules of medical science to guide them in their work they also use the benefit of their subjective experience to enhance their skills within that work. The use of qualitative methods has increased in popularity in health research, to answer to the lack of rich description that traditional quantitative methods typically provide (Sofaer, 2002, Urquhart, 2001). Green and Britten (1998) illustrate an understanding of behaviour is needed, in addition to the objective rules.

As stated in section 4.2, the research is from a subjective ontology and is interpretative in nature. The approach of interpretive qualitative research can vary greatly, Green & Thorogood (2009) suggest that all interpretive qualitative research shares four characteristics; a commitment to naturalism, reflexivity, a focus on understanding and a flexible approach to research strategy. To these characteristics Bryman (1988) adds two more characteristics; description and process. These six characteristics and how they support the approach adopted for this research are presented as follows.

COMMITMENT TO NATURALISM

Commitment to naturalism shows a preference for studying phenomena in the natural environment or setting. Previous literature (Benbasat, 1987, Willis, 2007) has noted qualitative research is a well-suited approach when the phenomenon is to be studied in the natural setting. Cavaye (1996) adds to this argument through making this characteristic as one of Cavaye's four characteristics of case study research. This research is scoped towards the introduction of an online symptom monitoring diary to the CF community of Tasmania. The study is undertaken in the participant's natural environments.

REFLEXIVITY

Reflexivity illustrates how researchers should subject their research practice to the same critical analysis they do when reviewing research. Darke et al (1998) highlight the importance of triangulation in order to create cross comparison. Yin (1992) although positivist in nature, aptly highlights that the case study findings are strengthened by the application of information from a variety of sources, providing multiple reflections of the same phenomena. In addition to triangulation, the researcher additionally acknowledges their subjectivity within the collection of data, and ensures the explanation of the phenomena derived from the data is the result of appropriate analysis. A qualitative methodology is abundant in potentially complex information and demonstrates the flexibility to allow for this to occur.

FOCUS ON UNDERSTANDING

Focus on understanding illustrates the need to understand the world from the participants point of view. Case studies are a rich description of the research situation, allowing the researcher to form inductive opinions on the data being analysed. Interviews and observational techniques will allow the researcher to reveal insights from the participant's point of view. Narrative analysis, field notes and documentation supplement these two main data collection techniques. The combination of the various data collection techniques has provided the researcher several aspects for each participant's experience, fulfilling the need to understand the world from the participant's point of view (Green & Thorogood, 2009).

FLEXIBLE APPROACH TO RESEARCH STRATEGY

Flexible approach to research strategy illustrates the need for a research design where the exploratory nature of the research can adapt the original plan and allow the data to show the holistic nature of the phenomena under study (Green & Thorogood, 2009). Meyer (2001) argues that there are no specific requirements in qualitative research thus allowing the methodology to be tailored to the design requirements of the research phenomena. This research has maintained a flexible approach through the application of several complementing research techniques including semi-structured interviews, observation, field notes, web-logs and unstructured interviews that are supportive of a qualitative case study method.

DESCRIPTION

Description illustrates the use of a thick description of the phenomena, rather than just explaining the phenomena. The multiple methods of data collection enhanced the researcher's ability to describe the phenomena in detail, providing understanding of the participants actions. Through the interpretative analysis, themes and concepts will arise from the data. Ezzy (2002) explains the procedure of thematic data analysis can assist the researcher to move outside the boundaries of pre-existing theory and reveal individual interpretations. The use of an inductive approach through the data analysis in this research assists in ensuring this characteristic of qualitative research is present. The participants actions, as well as understanding those actions, are of particular importance in this research.

PROCESS

Process shows an emphasis on the processes underpinning social activity through detailed descriptions of the participant's behaviours (Bryman, 1988). Case study method is dependent on the ongoing comparison of data and the theory used for data collection (Eisenhardt 1989). It focuses on the dynamics and interrelationships present within the captured research situation. As this research is an interpretive study the focus is on the underlying social constructs and understanding the participants' behaviour.

As presented in section 4.2 this research has adopted an interpretative qualitative approach to understand the attitudes, insights and perceptions of people living with CF while being

involved with the myCF pilot implementation. The nature of the data sourced to address the research aims and research questions (see sections 1.3.1 and 1.3.2) required the research to be structured to capture the richness of the participants' experiences. This approach was captured both the individual and collective participant experiences.

The research strategy provided the mechanism for participant experiences of the myCF pilot implementation to be captured in multiple ways, reflecting the interpretative nature of this research (Orlikowski and Baroudi, 1991). The use of case study and three stage data collection as the research strategy enabled multiple snap shots to be gathered during the course of the myCF pilot implementation, overcoming an often cited limitation of a single snap shot case study which has been criticised as only capturing one instance of the research phenomena (Walsham, 1995). Despite this, the use of case study as a method within the research strategy would have provided a comprehensive description of the myCF pilot implementation if a single holistic overview was all that was required (Cavaye, 1996, Meyer, 2001). A rich description over multiple snapshots supported the research aim and research questions (see sections 1.3.1 and 1.3.2). The combined use of case study and three stage data collection aimed to capture why people elected to interact or not interact with the myCF pilot implementation and provided insight to how the myCF pilot implementation aligned with other aspects of their life. The research design supported the staged research strategy by gathering data at three definite intervals of the myCF pilot implementation thereby strengthening the case study strategy with an embedded approach (Eisenhardt, 1989). The three stage design provided depth and insight as each stage of data collection focused on specific intervals within the myCF pilot implementation and the participants life context. The tools and techniques used had the flexibility to be adapted to the design requirements of this research and additionally enabled data to be captured at three stages, through multiple techniques (Darke et al., 1998). Interviews were used as a primary data source as the participants views and interpretations could be effectively explored with (Walsham, 1995) and were supplemented through observations, field notes and web-logs to provide an alternative perspective on the interview data, a common occurrence in interpretative case study research (Myers, 1997). The combined use of multiple data collection techniques facilitated the development of depth and insight during data collection (Baxter and Jack, 2008). Interviews not only support the case study strategy in developing a understanding of the research phenomena but additionally supports the research philosophy in developing an understanding of the participants interactions with the myCF pilot implementation (King and Horrocks, 2010).

Section 4.2 presented the underpinning reasons for why this research was conducted with a subjective ontology and an interpretivist epistemology through a qualitative philosophy and method. The next section introduces the research strategy of this study.

4.3 RESEARCH STRATEGY

This section introduces the research strategy. The research strategy assists in understanding the motivations behind the methods used by the researcher in the exploration of the research questions presented in chapter 1, section 1.3.2. A review of the eHealth literature has indicated that access to patients may be problematic (see section 3.3.3). The research

focused on the use of case study as a strategy to follow the involvement of patients in an eHealth project, capitalising on the opportunity for rich data to be collected in a natural setting. In addition, a review case study literature has highlighted the potential limitations of the singular case study method (see section 4.3.1). To acknowledge and assist with this limitation, a three-stage data collection in three research stages is employed as part of the research strategy. The larger myCF pilot implementation case study is additionally explored at multiple individual case study levels. The two key components of case study and three-stage data collection are discussed in sections 4.3.1 and 4.3.2.

4.3.1   <u>CASE STUDY</u>

Case study research allows rich data to be collected in the natural setting of the research phenomena (Willis, 2007). It is holistic in nature and supports the participant centred approach in this study. Each participant has an equal right to be included, allowing for each to have his or her perspective presented and explored. Yin (1994) argues that a case study methodology is appropriate when researchers need to understand the how or why of a research phenomena and when the researcher has little control over the events occurring.

The term case study is diverse and has been used interchangeably with other research methodologies such as ethnography and exploratory research (Willis, 2007). For the purposes of this research, case study is defined as a method that explores predefined phenomena but does not involve explicit control or the manipulation of variables (Cavaye, 1996). The focus is on in-depth understanding of a phenomenon and its context (Cavaye, 1996). Adding to this definition is the observation that case study methodology is not limited to a quantitative or qualitative data set (Yin, 1994).

While Darke et al. (1998) argues that case study research is only appropriate when there is little knowledge about the research phenomena, Cavaye (1996) disagrees and presents that case study research can additionally be used for theory testing, where knowledge of the phenomena is at a greater level. It could be argued that the appropriate application of case study research depends on the epistemological position of the research and the intent to explore or explain the phenomena. The application of the case study method under Darke et al's (1998) limited knowledge viewpoint is appropriate for this exploratory research with an interpretive epistemology. A supporting factor for the research method is the identification by several authors that case study research is particularly appropriate for the design, implementation and use of information systems within organisations (Benbasat et al., 1987, Myers, 1997).

Case studies can have single or multiple cases (Walsham, 1993). Multiple case studies add to the depth achieved in single case studies by the cross comparison of cases (Darke et al, 1998). This research is one of exploration; according to Benbasat (1987) it is suited to either a single or multiple case study approach. Yin (1984) reduces the applicability of a single case study to three criteria; it is a case previously inaccessible, it is representative of a critical case to test previously developed theory, or if it is an extreme or critical case. This research could be successfully applied to the first and second of Yin's (1984) criteria as access to individuals with CF can be difficult however previous research exists in the area of CF self-

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management. Under the interpretive epistemology of this research, the individual perspectives that form the myCF pilot implementation case study are of equal interest and will enrich the data obtained.

Case study has been presented as the chosen method for this research. Creswell (1998) states that case study research is of a "bounded system". The boundaries that are placed upon the case are time and place (Creswell, 1998). The myCF project has different organisations sponsoring the project and so this research is limited to the myCF pilot implementation. The research is additionally bounded by time, 2010 to 2011 (a 6 month period), during which three stages of data collection occurred.

The use of multiple individual case studies inside the larger myCF pilot implementation case study overcomes the limitations of a single case study and complements the three research stages with the longitudinal view of data collection. The use of the multiple individual case studies insider the larger myCF pilot implementation case study additionally acknowledges the individual points of view present in this research. The individual points of view build on the entirety of the myCF pilot implementation, aligning with the interpretive epistemological nature of this research. An important advantage of the case study strategy was the comparison of cases of the myCF pilot implementation experience, adding to the depth of the exploration (Darke et al, 1998).

PRE-RESEARCH ACTIVITIES

This element of the case study strategy addressed the researcher's initial involvement with the myCF pilot implementation and the myCF pilot implementation team. The researcher joined the myCF pilot with the intent to explore the implementation and participant evaluation of the myCF pilot implementation. Relationships built from previous research allowed for a smooth transition and a greater acceptance as a participant in the myCF pilot team meetings.

From the previous collaborations already commenced with the University of Tasmania, it was assumed by the myCF pilot team that researcher held the required level of project knowledge for the myCF pilot. This assumption assisted the researcher in maintaining a participant as observer role at the commencement of the researchers involvement of the myCF pilot implementation, creating the necessary distance for familiarisation of the myCF pilot implementation, and for team members to become accustomed to the researchers presence.

As time passed, the researcher moved from a complete observer, to that of an active team member, or participant as observer (McCall and Simmons, 1969) (see section 2.4). This was a gradual process that allowed for trust and understanding to develop between the researcher and the project team (Walsham, 1995). The move from complete observer to participant as observer was achieved during the myCF pilot implementation.

4.3.2   THREE STAGE DATA COLLECTION

A three stage data collection was used to overcome the limitations of a single case study approach (see section 4.3.1). The first two data collection stages occurred between June 2011 and September 2011. The final data collection stage occurred between November and December 2011. The data collection for the research was structured into the following three research stages.

The first stage of data collection focused on the experiences of the participants as they were introduced to the myCF pilot implementation. The second data collection stage focused on the myCF pilot implementation with a view on exploring the myCF pilot implementation experience from the participants' point of view. This data collection stage focused on following up from the participant experience during their participation period. Stage three of the data collection aimed to develop a detailed description and deep understanding of the lives of the participants. Stage three data was used to develop individual case studies. Data from stages one and two was used to complement stage three data.

Section 4.3 has presented the research strategy utilised to ensure the research objectives were fulfilled and that detailed insights were obtained in regards to the research questions. This section has illustrated how case study and three stage data collection strategy was appropriate for the philosophy position of this research and the phenomena under exploration.

The next section presents the design of the research.

4.4 RESEARCH DESIGN

This section describes the research design for the research. The research aimed to explore the pilot implementation of an online symptom monitoring diary that was developed to support people living with CF through symptom monitoring.

The research design enabled the research to address the following research questions.

RQ1: **How can an online symptom monitoring diary support an individual's self-management of cystic fibrosis?**

>   *RQ1 O1:*   *To identify what individuals understand as cystic fibrosis self-management.*

>   *RQ1 O2:*   *To identify whether an online symptom monitoring diary can support an individual's self-management of cystic fibrosis.*

>   *RQ1 O3:*   *To explore the interaction between self-management knowledge and use of the online symptom monitoring diary.*

RQ2: How do people with cystic fibrosis incorporate symptom monitoring into their daily life?

> *RQ2 O1:*   *To understand the nature of the choices that people living with cystic fibrosis make about their lifestyle.*

> *RQ2 O2:*   *To understand the interaction between the lifestyle of people living with cystic fibrosis and symptom monitoring.*

The research design was guided by the research philosophy (see section 4.2) and the research strategy (see section 4.3).

The research design mirrored the three stage research strategy and was arranged into three research stages; stage one – **Foundation Building**, stage two - **Implementation Experience** and stage three – **Life Context**. This design ensured a holistic viewpoint on the research questions presented in chapter 1, section 1.3.2. The holistic viewpoint was achieved by the focus of the myCF pilot implementation experience in research stages one and two and through the focus of the participant's life context in research stage three.

Stage one – **Foundation Building** included the use of semi structured interviews, observations and field notes to gather data on the participants expectations of the myCF pilot implementation, knowledge of computers, knowledge of self-management, system needs, and experiences of the participants as they were introduced to the myCF pilot implementation. Fifteen interviews were undertaken in this research design stage. The data gathered in stage one - **Foundation Building** complimented stage three – **Life Context**.

Stage two – **Implementation Experience**, involved using semi-structured interviews, observations and field notes to gather data that was concerned with the participants in their experience of the myCF pilot implementation. This stage also used web-logs to gather data about the participants' use of the myCF pilot implementation and complemented the semi structured interview responses. Fourteen interviews were undertaken in this research design stage. The data gathered in stage two – **Implementation Experience** complimented stage three – **Life Context.**

The third research stage – **Life Context**, involved unstructured interviews, observations and field notes concerned with participants and enabled the development of rich case studies. Nine interviews were undertaken in this research design stage to form the individual case studies. The data gathered during stage three – **Life Context** was complemented by data from stage one – **Foundation Building** and stage two – **Implementation Experience**. Figure 4.1 illustrates the research design.
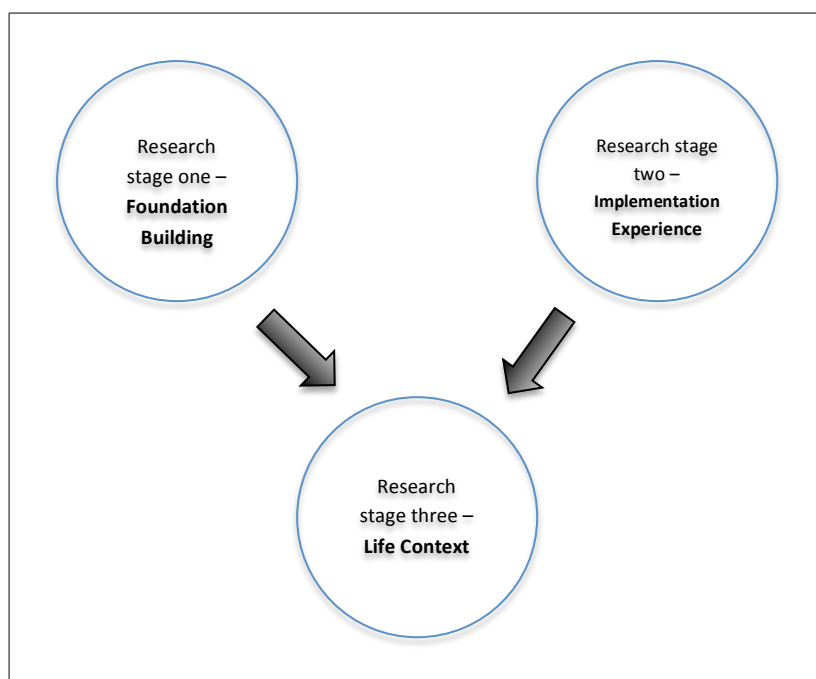
Figure 4-1 Research design

Participants for this research were identified through the myCF project by their attendance at one of the Tasmanian CF clinics, in accordance with the myCF project study guidelines. Recruitment was through random selection of subjects in three groups (paediatric, teenagers and adults) to allow comparison within each age group in their interaction and use of myCF. All participants were involved in each of the three stages of the research. A total of 15 participants were involved in this research. One adult participant was lost to follow up and their data was subsequently excluded.

Section 4.4 has presented the research design that supported the research strategy in its location and three stage data collection approach. The next section presents the tools and techniques that support the research strategy and research design.

4.5 TOOLS AND TECHNIQUES

This section presents the tools and techniques that support the research strategy (see section 4.3) and carries out the research design (see section 4.4). The tools and techniques included semi-structured interviews, observation, field notes, web-logs and unstructured interviews. These data collection techniques supported the aim of the research, as presented in section 1.3.1. The research tools and research techniques are detailed in the following subsections and represented in Figure 4.2 for easy reference.

The tools and techniques for this research are represented in in Figure 4.2.
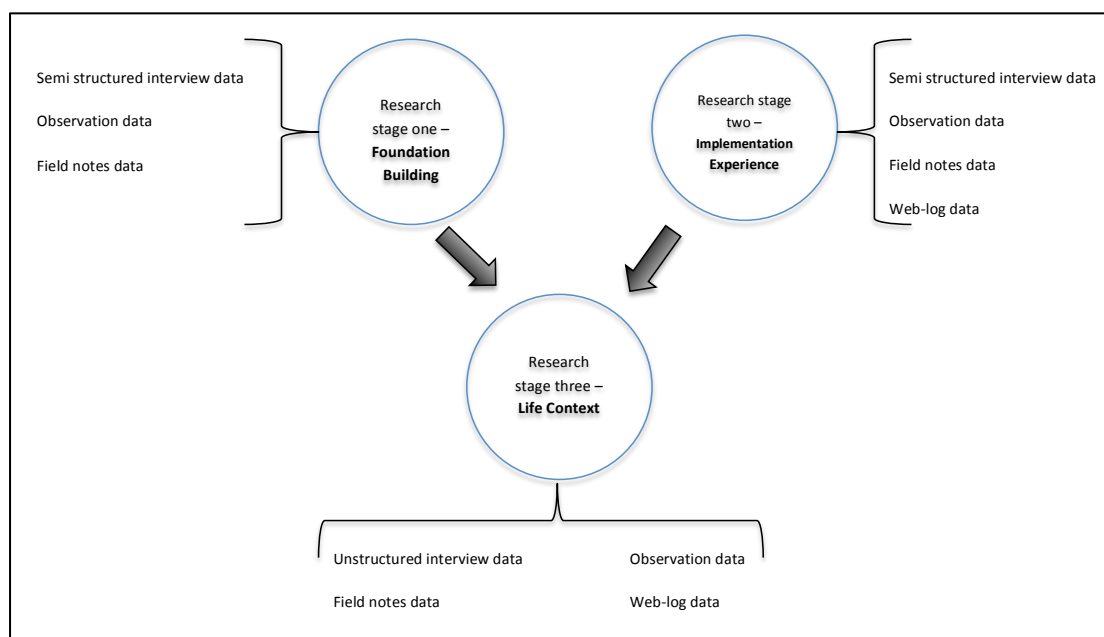
Figure 4-2 Research tools and techniques

4.5.1   INTERVIEWS

Interviews were used in the research as the primary data source in the form of semi structured interviews and unstructured interviews. Darke et al (1998) argue that not only are interviews an essential information source for case study research but they are also, most commonly, the primary source of data. This data collection technique can be grouped in three types; structured, semi-structured and unstructured (Cairns & Cox, 2008). Structured interviews follow a pre-prepared base of questions, in an open or closed style, much like that of a survey or questionnaire (Cairns & Cox, 2008). Whilst Cairns & Cox (2008) note that the more structured an interview is, the easier it is to analyse, they additionally allow that a structured interview is unlikely to put the participants at ease, prohibiting important revelations that may occur in a less structured setting.

Semi structured interviews offers a base structure with open questions yet allows unseen perspectives to be explored (Meyer, 2001). Semi-structured interviews provide a rough guide as to what the interviewer wishes to discuss. As each element arises in the interview, the interviewer can then decide to further pursue or drop that element. Researchers have a vague idea of the important issues and it is the participants that bring those ideas to the forefront (Sekaran, 2000).

Unstructured interviews have a base list of issues the researcher would like to cover, but there is no preconceived structure applied, allowing the interview to be led by the interaction between the interviewer and the interviewee (Sekaran, 2000). The interview technique may be used in a face to face or non-face to face (commonly telephone) context

(Sekaran 2000). King and Horrocks (2010) suggest there are three defining characteristics of qualitative interviews; flexibility and open ended in style, a focus on peoples' experiences rather than general beliefs and opinions, and the crucial nature of the relationship between the interviewer and interviewee. These characteristics may translate into practice differently, depending on what type of interview is used but the core element of the characteristics remain the same.

As this research is interpretative in nature, it is the participant's perceptions, experiences and reactions that are of a concern. In this research, semi-structured interviews that were delivered face to face allowed the researcher to ensure the data could be collected with the flexibility of capturing unforeseen points of discussion. Face to face interviews provided the researcher with the ideal data collection technique, as it allowed for non-verbal cues to be observed.

The interviews conducted in this research were semi-structured and unstructured in design. Permission was sought and granted from all interviewees to be involved in the interview process. Each interview was audio recorded, with the permission for the recording obtained at the commencement of each recording. Observations (see section 4.5.3) were utilised during the interviews in this research. The researcher looked for visual cues to assist in directing questions or identifying a potential area for exploration (Patton, 2001).

4.5.2 SEMI-STRUCTURED INTERVIEWS

The interviews ranged from 30 minutes to 1.5 hours in length. The researcher followed the question guide while using probes and follow-up questions where additional information was required. Questions for the interviews were framed into four broad discussion topics. A full list of the questions used in the participant interviews can be found in Appendix C. The broad discussion topics were used in both the stage one – **Foundation Building** and stage two – **Implementation Experience** interviews. The questions were changed to reflect the initial exploration, or follow-up required for the respective stage one – **Foundation Building** and stage two – **Implementation Experience** interview sets.

The interviews for the stage one – **Foundation Experience** sessions were conducted at each of the participant's home, as part of the introduction of the myCF pilot implementation. A specialised CF health care professional team member accompanied the researcher during the introduction sessions. The specialised CF health care professional team member collected the clinical data relevant for the myCF project data needs.

The interviews for the stage two – **Implementation Experience** sessions were conducted at each of the participant's home, as part of the follow up sessions. The researcher conducted these sessions without the assistance of a specialised CF health care professional team member.

The discussion topics for stage one – **Foundation Building** and stage two – **Implementation Experience** interviews are presented below in table 4.2.

Table 4-2 Participant interview discussion topics for stages one and two

Usability	Participant expectations vs user actual fit Barriers to use Usability concepts Participant needs requirements
User Centred Design (UCD)	UCD theory Participant involvement Participant definition
Sustainability	Platform sustainability Participant change requirements
Self-management	Self-management behaviours Participant centred

Usability focused on creating an understanding of the expectations of the online symptom monitoring dairy and how those expectations compared to the actual use of the myCF pilot implementation. As presented in section 3.6, the discussion topic assisted to explore whether participant expectations had been met. An understanding of the usability concepts involved in the myCF pilot implementation was also explored in this discussion topic. The discussion topic *usability* additionally gave the researcher an opportunity to explore the perceived barriers to using the myCF pilot implementation.

User Centred Design (UCD) aimed to assist the research in creating a participant definition for the myCF pilot implementation, through the participant's point of view. As illustrated in section 3.6 the concept of participant involvement in the design and implementation of the online symptom monitoring diary was also explored in this discussion topic. By including this discussion topic in the interview, the researcher was able to create a comparison between what UCD theory suggests and the reality of the myCF pilot implementation, from a participant perspective.

Sustainability focused on developing an understanding of the acceptance of the myCF pilot implementation and any change that might be required to be able to effectively engage with the site. Through the exploration of this discussion topic the researcher was able to develop an understanding of the perceived current and future use of the myCF pilot implementation

and how this perception compared to the expectations and the myCF pilot implementation aims and objectives (see section 3.6).

Self-management was focused on developing an understanding of current self-management behaviours and how the myCF pilot implementation was perceived to impact on those behaviours. As presented in section 3.6, this discussion topic assisted with gaining insight on what each participant understood self-management to consist of, and their own perceptions towards that understanding and their management of CF.

At the conclusion of each interview, the researcher reviewed the audio file for further reflection on the participants' detailed answers or answers where a closed response was given and probes were used. The reflection of the interview assisted the researcher to complete the field note pro-forma (see section 4.5.4).

4.5.3   OBSERVATION

Observation was a secondary data collection method employed in all three of the research design stages. McCall and Simmons (1969) present the different modes of observation that may be used in data collection. These different modes are;

- *Complete observer* – researcher remains in the background for data collection
- *Observer as participant* – researcher participates as if she is a project team member
- *Participant as observer* – researcher participates fully as a project team member but overtly as a researcher
- *Complete participant*- researcher acts as a project team member.

   (McCall and Simmons, 1969).

During the involvement in the myCF pilot implementation the researcher used the observation mode of participant as observer. The direct participation by the researcher in the myCF pilot implementation data collection assisted in embedding the researcher's role as participant as observer (McCall-Simmons, 1969).

The research questions guided the focus of the observations conducted by the researcher. During each research stage the participants perceived the researcher to be a member of the myCF pilot implementation team. During the participant interviews the researcher wrote observations made in note form. After each participant interview the research expanded on the observations so the field note pro-forma could be completed.

4.5.4   FIELD NOTES

Field notes provided additional assistance and detail in the data analysis of the research, allowing for a recollection of reflections and assumptions made when interpreting the data (Silverman, 2010). A reflective diary and a factual event listing were kept for each interaction or exchange of information in relation to the myCF pilot implementation. This data source was then used to supplement the interviews with the participants.

The use of field notes has an ethnographic background and assisted the researcher to recapture previous events through the addition of comprehensive observations of what has

been seen and heard (Silverman, 2010). Emerson et al. (1995) details the functions of field notes as follows:

- To identify and follow processes in witnessed events
- To understand how members themselves characterise and describe particular activities, events and groups
- To convey members' explanations for when, why or how particular things happen and, thereby, to elicit members' theories of the causes of particular happening
- To identify the practical concerns, conditions and constraints that people confront and deal with in their everyday lives and actions. (adapted from Emerson et al, 1995 in Silverman, 2010, p230)

In this research, the use of field notes was closely linked with observations. Each field note pro-forma was completed onsite (when the researcher used a laptop) or once the researcher returned to an environment where it was possible to transfer the hand written observations from the exercise book to the pro-forma. The field note pro-forma was filled out after each meeting or interview conducted in this research (Newman, 2000). Appendix D has an example of a field note from an observation session.

In addition to the capture of information such as date, place, time, topic, participants and observations, the field note pro-forma allowed the researcher to capture the personal reflections for that observation, keeping the factual and reflective elements of the field note separate (Berg, 2004). This allowed the researcher to use the personal reflections as a trigger to assist not only in the recall of the event, but to assist with the interpretation of the data (Berg, 2004).

The field notes were used as a secondary data collection source to supplement the interviews as the primary data source and were integrated into the analysis process. The observations and field notes assisted to provide depth in both the analysis and interpretation of the interview data.

4.5.5   WEB-LOGS

The web-logs were gathered through Google Analytics. All data was collected continuously while participants were involved in the 6-week myCF pilot implementation and then followed the participants through research stage three. The web-logs specifically collected data relating to login rates, time of day when logging in, IP address, mode of site access and pages visited with length of stay on that page.

The webs-logs were used as a secondary data source and were integrated with the data gathered during the semi-structured and unstructured interviews.

4.5.6   UNSTRUCTURED INTERVIEWS

Unstructured interviews were conducted in stage three to support the development of the individual case studies. A rapport had been developed between the researcher and the participants during the myCF pilot implementation. Life activities were used to prompt for

conversation. The unstructured interviews ranged from 20 minutes to 1 hour and were digitally recorded.

The researcher's control over the unstructured interview was minimal. The researcher encouraged the interviewees to relate experiences and perspectives that were relevant to the problems of interest to the researcher (Burgess, 1982). For the purposes of the unstructured interview, the researcher's interest was focused towards building a holistic picture of the participant, their lives and their support networks. The wide focus for the unstructured interviews enabled relevance toward the research aims and objectives.

4.5.7 **ETHICS**

Ethics approval for the myCF project was received under reference number H0009998. The researcher was listed as a student researcher for the myCF project. As this research is separate from the myCF project, ethics approval was received from the Human Research Ethics Committee (Tasmania) Network under reference number H11633.

This section of the chapter has presented the research tools and research techniques used in data collection which supported the research strategy (see section 4.3) and informed the research design. Semi structured interviews were used to fulfil the research strategy requirements. Observations assisted in creating detailed descriptions of the interviews and interactions in each research stage. The use of field notes allowed for the capture of information made in the observations by the researcher.

The next section presents the methods used in the analysis of the data collected for the research.

4.6 DATA ANALYSIS

As discussed in this chapter, the research data was qualitative in nature (see sections 4.2.3 and 4.5) required a subjective ontological and an interpretative epistemological research philosophy (see sections 4.2.1 and 4.2.2). The data was analysed with an inductive thematic approach that developed abstracted themes for each stage of the research, which generated insight and discussion from three different lenses for this research; the research stages, the individual cases, and at a holistic level. In this section the data analysis approach is presented with examples from each research stages is presented.

The aim of this research was to explore the pilot implementation of an online symptom monitoring diary that was developed to support people living with CF through symptom monitoring (see section 1.3.1). Thematic analysis assisted in achieving the research aim as it allowed the researcher to form a holistic view of the research situation and ensure all avenues of interest were explored (Boyatzis, 1998). The research questions and research objectives (see section 1.3.2) required the data analysis to provide insight into the participants' involvement with the myCF pilot implementation. The research question guided the coding paradigm and the direction of the analysis. Thematic analysis, while providing insight, lacks structured guidance (Attride-Stirling, 2001) therefore assistance was sought by applying the principles of grounded theory. Strauss and Corbin (1990), when

describing open codes, acknowledge they can also be used to develop themes. However the open codes developed in this research were not sufficiently abstracted to assist in addressing the research aim. To facilitate further abstraction it was decided to use the process of axial coding to take the data past just a listing of concepts (Strauss and Corbin, 1990), this enabled the final development of latent themes. The abstraction of the codes enabled the capturing of participants views, and the collective view. At the final level of analysis, the resulting themes moved past description of the data into the initial stages of interpretation of the data (Braun and Clarke, 2006). The use of the adapted thematic analysis that was informed by an inductive approach enabled theme generation that had strong links to the data but were also abstracted to provide a cross comparison of the different points of view in this research.

4.6.1 THEORY OF ANALYSIS

Thematic analysis is a widely used qualitative method of analysis. It has the flexibility of method to be used in conjunction with a number of qualitative analysis approaches (Boyatzis, 1998, Floersch et al., 2010), whilst still remaining a method in itself (Braun and Clarke, 2006). Thematic analysis lacks solid structure and guidance (Attride-Stirling, 2001). Thematic analysis differs from other qualitative methods of analysis that seek patterns across the data as it not only seeks patterns across the entire data set but also within each individual case study present (Murray, 2003). It is not pre-defined to any existing theoretical framework and therefore can be used with a multiple of frameworks or none at all (Braun and Clarke, 2006).

Thematic analysis is used to identify themes within the data (Ezzy, 2002). It provides a detailed description of the data (Braun and Clarke, 2006). The categories used to create the themes are inductively formed, gathering insights from the data itself (Ezzy 2002). This allows the researcher to explore issues that they had not originally thought to explore (Ezzy, 2002). Thematic analysis allows the researcher to form a holistic view of the research situation and ensure all avenues of interest are covered. The act of analysis by the researcher is an active one (Braun and Clarke, 2006). Ezzy (2002) states that the procedure of coding can help the researcher move outside the boundaries of pre-existing theory and reveal individual interpretations. The information gathering of thematic analysis and the inductive process makes this a valid approach to this research. In this research, thematic analysis was applied a latent level, attempting to understand the meaning beyond the mere content of the data. It is this move from the semantic level to the latent level that not only allows patterns to be seen in the data but to also see how the patterns are formed and provide meaning (Braun and Clarke, 2005).

The data analysis approach for this study incorporates a coding paradigm that uses open and axial codes before the theme development[3]. Grounded theory has become a popular research method within the information systems domain (Urquhart and Fernandez, 2006).

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[3] The coding paradigm used in this research has been adapted from Strauss and Corbin (1990) who developed the paradigm as a part of what is now known as grounded theory. Open and axial codes are commonly connected to grounded theory and are the first two stages of Strauss and Corbin's (1990) coding paradigm.

Glaser (1999) supports that most researchers mix grounded theory with other methods, using the principles that they have judged to be relevant to their area of interest. Grounded theory principles assisted to provide the framework to commence the coding process. The data analysis was conducted at three conceptual coding levels; open, axial and themes. The use of open codes is a common element in an inductive coding process. In the axial code level, the detail of analysis depends the iterative nature, reflecting commentary by Ely et al. (1997) - thematic analysis should develop over time and as a deep and responsive process. The open codes developed in this research were not abstracted enough to assist in addressing the research aims. Axial codes took the data past just a listing of concepts (Strauss and Corbin, 1990). The guidance of grounded theory principles assisted with the abstraction of the codes through to the theme level, where the required abstraction was achieved. The abstraction of the codes enabled the capturing of points of view of participants, and the collective participant viewpoint. At the final level of analysis, the resulting themes moved past description of the data into the initial stages of interpretation of the data (Braun and Clarke, 2006). It also increased the potential to allow for the unseen-unheard-unaccounted perspectives to emerge, giving a voice to all the orientations included in the research. Through the absorption of the axial codes into the final themes, the thematic analysis in this research is illustrative of how the axial codes can be correlated to the final themes, rather than correlation between the axial codes themselves.

This research seeks to provide multiple perspectives to the research problem and to explore what is happening in those perspectives to the current theory in the domain. Boyatzis (1998) likens thematic analysis to a method that allows the researcher to capture insights that others may not see, to code it so it can be seen and then provide the interpretation of that captured insight. Thematic analysis also enables a way of making sense out of seemingly unrelated material (Boyatzis, 1998). These strengths of thematic analysis directly aligned with the aim of this research. By the generation of codes that allow for the unseen to be captured, and the unrelated related, thematic analysis assisted in building an understanding of the research area that covers a range of multiple perspectives.

The inductive coding approach used for the data analysis was applied at sentence level. This level of detail allowed the researcher to capture the essential elements that were associated with the research phenomena. Throughout the coding process, memos assisted the researcher to recapture thought processes and to provide a link between the coding and the first draft of the overall analysis (Charmaz, 2000).

4.6.2   ANALYTICAL APPROACH

In this sub section, the research method of analysis is presented. The process of analysis is firstly presented with the development of the summary codes. This is followed with the coding process for all three stages of the research.
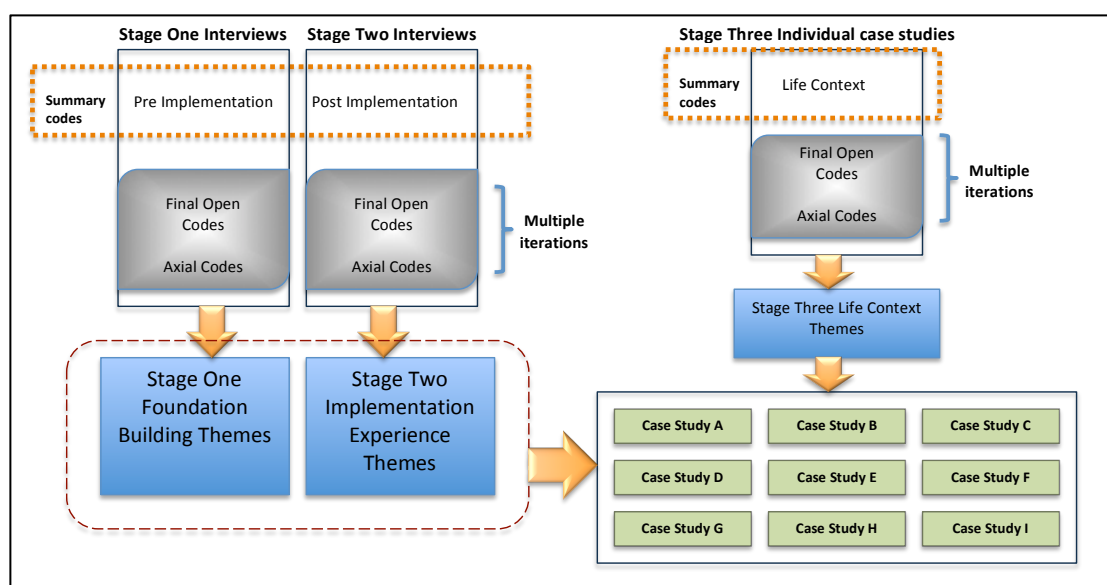
Figure 4-3 Visual representation of data analysis

Figure 4.3 illustrates the analysis process used throughout the three stages of the research. Stage one and two underwent the summary coding before the open and axial codes were developed. The themes were independently developed for each stage. Figure 4.3 shows the development of the case studies used in this research. The themes from stage three formed the basis of the individual case studies. Themes from stage one and stage two were used in each individual case study when they were applicable to the participants. This placed an individual focus for each of the stage one and stage two themes in each individual case study.

SUMMARY CODES

The summary coding process used for the data analysis was developed to ensure that the resulting analysis was connected to the raw data. This stage can have one or more iterations, depending on the aims of the research (Urquhart, 2001). The summary codes are strongly linked to the data with the code name providing a description of the component at a sentence level (Urquhart, 2001). Summary coding was completed on research stage one and research stage two interviews before moving on to the open coding. The interview transcript from Microsoft Word was printed and reviewed prior to the coding so the researcher became re-introduced to the data. Coding for the interview transcripts was completed at a sentence level, with the corresponding summary code text highlighted on the interview hardcopy. The summary codes of the interview were the first stage of removing the data from the interview transcripts. A total of 6,102 unique summary codes were developed.

Each interview summary codes were reviewed at completion to ensure the code reflected only what was in the interview transcript. This review served two purposes; it ensured that the summary codes reflected the data, emphasising the inductive approach that was used in the thematic data analysis (Glaser, 1992) and it ensured that each code had sufficient

meaning allowing the codes to become separated from the raw data. This maintained the inductive approach in the analysis and ensured the analysis represented the raw data.

All summary codes for stage one and stage two were completed before the next stage of data analysis occurred. This was done to ensure that any potential researcher bias was restricted. The complete transformation of the interviews to the summary codes ensured that each separate data set did not bias other data sets when moving up to the next level of data analysis. The data sets included the stage one – **Foundation Building** and stage two – **Implementation Experience** semi structured interviews. The development of the stage three – **Life Context** summary codes followed the same process as in in the previous research stages. Stage three – **Life Context** summary codes were developed once the final themes for the previous two research stages had been developed.

The original summary codes represented short sentences. The analysis of the interview transcripts into the summary codes went through several iterations to developed complete summary codes. As detailed in Figure 4.4 the summary codes were referenced to the interview transcripts through line number and highlighting the relevance stages.

Line Nº	
54	*does not self manage* *participant suggests things to* Self-management. **Um, well I- I feel that I don't self manage** I **suggest a lot of things to**
55	*doctors* *participant and doctor work together* *treatment planned* **the doctors** and they **bounce back with me** and*,* **with the treatment** and self manage well, I mean the
56	*self management is with planned medication* *self management is medication focused* **only time I self manage is when I take a histamine** or something, **or an anti-inflammatory** but **I don't**
57	*self management is with current medication* *participant may self commenced antibiotics* *antibiotics taken with Dr knowledge* **really self** – I mean **I might start an antibiotic but that's usually when I've asked the Dr**,……

Figure 4-4 Interview transcript with summary code identified

Figure 4.5 provides an example of the summary codes undergoing iterations before the final code was finalised.

Summary code (First iteration)	Summary code (Second iteration)
Clinician involved by patient	Keeps CF team informed of treatment
Non-patient clinician communication	Family concern leads to clinic contact
Clinics include dietician	Clinics include dietician
Medications understood	Child aware of enzyme requirement
Importance of condition management	Child management of condition important
Routines	Response to condition is routine
Current diary activities	Parents keep a mental diary
Diary is required	Must keep a diary
Documentation required	Child's condition should be documented
Seeks CF news	Seeks CF news

Figure 4-5 Summary codes with several iterations

OPEN CODING

The open codes went through a number of iterations and moved beyond the descriptive nature of the summary codes, to an analytical label (Dey, 1993, Urquhart, 2001). Strauss and Corbin (1990) describe open coding as analysis that questions the researchers assumptions about the data. The close scrutiny allowed for the data to present all views of the participants. As the researcher moves from the raw data, codes or concepts are be used to slightly abstract the data.

Once the open codes were finalised, they were placed into a separate Microsoft Excel worksheet. The development of the summary codes reduced the number of unique data attributes as the summary codes were abstracted to similar open codes. A total of 2,852 unique open codes were developed.

During this process any duplication of codes was removed, with the open codes copied and transferred to a new Excel worksheet. This facilitated the clean removal of the codes from the raw data.

Figure 4.6 shows the relationship between the summary codes and the open codes.

Summary code	Open Code
Internet access at home through broadband	Has access to the Internet
Internet connection can be slow	Internet connection can be slow
Must have Internet access to function day to day	Internet access is non-optional
No home Internet - access is through grandparents.	No Internet access at home
Difficult diary use will end in giving up and not using	Difficulties in use prevent sustained use
Parent treatment reminders are viewed as negative nagging	Child views parents prompts as nagging
Teenager child prefers to avoid information sharing	Teenagers don't communicate
Feels computer knowledge levels are low	Computer knowledge lacking
Need to be aware of parent computer literacy	Parent computer literacy awareness
Parent not a computer person	Parent computer literacy
Being centre of attention is not always a good thing	Centre of attention not always good
Unsure of correct response to question	Providing appropriate response

Figure 4-6 Open codes developed from summary codes

AXIAL CODING

Axial coding abstracted codes to a higher level than that of the open codes (Bernard and Ryan, 2010). Abstraction moved the label of the open code to a concept. Axial coding pulls the basic concepts developed with the open coding together into categories, enabling collection of similar conceptual themes (Glaser, 1992). The context of the underlying concepts is important when naming and framing the category, ensuring the data is still leading the analysis (Strauss and Corbin, 1990). The axial codes do not form the final themes; yet become the sub-components of that process. Once the concepts have been formed into axial coding, the final level of analysis began. A total of 153 final axial codes were developed.

Figure 4.7 shows the relationship between the open codes and the axial codes.

Open Code	Axial Code
Has access to the Internet	Access
Internet connection can be slow	Access characteristics
Internet access in non-optional	Access characteristics
No Internet access at home	No Access
Difficulties in use prevent sustained use	Barriers to Use
Child views parents prompts as nagging	Child negative perception parent prompts
Teenagers don't communicate	Teenagers non-communicative
Computer knowledge lacking	Low computer literacy
Parent computer literacy awareness	Parent computer literacy
Parent computer literacy	Parent computer literacy
Centre of attention not always good	Attention focus problematic
Providing appropriate response	Appropriate response

Figure 4-7 Axial coding developed from open codes

The axial codes underwent a number of iterations in this stage of coding. This process builds upon the refining and focusing of themes as discussed by (Donovan and Blake, 2000) and Tuckett (2005). The multiple iterations of the axial code development was a pragmatic approach to Miles and Huberman (1994) concept of data reduction. For this research the process was applied to axial codes instead of the theme level of analysis. The evolution of codes occurred before theme generation and without the bias of literature, differing from the method applied by Tuckett (2005). The iterations were incremental in nature, slightly abstracting the data from the previous axial code iteration. The iterative axial code development prevented misinterpretation of the data and assisted the researcher in justifying the grouping of the open codes. The process addressed the lack of constant comparison in thematic coding as identified by Boyatzis (1998) and draws on the constant comparison method attributed to grounded theory principles (Strauss and Corbin, 1990). The iterative code development reduced the 895 initial axial codes to 195 final axial codes.

The process of the axial coding is shown in figure 4.8.

Axial Codes (First Iteration)	Axial Codes (Second Iteration)	Axial Codes (Third Iteration)
Access	Access	Accessibility
Access Characteristics		
No Access		
myCF barriers to use	Barriers to Use	Barriers to Use
Child negative perception parent prompts	Parental prompt problematic	Communication Issues
Teenagers non-communicative	Communication Issues	
Low computer literacy	Computer Literacy	Computer Literacy
Parent computer literacy		
Attention focus problematic	Attention Negative	Attention Negative
Appropriate response	Appropriate response	Model Responses

Figure 4-8 Axial coding with multiple iterations

THEME DEVELOPMENT

The final level of data analysis involved looking at the attributes of each axial code and then creating the final level themes. The themes were illustrative of all the underlying codes, thus standing as a detailed description of the elements of the research phenomena of interest. The concept of the final level themes can be likened to 'global themes' as referred to by Attride-Stirling (2001). Attride-Stirling describes 'global themes' holding the principal metaphors of the entire data set. Braun and Clarke (2006) highlight that thematic analysis involves a constant review of the raw data, the codes produced and the resulting theme. The iterative axial code development process was vital in producing the comprehensive and meaningful themes that were the end result of the data analysis. These themes are the ultimate level of conceptualisation within this analysis.

The axial codes were printed onto small cards in order to allow the researcher to group the axial codes where similar concepts became apparent. Multiple attempts of the axial code groupings occurred in order to ensure that the obvious groupings of the axial codes and then new discoveries of concepts could then guide the new groupings. Once the final themes were determined, the axial codes in that theme were examined a final time to ensure that it held the necessary connection to the theme.

Figure 4.9 illustrates the final grouping of a theme from stage one – **Foundation Building**.

Axial Code	Theme
Model Responses	
Attention Negative	
Barriers to Use	Blockage
Computer Literacy	
Communication Issues	
Accessibility	

Figure 4-9 Final Theme

A total of nineteen unique themes were developed during this stage of analysis. Figure 4.10 lists the final themes for each research stage.

Stage One - Foundation Building	Stage Two - Implementation Experience	Stage Three – Life Context
Condition	Expectations	Attitudes
Management	Relevance	Trying to be Normal
Support	Usability	Condition & Social Interaction
Considerations	Facilitation	CF Knowledge
Expectations	Connecting	
Development	Care	
Blockage	Apathy	
	Life	

Figure 4-10 Themes developed for each research stage

RESEARCH STAGE THREE – LIFE CONTEXT

The method of analysis in stage three – **Life Context** followed the same inductive thematic analysis as the previous two research stages. Whilst stage one and stage two were analysed to answer the research questions, research stage three analysis developed context for the answers to the research questions and provided insight of the decision making by participants to use the myCF pilot implementation. The researcher did not exclude non-life concepts if they were found in the raw data. The purpose of the case study data was to provide comprehensive description of the participants involved with the myCF pilot implementation, and explore how those participants compared to the overall analysis of this research.

Themes from research stage one and research stage two that directly related to the individuals in the case study were used to complement the research stage three themes. The presence of research stage three themes across all of the individual case studies were then summarised to form a holistic view of the research stage three data analysis. The case studies were also compared to the research stage one and research stage two data analysis that allowed the individual voice to be placed on the developed research stage one and research stage two themes from all participants involved in this research.

This section has detailed the method of analysis used in the research. By using thematic analysis that drew on an inductive approach in building the axial codes the researcher developed themes that were abstracted while still being inductive in nature. This enabled the generation of insight and discussion at three different levels for this research; the research stages, the individual cases and the entire myCF case study.

Traditionally, the themes would be clustered to develop the findings for the research (Attride-Stirling, 2001, Braun and Clarke, 2006, Floersch et al., 2010, Tuckett, 2005, Boyatzis, 1998). The data from each stage of the research underwent rigorous analysis that resulted in nineteen themes. The developed themes were independent in each stage. Once developed, the themes were interpreted to gain insights at each research stage, resulting in twenty-one initial findings (see sections 5.4, 6.3 and 7.13). The development of the initial findings signalled the commencement of the interpretation process for this research.

The next section will present the approach taken to interpret and discuss the initial findings from each research stage.

4.7 INTERPRETATION AND DISCUSSION

The interpretation of the initial findings is presented in sections 5.4, 6.3 and 7.13. The interpretation and discussion of this research is presented in chapter 8. The interpretation and discussion occurred in relation to the aim of the research and the research questions (see sections 1.3.1 and 1.3.2). The interpretation of the initial findings was assisted by the use of concept mapping (see sections 4.7.1 and 7.14). The process of interpretation developed findings that reflected both the individual and group perspectives present in this research. The research questions and associated research objectives stated in section 1.3 were answered by the interpretation of the eight research findings that produced four key findings (see section 8.3).

4.7.1 CONCEPT MAPS

Concept maps have been used in exploring student learning (Nesbit and Adesope, 2006, Novak, 1990), assisting with data collection (Wheeldon and Faubert, 2009), data analysis (Jackson and Trochim, 2002, Markham et al., 1994) and communicating implicit and explicit knowledge (Ebener et al., 2006, Nesbit and Adesope, 2006). The term concept mapping is often interchanged with knowledge mapping as both methods represent ideas with node-link diagrams (Nesbit and Adesope, 2006). Concept maps assist in identifying the multiple relationships between sub-concepts to one main concept (Novak, 1990) whilst knowledge mapping has been represented as an association of information, resulting in new action (Vail, 1999).

Concept maps are a systematic and proven approach that emphasises relationships and connections among concepts (Eppler, 2006, Novak, 1990, Wheeldon and Faubert, 2009). The data collection, data analysis and initial interpretation in this research resulted in the development of twenty-one initial findings. Concept maps was suited to clustering the

independent initial findings in order to produce eight comprehensive research findings (see Appendices E – M).[4]

As presented in section 1.3.1, this research aimed to explore the pilot implementation of an online symptom monitoring diary that was developed to support people living with CF through symptom monitoring. As a part of this aim, this research examined why people elected to interact or not interact with the myCF pilot implementation and to develop an understanding of the perceived role the myCF pilot implementation had for self-management of CF. As the initial findings were developed within each research stage, they were independent of each other. Each of the initial findings developed in each research stage did not completely address the research questions and research aims. Concept mapping provided a method for interpretation that ensured the key findings addressed the individual and group perspectives of the research problem.

In the past, concept mapping has been utilised with both formal and informal guidelines (Ebener et al., 2006, Nesbit and Adesope, 2006, Wexler, 2001, Wheeldon and Faubert, 2009). The interpretation of the initial findings was facilitated through the use of a flexible approach to concept mapping. The use of the research problem (see section 1.3) as the central concept draws on the techniques of knowledge mapping, where the requirement for knowledge generation can result in a variety of different ways to how the map is formed (Wexler, 2001). The flexible approach used in developing the concept map assisted in developing comprehensive insights that addressed the research questions, as presented in section 1.3.2 and supported the philosophical approach of this research (see section 4.2). The concept maps were a demonstration of how the initial findings from each research stage could be further interpreted to provide a combined representation of the participants experience in the myCF pilot implementation.

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[4] The independent initial findings developed by the initial stages of interpretation in this research could have been further clustered and interpreted through other interpretative techniques such as content analysis (Hsieh and Shannon, 2005). Content mapping represented the inductive nature of the research and had the ability to retain the individual strengths of each of the initial findings in the development of a holistic map to the research problem.

1. Manipulating the Initial Findings

Initial Finding 1	Initial Finding 7	Initial Finding 17
Initial Finding 2	Initial Finding 8	Initial Finding 18
Initial Finding 3	Initial Finding 9	Initial Finding 19
Initial Finding 4	Initial Finding 10	Initial Finding 20
Initial Finding 5	Initial Finding 11	Initial Finding 21
Initial Finding 6	Initial Finding 12	
	Initial Finding 13	
	Initial Finding 14	
	Initial Finding 15	
	Initial Finding 16	

2. Applying the Initial Findings to the research problem

Initial Finding 1 → Initial Finding 9
Initial Finding 9 → Initial Finding 19
Initial Finding 20
Initial Finding 9 → Initial Finding 21
Initial Finding 21 → Initial Finding 4

3. Applying the findings to the research questions

Finding 1	Finding 2	Finding 3	Finding 4
Finding 5	Finding 6	Finding 7	Finding 8

Research Questions

Figure 4-11 Concept Mapping process

Figure 4.11 illustrates the concept mapping process taken in this research. This process has been adapted from (Jackson and Trochim, 2002) concept mapping and Ebener et al. (2006) knowledge mapping processes. The concept mapping started after the initial interpretation was completed for all three stages of the research. The interpretation of the nineteen themes resulted in twenty-one initial findings across all the research stages. Each initial finding was written down under the research stage heading, therefore the framework of the map had three columns. The initial findings were compared to each other across the three research stages. The groupings of the initial findings were also applied to the other groupings across the research. Once the concept map was complete, the initial findings has been combined and abstracted to eight findings (see Appendix E).

The concept map was created to gain further insight into the initial findings. By creating the concept map, the initial findings were raised to research findings that had relevance for the research as a group and for each individual in the research. The concept map provided direction for the interpretation of the initial findings and enabled the development of findings when an obvious relationship was not apparent.

The concept map assisted in thinking through and questioning the initial findings, in the process of developing the research findings. It presented the multiple initial findings so that the research stages no longer governed the grouping of initial findings. This assisted to ensure that the findings represented the individual and group perspectives.

The next section discusses the consideration of researcher bias in this research.

4.8 RESEARCHER BIAS

Qualitative research draws on individual perceptions and experiences (Liamputtong and Ezzy, 2005). It is important that each point of view in the research has been offered the opportunity to be clearly heard and treated equally (Guba and Lincoln, 2005). Qualitative

research requires transparency and an appropriate method to evaluate the research content. One such way is through Lincoln and Guba's four trustworthiness criteria (Lincoln and Guba, 1985), as listed below:

- Credibility
- Transferability
- Dependability
- Confirmability

Credibility is referred to as 'truth value' and refers to the level of representation the researcher has achieved with the multiple points of view present in the research (Lincoln and Guba, 1985). The credibility of this research is provided in the research design. Lincoln and Guba (1985) refer to the researcher having a significant time involvement with the phenomena under study, with continual observations to ensure credibility. The use of triangulation, through several methods including data sources, is also referenced as a means to establish credibility. The design of this research (see section 4.4) was based on the researchers involvement with the myCF project for a period of one year. During this time, observations were undertaken by the researcher and are supported through the documentation of field notes. The adoption of participant as observer allowed the researcher to assist in completing the necessary project tasks while forcing the researcher to remain at a level of impartiality to the myCF pilot implementation, ensuring each team members perspective and role was captured and the research objectives were still being considered (Patton, 2002). Three different frames of reference were used in the data collection of the research, supporting the triangulation method of ensuring credibility.

Transferability is also referred to as applicability (Lincoln and Guba, 1985). Lincoln and Guba discuss transferability as the ability of the findings from this research to be applicable (or transferable) to other situations (Lincoln and Guba, 1985). In order to achieve transferability researchers are required to gather sufficient data for the readers of the research to draw comparisons to other contexts, if so desired (Bradley, 1993). The transferability of this research has been provided through the transparent provision of data that was used in the research. In addition, the discussion of cases in chapter 7 and the background of the myCF project (see chapter 2) further add to the transferability of this study.

Dependability refers to the clarity of the internal processes and how changing conditions in the research is accounted for (Bradley, 1993). The methodology outlined in Chapter 4 illustrated how the dependability of this research was achieved. The use of multiple data collection techniques and sources throughout the three research stages adds to the dependability of this research. The data collection included the use of repeating questions of enquiry in the last two research stages. The data analysis outlined in section 4.6 was applied separately to each of the three research stages before observing the inter-relationships and moving to the development of the individual case studies. To reduce the impact of bias, the base codes for the research stages were completed before moving onto the next stage of analysis. Research stage three base codes were not completed until the data analysis was complete on the previous two research stages. The interviews for this

research were transformed into base codes in a random order to ensure that patterns in coding would be difficult to establish.

Confirmability is how well the data of the research can be confirmed by others (Bradley, 1993). The confirmability of this research is achieved through the insights gathered by the data collection and analysis that occurred over the one-year period. The myCF pilot concept and implementation is presented through this thesis and the characteristics of the data and research results are clearly detailed. Additionally, the use of the reflective journal that formed part of the researchers field notes adds to the confirmability of this research.

This section has presented the method used to address researcher bias for this research. The evaluation used for this research draws on Lincoln and Guba's (1985) 'trustworthiness criteria'.

4.9 CHAPTER SUMMARY

This chapter has presented the philosophical position of this research. The use of a qualitative approach that underpinned the subjective ontological and interpretative epistemological perspectives suited the exploratory nature of this research. The research strategy consisted of case study and a three-stage data collection.

The research design consisted of three research stages. The design of each research stage enabled the researcher to align with each research stages focus.

The chapter has discussed the tools and techniques for the collection of data across the three stages of the research. Semi-structured interviews, observation, field notes, web-logs and unstructured interviews were used throughout the three stages.

The data analysis for the research was presented. The method of analysis illustrated the development of open and axial codes through thematic analysis. In the axial code development the iterative nature was highlighted. The analysis resulted in the production of final level themes. This process was followed for all three stages of the research.

The last sections of this chapter concerned the process used to interpret and discuss the research. Concept maps were used to cluster points of interest from across all three stages of the research. The clusters and their inter-relationships were then discussed and compared to the current literature. Eight findings resulted from this processed and answered the research questions. Answering the research questions and research objectives produced four key findings.

The next chapter presents the stage one data analysis of this research.

CHAPTER 5   STAGE ONE - FOUNDATION BUILDING

5.1 INTRODUCTION

This chapter describes the data analysis of research stage one - **Foundation Building**. The focus of this stage was to explore the participants' expectations of the myCF pilot implementation, knowledge of computers, knowledge of self-management, system needs, and experiences of the participants as they were introduced to the myCF pilot implementation. The data analysis followed the method detailed in Chapter 4, section 4.6. The chapter is divided into two parts. In the first part the data analysis method is briefly re-introduced. In the second part of this chapter, the themes produced as a result of the inductive coding process are presented and related back to research stage one - **Foundation Building**. The data collection techniques for this stage included semi-structured interviews as the primary data source (see section 4.5.2), and observation and field notes as a secondary data source (see sections 4.5.3 and 4.5.4). The data analysis of this stage generated thirty-five axial codes and seven themes. The chapter is divided into the following sections:

- Section 5.2 presents a brief re-introduction to the data analysis method used in this research.

- Section 5.3 presents the seven themes of the research stage one - **Foundation Building**. The seven themes are: *CONDITION, MANAGEMENT, SUPPORT, CONSIDERATIONS, EXPECTATIONS, DEVELOPMENT,* and *BLOCKAGE.* The theme is defined and the relation of each axial code to the theme is first described. The axial codes within each the theme is presented with an example of that axial code from the research data. At the conclusion of each theme the initial interpretation is presented.

- Section 5.4 provides a reflection on the interpretation of stage one – **Foundation Building** and presents the initial findings from this stage.

- Section 5.5 provides a summary of the chapter.

5.2 RESEARCH STAGE ONE – FOUNDATION BUILDING

Thematic analysis was used for the data of this research (see section 4.6). The analysis was conducted at three conceptual coding levels; open, axial and final themes. Development of the open codes underwent several iterations before the final open codes were abstracted to the second stage of analysis, axial coding. In the axial code level, the detail of analysis is enriched by the iterative nature of the axial code development. The final level of data analysis involved looking at the attributes of each axial code to create the final level themes.

5.3 STAGE ONE THEMES

The focus of research stage one – **Foundation Building** was to explore the myCF pilot implementation as experienced by the participants. The analysis of research stage one focused on the experiences of the participants as they were introduced to the myCF pilot implementation, the pre-pilot experience (see section 4.4). The following sub sections explore each theme that resulted from the research stage one – **Foundation Building** data analysis. Each of the seven themes in this stage is presented through the discussion of each connected axial code. The connection of each axial code to the theme is described in relation to research stage one – **Foundation Building**. This detailed discussion is supported by the use of interview experts and links back to the concept of each axial code. At the conclusion of each theme, the association back to the overall intent of this stage is discussed. The research stage one – **Foundation Building** analysis resulted in seven themes: *CONDITION, MANAGEMENT, SUPPORT, CONSIDERATIONS, EXPECTATIONS, DEVELOPMENT,* and *BLOCKAGE.*

5.3.1 <u>CONDITION</u>

> *CONDITION* refers to the CF condition and the day-to-day individual management as perceived by the participants. It is the exploration of the activities required to treat, manage or provide care.

Physio, treatment issues, symptom presentation, symptom reactions and medication are included in this theme. *CONDITION* focuses on the treatment of the condition of the participant and their family with secondary assistance provided by health care practitioners. The six axial codes that are incorporated into this theme are *Symptoms, Symptom Response, Symptom Memory, Symptom Decline, Treatment Considerations,* and *Medical Condition.*

Symptoms are concerned with the symptom combinations for each participant and their reactions to those symptoms. Each participant with CF may have the same condition diagnosis yet the makeup of the diagnosis differs for each individual. Each participant may also experience different symptom combinations depending on a particular day. Participants add to the illustration of *Symptoms* as a descriptive axial code, the discussion of CF symptoms is not possible without commenting on the current status of those symptoms. *Symptoms* connects to *CONDITION* as the participants treat the symptoms and the symptom make up as the condition experience.

Symptom Response is the reaction to symptoms by participants once they become aware of the symptoms. The nature of *Symptom Response* is reactive. Participants rarely have proactive response. *Symptom Response* has the potential to lead into treatment options. The axial code additionally explores changing symptoms and how participants do not change their management of those symptoms. *Symptom Response* connects to *CONDITION* through participant reaction to the symptoms that form their CF condition. It is the reactive or responsive aspect towards their condition symptoms.

Symptom Memory is explored as a requirement for clinical or formal care. The axial code explores the need for the recollection of symptoms in order to provide information regarding their condition to the health care practitioners. The recall of symptoms is rarely used for personal management of symptoms and is an activity that becomes a focus closer to formal care appointments. *Symptom Memory* connects to *CONDITION* through the requirement to contribute to the formal care catalogue of symptoms during care interactions.

Symptom Decline is the negative aspect of experiencing periods of symptom change. *Symptom Decline* is concern with the illustration of unstable symptoms that can lead to periods of ill health, or frustration with CF. The nature of *Symptom Decline* is attributed as resulting from the CF condition, or treatment non-compliance. *Symptom Decline* connects to *CONDITION* through the negative representation of symptom impact on the individuals CF diagnosis.

The axial code *Treatment Considerations* connects to *CONDITION* by how CF can be treated. *Treatment Considerations* is the activity of the management for CF. The axial code is concerned with how individual treatment activities are designed to compliment the participant and family environment. The two main aspects of treatment of CF are presented as physiotherapy activities (physio) and medication. Physio activities range from the formally prescribed activities to those that are more informal in nature. Physio is expressed as either beneficial or presenting participants with completion issues. The benefits of physio are from the positive outcomes of completing physio. Children explore how completing physio may not only assist with their condition; it removes the reminders that parents provide. Issues with physio include a lack of interest or routine. Through the exploration of physio activities, participants touch upon the frequency of those activities. How often physio is undertaken depends on the established routine, surrounding life events and the current status of the participant's condition. The ways that participants create physio activities that encourage the participant to participate in their physio treatment is additionally presented in this axial code. Medication activities are presented as the non-physio treatment of CF. The medication method assists their organs to cope with some of the implications of CF. Like physio, medication is a daily occurrence.

Finally, the presentation of the formal diagnosis and the particular make up of the symptoms that each individual experience informs the axial code *Medical Condition.* This axial code relates specifically to the presentation of CF as a different set of symptoms, depending on the gene-type that the participant has been diagnosed with. *Medical Condition* connects to *CONDITION* through the diagnosis elements of CF.

The axial codes are presented below and supported with extracts from interviews and field notes to illustrate the development of each theme.

SYMPTOMS

Symptoms considers several aspects that relate to the nature of, or reaction to, symptoms by the participants. This axial code explores the symptom combinations that each participant experiences and how that symptom combination is currently viewed. The exploration of this axial code shows how symptoms can be viewed as singular occurrences or multiple occurrences. *Symptoms* additionally explore the preferred viewing habits of the participant and the health care practitioner.

> *[And just looking at the machine and looking at a few highs and lows, it's not just the same as seeing here is a scatter diagram of all the points over the last three months…] Adult Participant*

Symptoms are viewed as singular events and are viewed by participants at specific time points. Participants describe the rarity of combining symptom statuses, as participants do not automatically connect some symptoms with CF. Participants acknowledge the benefit of combining symptom views. However the current management of symptoms may not automatically allow for this.

SYMPTOM RESPONSE

Symptom Response details how participants respond to the CF symptoms, usually during an occurrence of change. This axial code illustrates the suggestion of potentially developed routines of symptom response. In *Symptom Response* the reactive vs. proactive nature of response is explored at a symptom only level.

> *[I just try to get on with things do and cover what I need to do to manage things, rather than being a suppose a bit more proactive at times.] Adult Participant*

The axial codes focuses on the tendency for the response to symptoms to remain in the background. The removal of symptom focus in favour of life elements was especially illustrated during times of stable symptoms. The axial code supports the acknowledgement of the symptom change, or the need to respond to a particular symptom. The response is reactive in nature; they do not usually respond to symptoms through the prevention of what may be coming.

SYMPTOM MEMORY

Symptom Memory relates to the capacity for remembering symptom statuses by participants. This axial code explores how periods of illness and wellness can be difficult to recollect between formal care appointments.

The existence of symptom memory is concerned with the symptom recollection for formal care reporting purposes.

> *[Yes um, because yes you do forget and three months is a long time between clinics and he could get a cough for a few weeks and I've thought I've got antibiotics in the draw at the chemist I'll give it to him for two weeks and I go and see **Doctor** and he's then okay…] Parent Participant*

The need for symptom memory is present in this axial code with emphasis, in particular for those parents whose children may not be able to compliment the interactions during formal care appointments. Events between formal care appointments are commonly lost in everyday activities, particularly if the symptoms that were once concerning have become stable. *Symptom Memory* was largely presented as a formal care requirement; the daily management of symptoms was not linked with such clarity.

SYMPTOM DECLINE

Symptom Decline is focused on an individual's condition exacerbations. The period of decline may be short-lived, acute episodes or a gradual increase of impact on the participants health. This axial code is also concerned with the decline of symptoms due to treatment non-compliance.

> *[The bowel motions and things so yes there are always those downsides.] Teenage Participant*

Symptom decline is generally linked with treatment non-compliance. The decline of symptoms through other means is rarely explored, with the occasional symptom exacerbation being explained by an outside influence, such as a cold. *Symptom Decline* is highlighted as an inconveniencing event that can be overcome through management and treatment.

TREATMENT CONSIDERATIONS

Treatment Considerations relates to the physio and medication the participant partakes in as part of CF management. The axial code has a mixture of descriptive, beneficial and concerning elements. The nature of the physio and medical activities is explored, with emphasis on the benefits and type of activities included in the physio they complete. *Treatment Considerations* is additionally related to the ways that people living with CF use traditional and non-traditional physio activities as part of physio.

> *[He does jumping on the trampoline; he does exercises on the fit ball.] Parent Participant*

Physio treatments are rarely present in *Treatment Considerations* without the benefits or issues encountered as a result of the physio activity. Physio activities are linked with symptom improvement and the maintenance of improved symptoms. The role of physio during ill health is from a symptom improvement point of view.

[…but you can tell, or if he hasn't done good physio you can tell.] Parent Participant

The issues of physio are activities that may prevent physio completion. At times, formally prescribed physio does not motivate participants to complete the required activities.

[Yeah and if I did my physio the old fashion physio I just don't do it, I work so I just don't do it.] Adult Participant

The issue of prescribed physio as a completion barrier introduces how participants use innovation to assist in physio compliance. Physio innovation focuses on the way participants create a treatment environment that enables treatment and fits in with their own preferences.

[And even a good tickle, the good tickle makes them if they've got a bit of a cough, that gets them laughing.] Parent Participant

Parents in particular explore ways to encourage their children to complete physio activities without creating a focus on airway clearance or other formal physio techniques. The incorporation of physio into play is the integration of new methods that will help when formal physio cannot always be completed.

Finally, the medication treatment of CF is explored in the axial code *Treatment Considerations* and the role it plays in the management and maintenance of CF. The familiarity of medication is highlighted, and the understanding of the necessity for medication use and the sourcing of medication are explored. The need for medication planning and the individual medication requirements are additionally explored.

[…have been born with that you know that been having antibiotics since they were born and enzymes since they were one.] Parent Participant

In this aspect of *Treatment Considerations,* the implications of non-compliance are of concern. Childhood does not usually present that barrier, as the administration of medication is something experienced since birth. Teenage participants indicate medication compliance as something that does not interest them, and the parents of the teenagers express concern on how to manage that treatment non-compliance. Adult participants indicate medication as something that becomes apart of routine, but is again not a focus of their daily activities.

MEDICAL CONDITION

Medical Condition is concerned with CF diagnosis and the status of CF in the participants support environment. This axial code explores the use of diagnostic tools and the nature of the CF condition. *Medical Condition* additionally relates to the diagnostic status, including co-morbid conditions, of the participant.

[…I've got bad joints and bad bones, …] Adult Participant

The make-up of symptoms that form the participants CF diagnosis are explored in *Medical Condition*. The exploration is not of the symptom status but the existence of that symptom. The CF condition is focused as a level of severity, indicating they have a mild or moderate case of CF. Finally, in *Medical Condition* participants discuss the gene type, or how common, their own CF diagnosis is.

The axial codes in the theme *CONDITION* have illustrated the activities required to treat, manage or care for CF. *CONDITION* is the theme where the management of the condition by the participant or family as the main care provider is explored and described the axial codes *Symptoms, Symptom Response, Symptom Memory, Symptom Decline, Treatment Considerations,* and *Medical Condition*.

CONDITION provides an overview of the participants CF condition and how they currently view and respond to their symptoms. This theme reveals that *Symptom Recall* is largely used for formal care interaction. The body language of participants with CF also reflected that participants were dismissive of small changes in their condition. When discussing these changes they used gestures of dismissal (for example, waiving hand away) when attributing small changes to some other than their CF. The response to symptoms is largely reactive and in response to changes in their condition. Participants additionally illustrate the response to symptoms is a background activity during periods of stable symptoms and only become a focal point during the times when the symptoms prevent them for their daily activities. Finally, the need for daily treatment is a regular event that moves from acceptance during childhood, to frustration when in the teenager years. Once the individual reaches adulthood, the daily treatment becomes part of the routine, to varying degrees of compliance.

5.3.2   MANAGEMENT

> *MANAGEMENT* refers to the management of the participant's condition from a medical point of view. It also includes elements that impact on clinic care management and accessibility.

The three axial codes that are incorporated into this theme are *Routine Fundamentals, Care Accessibility* and *Care Continuity.*

Routine Fundamentals is related to stable condition management. The act of managing the CF condition is viewed as unremarkable and is sometimes seen to become lost between life events. *Routine Fundamentals* connects to *MANAGEMENT* through the management of CF and the tendency in that management to become routine or habit forming. While their condition is stable, response to condition symptoms are sometimes background events, not governed by a formal timetable.

Care Accessibility connects to *MANAGEMENT* through two methods, the physical accessibility of clinic contact and the actual attendance of clinic. The physicality of *Care Accessibility* influences how participants use formal care in their management of CF. The second way *Care Accessibility* connects to *MANAGEMENT* is the approachability of the health care practitioners involved with CF care. The approachability of health care

practitioners is always easy and welcoming, despite sometimes experiencing difficulties in reaching care.

Finally, *Care Continuity* connects to *MANAGEMENT* through the comparison of completeness between their own individual management of CF and the formal care management. The activity each participant may be involved in through CF management is seen to be uncoordinated when involving care outside of clinical and allied health. myCF is perceived as potentially providing a record where all management and care interactions can be recording to ensure *Care Continuity.*

The axial codes are presented below and supported with extracts from interviews and field notes to illustrate the development of each theme.

ROUTINE FUNDAMENTALS

Routine Fundamentals explores the nature of regular condition maintenance or treatment activities. This axial code is concerned with how participants may use myCF as part of the management routine. The lack of formal routine is also explored in this axial code.

> *[… before dinner or something, because that's normally the time I do my treatments and stuff...] Teenage Participant*

The inclusion of routine relates to allocating time to specifically treat their condition. While the treatment of CF is usually identified as a background focus, participants identify a preference for a routine to complete these activities. For teenage participants the completion of treatment is perceived as a type of 'homework', completed in order to remove the parent focus they receive when treatments remain outstanding.

CARE ACCESSIBILITY

This axial code is focused on the accessibility of CF care. *Care Accessibility* reveals the physical aspects of accessing care through the distance to care centres and the method in reaching care centres. *Care Accessibility* additionally focuses on the perceived approachability of the CF care team towards participants.

> *[And all that all are really approachable so if it's a food issue I can ring James or if I've got the general question or a physio related question I can ring Jen.] Adult Participant*

The approachability of the CF care team is evident in *Care Accessibility*. Greater contact is perceived to be between the allied health professionals and the participants however all of the formal care team are approachable and contactable. The necessity for the approachability of the care team is perceived to be a requirement in *Care Accessibility* due to the sometimes complex issues that living with CF may bring through social interaction and general life milestones.

Care Continuity relates to how people living with CF perceive the completeness of their condition treatment records. The axial code is concerned with the knowledge each member of their health care team has of their prescribed and alternative treatment activities. The role that myCF may potentially have in enabling a more complete treatment record is additionally explored.

> *[Um right now every time I call up the clinic has to mentally remember what I was up to, because they don't record stuff like when I'm taking some mixture,…]*
> *Adult Participant*

The need for the formal care team to have correct recollection of each individual's circumstance and current treatment activities is a concern in this axial code. This is particularly highlighted when an individual is engaging in alternative treatment. The need for a greater record on all aspects of an individuals CF treatment is an important aspect of a holistic approach. The approachability of the formal care team can sometimes be limited by the incomplete understanding of the individual's current treatment activities. Despite this, observations of the participants during the interviews revealed open body language towards the health practitioner present and it was observed that a clear rapport had developed between the participant and specialised CF health care professional.

The axial codes in the theme *MANAGEMENT* have described the management of CF from a condition point of view. MANAGEMENT described the axial codes *Routine Fundamentals, Care Accessibility* and *Care Continuity*.

MANAGEMENT explores the activities that participants undertake in the formal management of the CF condition. *MANAGEMENT* focuses on the development of a routine in order to complete the daily treatment required to maintain stable CF symptoms. Clinic attendance is explored as a regular event, dependent on the individual symptom status. However the formal care team is described as approachable with access not restricted to the formal clinic appointments. The need for greater capture of non-prescribed treatment elements by the formal care team in the formal management of their condition is of additional concern in this axial code.

5.3.3   SUPPORT

> *SUPPORT* refers to the activities that create support for participant and their families. These activities are either performed by the participant or on behalf of the participant.

This theme additionally includes defining the support activities and the indication of relevance for participants. The four axial codes that are incorporated into this theme are *Care Communication, Seeking News, Individual Management,* and *Diary Status.*

Care Communication is the transfer of condition specific information between individuals, families and health care practitioners. The communication is initiated by either the health

care practitioners or the patient group and has been identified to contain both acute and routine information. *Care Communication* connects to *SUPPORT* through the provision of advice or information between the individuals involved in the patient's CF care.

Seeking News relates to the desire to be kept aware of diagnosis and event updates. The sharing of coping strategies and news events is particularly identified by parents of children who have CF. The axial code is additionally concerned with the desire to have a greater level of information from others in their condition group. The role of this information, as perceived by participants, is to create informal support outside of formal care. *Seeking News* connects to *SUPPORT* through the potential support mechanisms generated through information and news sharing, and the connecting of families.

The nature of condition and individual management is explored in the axial code *Individual Management*. Individual management provided by others in this axial code is often through the parent of a young individual with CF. *Individual Management* includes the different levels participants may manage CF. Participants discuss the ability and awareness of self-management and what activities they consider to be involved in self-managing. Participants demonstrate varying degrees of what they consider self-management to be. However this variety is mostly restricted in the treatment and medication of CF. *Individual Management* additionally includes the discussion of reacting purely to changes in the condition, rather than being proactive. *Individual Management* connects to *SUPPORT* through the coping ability to deal with symptom and condition change that individual management may bring. The participants rarely place a longitudinal focus toward how they treat condition changes and management of their CF is usually routine.

Finally, *Diary Status* is explored through the record keeping of condition details at the individual level. This axial code connects to *SUPPORT* by describing the status of keeping a symptom diary and the individual's perception of that current diary status. The role of the condition diary is aimed towards supporting participants when interacting with formal care. Participants identify that keeping a diary of condition items is a good idea however not all place priority on keeping, or starting, a diary.

The axial codes are presented below and supported with extracts from interviews and field notes to illustrate the development of each theme.

CARE COMMUNICATION

This axial code has both prescribed care aspects. *Care Communication* explores the communication participants have with health care practitioners in regard to their condition or seeking advice regarding their condition. Motivators for establishing contact with health care practitioners, and the communication received by participants from the health care practitioners, are also included. The depth of *Care Communication* is restricted to the event or content of the care communication.

> *[Um they ring me quite a bit, … the CF coordinator calls me quite a bit and …. calls a fair bit at the moment quite lately more her so than anyone else. You know they call a lot, yep] Parent Participant*

Frequent contact by the health care practitioner team is a regular occurrence. During times of illness, or increased symptoms, the health care practitioner team initiated contact once they were aware of symptom decline. The formal care team usually initiated regular health care practitioner contact. Patient initiated contact is purposeful in nature, for a specific reason.

SEEKING NEWS

Seeking News includes the expressing of a need or desire to seek news about the population and their perceived peers. *Seeking News* is concerned with both the condition and non-condition aspects of the Tasmania CF population. The act of seeking news is linked with two aspects, gaining knowledge about other individuals, and gaining knowledge about condition management strategies.

> *[It was in the newsletter that comes through so just finding out what's happening in around the place…keep an eye on things really.] Adult Participant*

The quarterly CF newsletter released by Cystic Fibrosis Tasmania acts as a regular source of community information regarding fundraising, diagnosis and birthday events.

INDIVIDUAL MANAGEMENT

Individual Management is concerned with how people living with CF manage the CF condition and is explored from an individual, condition and self-management perspective. While all three are linked with an individual's health, they change in focus from general health, the state of managing the condition and finally, to preventing sickness.   The condition management for general health includes the daily maintenance of health from a general point of view.

> *[…I try to look after myself……. I eat really well. Um, I am active but it's not in terms of organised sport or anything like that but you know…] Adult Participant*

The axial code is concerned with the maintenance of general health as the holistic approach to keeping well. It is not generally focused on their CF but is done because of their CF. Participants strive to maintain good health to help them cope with symptom fluctuation. The condition perspective of *Individual Management* is concerned with the daily management of the condition. It is concerned with the planned and reactive elements of symptom treatment. The axial code additionally explores the perception of acceptable condition management from a parental point of view. The child patient's awareness of what is required for the management of their condition additionally included.

> *[…it just becomes, just becomes part of your day-to-day routine so don't even think about it.] Parent Participant*

The concept of managing the condition is something that is described through a routine. Participants maintain a background focus to their condition management. The routine nature of condition management is present during times of stable symptoms. Finally, the prevention of sickness is included in the self-management perspective of *Individual*

Management. The focus for the prevention of sickness is around the mechanics of prescribed care guidance. Self-management is focused on long term planning aspects. This includes the use of medications and treatments in order to improve their condition status or to maintain the condition.

> *[That you take your enzymes, do your nebs, take care of yourself.]* Child
> *Participant*

Participants rarely explored self-management as a separate element from treatment and medications. The prevention of sickness and the maintenance of stable symptoms revolved around the participants adhering to their accepted treatment regimes. The concept of 'taking care of self' is linked to self-management, in conjunction with treatment activities.

DIARY STATUS

The axial code of *Diary Status* includes both the affirmative and negative to keeping a symptom diary in addition to the intention of diary use. The follow through of the desire to keep a record of their or their child's symptoms is augmented by the exploration of what the potential barriers are to diary keeping and how a diary may be kept in a non-traditional sense. Finally, *Diary Status* reveals the priority participants place on keeping a diary and the actual drivers for diary maintenance.

> *[No that's it that's right and I write it down and then lose a bit of paper.]* Parent
> *Participant*

The parents of individuals indicated they were more likely to keep a symptom diary, or contemplate keeping a symptom diary. Parents outlined the attempt to keep a paper diary, however organization of that diary prevented the habit to become routine. For parents unsuccessful in keeping a diary, it appeared that the paper diary was required to be a permanent formal fixture, rather than bits of paper or sections of unrelated books.

The axial codes in the theme *SUPPORT* explore the support and supporting activities for individuals in relation to CF. *SUPPORT* is the perspectives toward CF support mechanisms and described the axial codes *Care Communication, Seeking News, Individual Management,* and *Diary Status.*

SUPPORT is focused on the nature of care communication between individuals, families and the CF health care practitioners. The health care practitioners are seen to initiate the majority of care contact, particularly during times of unstable symptoms. Maintaining news through CF TAS newsletters is the main form of means individuals identify in finding out CF related events. While contact with other families is physically limited, the use of social media to find out community information is not indicated. The theme additionally explores the background focus to management during stable symptom periods. The management of the condition is generally routine focused. Self-management is separated from condition management through the active prevention of illness, largely through treatment options. The separation is largely through a future planning aspect. Finally, parents were more likely

to keep a symptom diary, or attempt to keep a symptom diary. The focus of the symptom diary was for use during formal treatment interaction.

5.3.4   <u>CONSIDERATIONS</u>

> *CONSIDERATIONS* is the perception of life activities combined with living with CF and some of the resulting behaviours that may be present when interacting with myCF.

CONSIDERATIONS refers to what is required to be considered when developing myCF. *CONSIDERATIONS* explores issues that stem from the condition or the attitudes that enable, or disable coping. The main focus of this theme is the attitude considerations of the individuals and their families. The eight axial codes that are incorporated into this theme are *Life Priorities, Life with CF, Isolation, Family Perceptions, Sustained Use, Condition Ownership, Child Manipulates* and *Consent Rationale.*

Life Priorities is explored in a number of ways, however emphasis appears to be placed either on the condition, or the placement of other life priorities. *Life Priorities* is the current state of everyday life. Consideration is not always firstly placed with CF but rather with the participant's family and their role in their family. Parents are identified as those who place priorities on young children, children who have greater awareness of their condition identify that their symptoms will determine the current CF focus. Participants discuss *Life Priorities* as a normalising element. While CF is a chronic life long condition; it is not necessarily one that frames all their life decisions. *Life Priorities* connects to *CONSIDERATIONS* through what is considered a life priority and the hierarchy of those life priorities in regards to CF treatment and management.

Life with CF is concerned with how exposure to the condition allows individuals to predict how condition status may impact on everyday life.   Participants highlight that the preferred life priorities are met the majority of the time. For those living with the condition the preferred priorities are re-considered or altered for unstable symptom periods.   This influences not only the individual priorities but also the family or support network. The influence of CF is not restricted to the diagnosed individual. The prediction of when the condition is more likely to impact of life events is something that participants associate with prolonged condition experience. *Life with CF* connects to *CONSIDERATIONS* through how participants' currently live with CF and control the potential impact periods of unstable symptoms may have on life events.

Isolation is concerned with the inability to have direct contact with others in the CF community due to cross contamination controls. The concept of *Isolation* is consistently linked to the medical reasons for non-physical contact. Geographical distance is not perceived to be the barrier preventing CF community networking and socialisation. It is the makeup of CF itself that prevents interaction with others living with the condition. The prevention of interaction is additionally explored as the inability to gain support form others who are experiencing similar situations in living with CF. *Isolation* connects to

CONSIDERATIONS by the participants ability to potentially connect through myCF, removing this perception of isolation.

The perception of family members on the management of CF is of focus in *Family Perceptions*. The exploration surrounding the management of CF also reveals the priority individuals may place on treating CF and their involvement with everyday activities and hobbies. Family members place judgement over the appropriateness of that perceived management, with participants usually found to be placing lower than family-desired focus on their symptoms. *Family Perceptions* connects to *CONSIDERATIONS* through the role the family may perceive myCF to have in enabling greater control over CF treatment and management of recorded symptoms.

The axial code *Sustained Use* relates to how often they might interact with myCF and what the future of myCF may look like. *Sustained Use* connects to *CONSIDERATIONS* through the preference for interaction and future platform design requirements, measuring against the health care practitioner project team members' predictions of interaction and design. Participants identify that the preferred method of interaction may not be a daily occurrence.

Condition Ownership is the placement of condition responsibility. *Condition Ownership* connects to *CONSIDERATIONS* through the need to understand the role people living with CF have in the treatment, management and decision making of CF for the affected individual. The responsibility of the condition lies with the parent for children with CF. The axial code hints at the gradual transfer, with varying degrees of success, of ownership to the child as they age. Adult participants may have control of the daily condition management. However family members still express the lack of ownership towards the condition. For some participants, the control of the condition is mainly with formal care, rather than the individual.

Child Manipulates relates to how the child affected by CF is unable to take ownership of their condition. The axial code explores the child tricking physio enabling devices to create short cuts in their treatment. The trickery is not usually deceitful in nature, rather the child is not interested in the treatment activities and would prefer to be engaged in an activity that holds greater entertainment. *Child Manipulates* connects to *CONSIDERATIONS* through how myCF may be subject to the child entering nonsensical data and how myCF may actually engage the child to successfully complete treatments.

Finally, *Consent Rationale* is the motivator for participating in the myCF pilot implementation. For participants under the age of 18, the motivation for pilot participation is explored through both the child and parent perspective. The underlying reasons for involvement includes the concept of helping out, and to help others. Improving their knowledge base additionally forms a part of *Consent Rationale. Consent Rationale* connects to *CONSIDERATIONS* through how myCF may address some of the reasons for pilot participation.

The axial codes are presented below and supported with extracts from interviews and field notes to illustrate the development of each theme.

LIFE PRIORITIES

Life Priorities are framed around the priority CF has in their own and their family's daily life. This includes the concept of placing family before condition management and life activities over consideration for impact on their condition. The emphasis of family and the need for 'normalisation' is present in this axial code. Additionally, life priorities highlight the importance of ensuring enjoyable life items always have focus and due attention.

> *[I run around on the treadmill, I do heaps of stuff – three kilometers an hour on the treadmill is half an hour of computer time!] Teenage Participant*

Trading treatment time for their preferred activities is especially highlighted with young teenagers. The treatment is completed in order to ensure they can add time, or create time, for the activities that hold interest for them. The treatment is not completed for compliance alone in the teenager age group; there is usually an external motivating factor.

LIFE WITH CF

Life with CF is centred on the knowledge and experience living with CF provides. The suggestion that the longer participants are exposed to CF, the greater their knowledge and practical experiences will be, is also explored.

> *[I've had to deal with this for 50 years, so I think I know bits and pieces about it.] Adult Participant*

Participants expressed that the life experience gained through living, and living past life expectancy, gives them the appropriate knowledge on dealing with the daily considerations living with CF requires. The individuals become the expert in their own care, and express the desire to share that knowledge with the younger generation.

ISOLATION

Isolation relates to the required separation of individuals due to the potential cross infection of different bacterium. *Isolation* stems from infection control and the prevention of spreading of germs. The impact of isolation appears to steam from the condition and from support of peers.

> *[…they've got each other, who else has he got, you know when you don't have an interaction with the other children and you feel so segregated it makes it hard.] Parent Participant*

For those participants with CF siblings, the interaction in dealing with CF elements is limited to the family unit. Parents in particular discuss their perception of child isolation toward CF support and experience sharing. Children with CF do not actively express a desire to meet with other children who have CF. The separation appears to be felt most keenly by the family, rather than the individual.

FAMILY PERCEPTIONS

Family Perceptions not only relates to how the family perceives the health of the participant but also how the family perceives the participant's priorities in relation to their CF. The dual lens that the health status of the participant can be viewed through – the individual and the surrounding family – is also reflected in how the participant manages their condition.

> *[...instead of us, nagging, yes, to do exercise all the time or to get outside, or to do something. Rather than play the computer, or read a book.] Parent Participant*

The *Family Perceptions* is provided mainly through the parent or the spouse of the participant. The parent role in the management of the child's CF condition places expectations of what are acceptable activities for the child to complete. The overlapping, deliberate or not, of attending to CF through everyday activities is one of the areas parents explore through *Family Perceptions.*

SUSTAINABLE USE

Sustainable Use is concerned with how people living with CF perceive the future use of myCF. This axial code additionally explores the perceived benefits that future use of myCF may bring. The willingness to allow for future myCF is also revealed through this axial code.

> *[I'm not saying I'll be on the website every day and I don't know what benefits it will be long-term to me or anyone else, but if you're not willing to have a go then you're never know.] Adult Participant*

Sustainable Use illustrated participants open to the suggestion of using myCF, without committing to a specific use pattern. The uncertain benefits cloud the potential of sustainable use for individuals however they do perceive some benefit that will be revealed with use. The sustained use is linked to the benefits that myCF will bring.

CONDITION OWNERSHIP

Condition Ownership relates to participants on several levels. This axial code firstly deals with the actual ownership of the condition, to the individual who has taken the responsibility of the chronic condition. This then leads onto why the condition responsibility is or is not with the affected individual. *Condition Ownership* is additionally concerned with the transfer of ownership of condition responsibility from the parent to the child as the child moves through the teenage years and the care transition. Finally *Condition Ownership* has a clinical communication component. Clinical communication revolves around how the level of *Condition Ownership* influences how participants interact and communication with the health care practitioners.

> *[I think I'm actually reasonably well with doing the treatments and stuff, - I haven't done that yet better do that before mum yells.] Teenage Participant*

The drivers for *Condition Ownership* can be linked back to family influences. Children with CF indicate the parent still has a controlling interest in their CF management. Compliance with what the parent perceives as acceptable management transfers some *Condition Ownership* to children and remove the parent focus.

CHILD MANIPULATES

Child Manipulates is concerned with how the child manoeuvres to create shortcuts when completing treatments and physio. Child created treatment shortcuts is additionally included.

> [..worked out at one stage okay to keep the pressure on there I'll just put my finger on the tube.] Parent Participant

Innovations used to assist with child treatment compliance reveals the manipulation some children used to skip through treatments to their preferred activities. The manipulation by the child is an escape mechanism by tricking the overseeing parent to believe treatment has been followed, avoiding arguments between the child and parent on how well treatment was adhered to.

CONSENT RATIONALE

Consent Rationale has a number of aspects. The underlying discussion of this axial code is why the participant chose to participate in the myCF pilot implementation. The reasons for participation ranged from individual benefits to the perception of their participation benefiting others in their community. The discussion of participation between the parent and the child is additionally explored in this axial code. The underlying component in *Consent Rationale* is that of helping – either the individual or others, through participation.

> [I guess I'm just happy to help with anything, with CF I suppose.] Parent Participant

Participants become involved in the myCF pilot implementation to assist the health care practitioner team and the surrounding CF community. While benefits of participation are perceived to be gained by participants from the health care practitioner point of view, participants indicate assisting others as the greater influencing factor for myCF involvement. The benefits they may gain are expressed as a secondary consideration.

The axial codes in the theme *CONSIDERATIONS* have described areas that needed to be considered when developing the myCF pilot implementation. *CONSIDERATIONS* is the theme where perspectives on the considerations toward life attitudes and activities were explored and described the axial codes Life, Life Priorities, Life with CF, Isolation, Family Perceptions, Sustainable Use, Condition Ownership, Child Manipulates and Consent Rationale.

CONSIDERATIONS explores how participants perceive *Life Priorities* competing with treatment priorities. *Life Priorities* take precedence over CF treatment during stable symptom periods. This was supported by the willingness to demonstrate their current

interests during the interviews. Discussions surrounding the participants' hobbies and interests appeared to be welcomed and prompts were rarely required for the participant to provide more information. Participants discuss how experience through CF exposure creates 'experts in self'. *Isolation* is discussed as a parent perception. Children with CF do not appear to have the same perception of isolation in regards to coping with their CF. Families attempt to maintain the balance of condition management and life activities. Participants express that most family perceptions indicate there is room for improvement. *Sustained Use* is a positive element but one where individuals are unsure just what the benefits of myCF use will be. Participants welcome the opportunity to interact with myCF in the future. Motivators for *Condition Ownership* are usually provided by the support or family network. The willingness for *Condition Ownership* can sometimes be seen as a source of peace making for children with CF. *Child Manipulates* is discussed as an escape mechanism to reduce arguments between parents and children over treatment compliance. Finally, the benefits of participation are discussed by participants as providing positive outcomes for others first, and the participant benefit as a secondary consideration.

5.3.5 <u>EXPECTATIONS</u>

> *EXPECTATIONS* refer to the participants expectations surrounding the use and interaction of myCF.

These expectations include what should form myCF, what myCF should enable or create resolution to and what interaction issues the users might expect. The five axial codes that are incorporated into this theme are *Wishlist, Benefits of Participation, Expectation of Issues, Expectation of Benefits* and *Interaction.*

Wishlist connects to *EXPECTATIONS* through the participant's ideal component inclusions for what they perceive myCF to be. This axial code is the inclusion of components for the ideal platform of their conceptualisation of an ICT designed for CF support.

Benefits of Participation is focused toward how participants perceive pilot participation in the pilot will benefit them personally. The predicted benefits that individuals include are both tangible and intangible. Improved knowledge of symptoms and their condition status are tangible benefits whilst satisfaction of helping others or CF Tasmania are intangible benefits. *Benefits of Participation* connects to *EXPECTATIONS* through the anticipation of perceived positive outcomes received by participants participating in the pilot.

Expectation of Issues relates to the negative expectations toward interacting with myCF. The level of usability of the platform and how symptom entry will be interpreted by participants are included in this axial code. The perceptions of participation not providing identifiable benefits are additionally explored. *Expectation of Issues* connects to *EXPECTATIONS* through the negative aspects that the predicted interaction of myCF would bring.

The alternative viewpoint is reflected in *Expectation of Benefits.* Both condition and non-condition benefits include condition discussion between family members and increased condition awareness. The expected benefits are developed through the current knowledge

held on what could be expected during the myCF pilot implementation experience. *Expectation of Benefits* connects to *EXPECTATIONS* through the positive aspects that perceived interaction of myCF would bring.

Finally, *Interactions* connects to *EXPECTATIONS* through the identification of how participants expect to interact with others through the myCF platform. The discussion on interaction is focused to the parent perspectives, with parent's outlined potential interaction situations that the use of myCF may create.

The axial codes are presented below and supported with extracts from interviews and field notes to illustrate the development of each theme.

WISHLIST

Wishlist is concerned with the desires of the participants from their perception of myCF. *Wishlist* surrounds the discussion of what the ideal myCF would look like as opposed to what has been outlined to the participants and is an idealised extension of the axial code *Predicted Functionality.*

> *[And his dad is looking at app things for his iPhone, so iPhone apps.] Parent Participant*

The inclusion of ICT tools currently used by individuals provides a source for items to be included in *Wishlist.* For those who have exposure to mobile technologies, this can include the inclusion of applications that plug into web portals. During the myCF pilot implementation period 19.89% of access was through mobile technologies. iPod Touch (48.15%), iPads (30.55%) and iPhones (21.30%) were the three types of mobile technologies used to access the online symptom monitoring diary during the implementation period. Participants use current knowledge of self-monitoring or health ICT to inform their ideal *Wishlist.*

BENEFITS OF PARTICIPATION

Benefits of Participation is focused with how individuals perceive participation in the pilot will benefit them personally. The benefit to be gained from participation may also be from the perception of helping others, or providing a benefit to others. *Benefits of Participation* includes condition and non-condition advantages, through gaining greater awareness of CF to meeting new people through myCF interaction.

> *[…it may benefit someone, maybe not the girls but someone else. Maybe.] Parent Participant*

A factor for participation is the perception of providing benefit to others with CF, or to the specialised CF health care professional team involved in the myCF pilot implementation. Participants indicate that while they were unable to highlight a particular benefit for their participation, they hoped that other people would benefit through increasing awareness or information.

EXPECTATION OF ISSUES

Expectation of Issues includes the potential interaction issues, such as how the individuals and the families may interpret the symptom tracking. *Expectation of Issues* is concerned with the limitation of foreseeable benefits. This axial code is associated with the perception of no or little benefit to be gained for participants.

> [Not sure. Yeah, um I don't know, don't know. It won't help us anyway will it?] Parent Participant

The gaining of neither an advantage nor disadvantage is expressed as a potential issue. The stable health status of the participant tended to create the concern that myCF would not provide any benefit through interaction. The uncertainty of what benefits interaction with myCF will provide for the participant was additionally highlighted in *Expectation of Issues.*

EXPECTATION OF BENEFITS

Expectation of Benefits is concerned with the advantages to be gained through using myCF. The advantages are either connected with the use of myCF or the mere presence of myCF in the participants' life. The exploration of this axial code revealed that parent to child condition communication benefited from the introduction of the myCF pilot implementation information.

> [I think, part of the- before when we had, we told *son* about it and then we sort of asked more questions, making sure that he fully understood about all the aspects of CF. And he did have a good grasp of some of the things, we had never sort of – not discussed - …] Parent Participant

The initiation of a CF agenda in parent and child discussions provided the opportunity for an open discussion that may have not occurred previously in such a direct manner. The confirmation of knowledge for the parent was perceived to be a benefit that appropriate knowledge was held by the child in order to manage and deal with CF.

INTERACTIONS

Interactions refer to how the participant's anticipate myCF to facilitate future interactions with their peers. This axial code additionally explores what the interaction between individuals may achieve and how this would be of benefit. *Interactions* mirror the axial code *Isolation.*

> […gee it would be lovely just to have a mum to, you know what did you do for this and how did you get the kids to do that and I'm having trouble getting to do this, that, and the other…] Parent Participant

The ability to connect to other parents for parenting support is connected with a supporting mechanism for managing their children's CF and for general parenting strategies. Contacting other parents as sounding boards for parenting difficulties is indicated to provide a partial solution to the perceived isolation parents may feel.

The axial codes in the theme *EXPECTATIONS* have described the expectations of myCF by participants. *EXPECTATIONS* is the theme that explored the perspectives of what the platform may offer and alternatively, issues that may arise with the interaction of myCF and described in the axial codes *Wishlist, Benefits of Participation, Expectation of Issues, Expectation of Benefits* and *Interaction.*

EXPECTATIONS provide insights on how the expectations of the myCF pilot implementation were framed by the technology people living with CF are currently familiar with. Observations made during the interview supported the participants stated level of technology use. Participants who used technology regularly had homes where there were laptops on the dinning table, tablets on the kitchen bench and their mobile phone close at hand. The participants who avoided technology did not own a laptop and the computer was not in the main living area/space. It was also observed for these participants that they did not keep their mobile phone close to them. Participants perceive the immediate benefit to be gained from myCF interaction is more for others, rather than the individuals themselves. The limitations of the system are with the frequency of use and difficulty of interacting with myCF. The potential for focusing unnecessarily on symptoms is an additional concern. The inability to perceive a direct benefit in using myCF is un-concerning to participants due to the perception that at least someone may benefit. Finally, interaction benefits are focused on by the parents of individuals to assist with CF specific and general parenting concerns.

5.3.6   DEVELOPMENT

> *DEVELOPMENT* refers to the functionality of the system and the communication of pilot information.

The four axial codes that are incorporated into this theme are *Pre-Pilot Knowledge, Predicted functionality, Development Involvement* and *Project Experience*.

Pre-Pilot Knowledge relates to the information held by participants about the myCF pilot implementation. This information was given through a variety of methods, the most common through the telephone and the information pack. Despite the provision of knowledge, participants indicated that the information held on the myCF pilot implementation and project was lacking. The lack of information was not due to the project team not providing adequate information but rather due to lack of memory or attention to the information sheet. *Pre-Pilot Knowledge* connects to *DEVELOPMENT* through the meaningful communication of pilot information to the myCF pilot implementation participants.

Predicted Functionality focuses on the ways myCF will deliver on the functionality anticipated. *Predicted Functionality* connects to *DEVELOPMENT* through how the functionality of the system is predicted, informed by the participants' current knowledge base. *Predicted Functionality* additionally connects to *DEVELOPMENT* through how the current knowledge base leads to the discussed functionality inclusions. It is the current

knowledge base, provided by the myCF pilot implementation participant communication that provided the ability to predict the functionality of myCF.

Development Involvement relates to the desire to be involved in the pre-pilot stages of myCF, particularly the concept design and development stages. This axial code is concerned with the desire of individuals to be involved in the myCF development in some form – either in the development stages or the actual pilot stages. Participants outline how involvement in the myCF development may be of both a personal and project benefit. *Development Involvement* connects to *DEVELOPMENT* through involvement preferences in the development of an ICT platform such as myCF.

Project Experience focuses on the participant's previous project experience. Previous project experience did not necessarily mandate involvement in the development of myCF but it did allow people living with CF to reflect on previous experiences. *Project Experience* connects to *DEVELOPMENT* through the exploration of the type of development involvement in previous projects and how that compares to the myCF pilot implementation.

The axial codes are presented below and supported with extracts from interviews and field notes to illustrate the development of each theme.

PRE-PILOT KNOWLEDGE

Recalling information provided about the myCF pilot implementation is the focus of this axial code. The meaningfulness of the pre-pilot information for each of the pilot participants is expressed during their ability to recollect the information provided during the myCF pre-pilot introduction sessions.

> *[Um, I think I have. I received some stuff in the mail and read through it and so um, I guess find out more today I suppose.] Adult Participant*

The pre-pilot material was intended to inform and prepare the participants for myCF pilot implementation participation. Participants received the pre-pilot information but indicated difficulty in the recall of the content of the information. Participants indicated a reliance on the introduction sessions to provide the required information.

PREDICTED FUNCTIONALITY

In this axial code, participant's predictions of what they had anticipated they would experience from the myCF pilot implementation are explored. *Predicated Functionality* differs from *Wishlist* as it is concerned only with the predicted functionality of myCF, not the ultimate desires for a system created for CF support. *Predicated Functionality* is bounded by the participant's knowledge of the myCF inclusions.

> *[…they can at least see and have a record and anybody can, anybody in the clinic can just call it up and say yes here it is, how is that going.] Adult Participant*

Participants use their interpretation of the pre-pilot information to predict how they feel the myCF system will be utilised.

DEVELOPMENT INVOLVEMENT

Development Involvement explores participant inclination to participate in the design and development of myCF. The axial code explores the reasons behind the level of involvement preferred and what activities any development involvement may consist of.

> *[…the start of a help for the future is CF so I'm happy to help out with that.]*
> *Teenage Participant*

The reasons for involvement are mixed in this axial code however the focus is on the actual development process, rather than the broader concept of pilot participation. Provision of assistance to others with CF, or impacted by CF, is again a reason for pilot participation in this axial code.

PROJECT EXPERIENCE

The participant's experience with ICT projects is included in *Project Experience*. Where previous project experience had been gained, the nature of that experience and any potential influence that experience had toward the consent of myCF participation is additionally explored.

> *[Just basically just to see what it is because all new to me, I've got no idea so*
> *yeah…] Parent Participant*

A mixture of experienced and non-experienced pilot participants were involved in the myCF pilot implementation. For those individuals with previous ICT experience, involvement in the concept design and development stages was not a part of their participation. The discussion of involvement in the design and development of an ICT platform to support chronic disease self-monitoring and self-management is a new concept to the participants.

The axial codes in the theme *DEVELOPMENT* have described the elements of the development process from the perspective of participants. DEVELOPMENT is the theme where the functionality of the system and the communication of pilot information were explored and described the axial codes *Pre-Pilot Knowledge*, *Predicted functionality*, *Development Involvement* and *Project Experience*.

DEVELOPMENT provides insight into the reactions toward the myCF pre-pilot information. Participants all indicated they received the information packs but the details contained in the pack are elusive. The anticipated functionality of myCF is determined by the knowledge of current chronic disease support ICTs, combined with the level of myCF pre-pilot knowledge. Involvement in the design and development of myCF is something that is unfamiliar to those participants with previous project experience. The willingness to become involved in the design and development of myCF is given greater consideration by the teenage participants. Finally, project experience is not seen to have influenced participants in their involvement with the myCF pilot implementation.

5.3.7   BLOCKAGE

> *BLOCKAGE* refers to barriers of sustained use and includes the attitudes and actions of the participants. This extents to the inclusion of the considerations that is required for interaction with ICTs.

These considerations include family or individual elements that may create problems when interacting with myCF or attempting to interact with myCF. Additionally, this theme includes the impacts concerned with assumptions of using an ICT to support chronic disease care.   The six axial codes that are incorporated into this theme are *Model Responses, Attention Negative, Barriers to Use, Computer Literacy, Communication Issues* and *Accessibility.*

Model Responses relates to participants seeking clarification that answers given during the myCF interview sessions are acceptable. Appropriate behaviour by children and their parents at clinics are additionally explored in *Model Responses*. *Model Responses* connects to *BLOCKAGE* with the potential for some participants to want to conform to behaviour they believe formal care would approve of. If participant perception of approved behaviour by formal care does not include myCF interaction this may be problematic for prolonged use.

Attention Negative connects to *BLOCKAGE* through attention avoidance due to CF. The drawing of attention to the CF condition is not always welcomed or perceived to be helpful. The avoidance in dealing with CF may discourage individuals from interacting with myCF. *Attention Negative* additionally relates to the development of condition autonomy during periods of stable symptoms.

Barriers to Use demonstrates perceptions, events or access issues that may discourage or prevent participants from using myCF in their desired manner. The layout of myCF may impair the preferred use of myCF. While *Barriers to Use* may not prevent participants from using myCF completely, the connection *BLOCKAGE* is the prevention of preferred interaction.

Computer Literacy focuses on how technology exposure that results in increased computer knowledge and confidence may be beneficial when interacting with myCF. The lack of this confidence and computer experience is seen as a preventer of use. *Computer Literacy* connects to *BLOCKAGE* through the perception of easy interaction requires a particular level of computer knowledge and experience.

Communication Issues is an intangible axial code that prevents the use of myCF by the teenage participant. The concepts of *Communication Issues* are explored as a complete block of use as the communication between the teenager and parent are not conducive to complying with condition management. This axial code *Communication Issues* connects to *BLOCKAGE* through the ability for the teenaged perception of parent condition management to prevent the potential use of myCF.

Finally, *Accessibility* informs *Barrier to Use* through the technology aspects that may impair or prevent use. *Accessibility* connects to *BLOCKAGE* as technological prevention. The

inability to access the technology that enables the use of myCF or their preferred mode of technology may prevent effective use.

The axial codes are presented below and supported with extracts from interviews and field notes to illustrate the development of each theme.

MODEL RESPONSES

Model Responses is concerned with the perceived requirement by the participant to deliver the 'acceptable' response. *Model Responses* appears to be mostly relevant during formal care interactions, rather than being connected to everyday CF treatment and management.

> [At the moment I'm feeling a little bit, I know nothing so I don't know what to expect, what to do or how to answer the questions.] Parent Participant

The myCF introduction sessions were indicated to form a part of the formal care interactions due to health care practitioner team members being present for these sessions. The requirement for a specific response is seen to be a particular area of concern for parents of individuals with CF.

ATTENTION NEGATIVE

Attention Negative relates to the negative perception of drawing attention to the individual's condition. *Attention Negative* is focused on the desire for autonomy in the individual's condition management. Additionally, the reflection of unwanted attention is explored in this axial code.

> [...it's about – you don't need someone looking over your shoulder. It's better just to get on with it.] Adult Participant

The concept of being supervised to perform tasks in conjunction with CF is explored as unnecessary and additional unwanted focus. The individual as 'expert in self' is a focus of this axial code, and can be related back to the saying 'making mountains out of molehills.' The perception of 'just getting on with it' indicates the preference for tasks to be completed quickly and with as less fuss as possible.

BARRIERS TO USE

Barriers to Use is largely concerned with the perceived barriers of use with myCF. This axial code relates to the usability of myCF and how the user-interface will appear to those using myCF.

> [Because if I get on something and I struggle, it'll be too hard and I won't bother.] Parent Participant

The anticipation of the interface creating use issues creates the potential for the platform to be viewed from a negative viewpoint, without first allowing the platform to be explored to the full extent. Unfamiliar use of an ICT initiates the inclination to judge based on the

platform interface, rather than the actual function of myCF. This poses as both a tangible and intangible usage barrier.

COMPUTER LITERACY

Computer Literacy revolves around how the participant perceives their skill level when using a computer. This perception also stems from the family, usually a parent. *Computer Literacy* additionally explores indirect communication issues that may inhibit the desire to use myCF and considerations of accessibility.

> *[I'm not really that savvy with computers and stuff like that, yeah.] Adult Participant.*

The varying levels of computer literacy held by participants includes the familiarity with computers for work function yet apprehensiveness when confronted with a new computer environment. The anxiety of perceptions of low or lacking *Computer Literacy* may be greater that the actual computer literacy levels held by the individual.

COMMUNICATION ISSUES

Communication Issues relates to how communication between the teenage participant and the parent may negatively influence the willingness of the teenager to use myCF for symptom monitoring. Additionally, the parental perspective of non-communicative teenagers is present.

> *[Gee you've explain that to me 50,000 times, how to do that, and I know how to do that.] Teenage Participant*

The exploration of repeated reminders for condition management or treatment tasks is a communication issue a parent may experience with their child. The mismatch of parent perception of the child's knowledge, and the child's perception of their own knowledge contributes to the repetitive or conflicting nature of *Communication Issues.*

ACCESSIBILITY

Accessibility revolves around the ability to access myCF and has two aspects. The first is the Internet, and the ability to connect to the Internet. Workarounds to a lack of Internet connection and how people living with CF intend to access the Internet are also present in this axial code. The second aspect is concerned with the technology that is used to access the Internet connection.

> *[But our Internet is normally very slow.] Teenage Participant*

Accessibility can be the complete or incomplete prevention of access. In the incomplete prevention of access, participants have the required access to the Internet and the technology to utilise myCF however the speed or mode of access does not allow them to access myCF in their ideal manner. Participants accessed the Internet at home and at work, using desktop based computers (80.11%) and mobile technologies (19.89%). The Internet

browsers used were Internet Explorer (45.12%), Safari (31.49%), Chrome (12.15%), Firefox (10.87%), and Morzilla Compatible Agent (0.37%). The versions of these Internet browsers varied, with a mixture of the current and earlier versions present for all Internet browsers. The networks used to connect to the Internet included dial-up, broadband and USB mobile connections. The complete prevention of access is largely concerned with the technology used to interact with myCF.

The axial codes in the theme *BLOCKAGE* have described barriers to the predicted and preferred use of myCF by participants. *BLOCKAGE* is the theme where the participant perspective toward the attitudes that may prevent myCF use were explored and described the axial codes *Model Responses, Attention Negative, Barriers to Use, Computer Literacy, Communication Issues* and *Accessibility.*

BLOCKAGE explores the need for participant behaviour to conform to acceptable formal care standards during formal care interactions. Interestingly, individuals generally require autonomy when managing CF during stable symptom periods and perceive that attention drawn to routine tasks questions their capabilities of task completion. During the discussion of their routine CF management it was observed that the participant body language became more formal and the participants' answers appeared to be delivered with an emphasis that they were capable of managing their systems. This type of statement appeared to be largely directed towards the specialised CF health care professional. myCF is required to present to participants as something that is both familiar and non threatening, in order for interaction to occur. Finally, while access to the Internet and myCF may be possible, the nature of that access may still prevent Internet interaction as ideally desired.

5.4 STAGE ONE – FOUNDATION BUILDING INITIAL FINDINGS

Research stage one – **Foundation Building** indicate that the accessibility of the myCF pilot implementation was focused on an available internet connection and the type of technology used to host the myCF pilot implementation. It was initially found that participants wished to feel socially connected to other people living with CF in some form. Specialised CF health care professionals generally initiated care communication and remained as the active participant who continuously initiated contact. Social media was not identified as a method to gain news and support. News items were generally received through the CF Tas quarterly newsletter. Participants anticipated using the myCF pilot implementation to assist them with obtaining information and experience from others living with CF in Tasmania. The technology used for the myCF pilot implementation was perceived to enable access to information that was perceived to be currently unavailable to participants. The perceived easy of use of the myCF pilot implementation was identified as an important consideration in using the online symptom monitoring diary.

Participants may desire to conform to formal care behaviour standards and this has the potential to influence their interaction with the myCF pilot implementation during the pilot period. Participants may interact with the myCF pilot implementation because they were directed to do so by their specialised CF health care professional. Interaction with the myCF

pilot implementation is motivated therefore by compliance rather than self-directed condition management. Interestingly, a requirement for participant condition management autonomy was also present. This was further supported by the indication that participants did not like close attention to treatment activities by people outside their family.

Symptom recall by individuals was predominantly carried out to report to the specialised CF health care professionals. The response to symptoms is of a routine nature and tends to carry a background focus during stable symptom periods. Treatment of the CF condition is accepted by the affected individual during childhood years and develops into a routine once into the adult years. The routine of the adult CF individual holds varying levels of compliance. It is the teenage years that are revealed to hold the most frustration with CF treatment.

The perceived relevance of the myCF pilot implementation is dependent on how the participant will be able to integrate the use of the online symptom monitoring diary into their current routines and the type of information they will be able to access by using the myCF pilot implementation. The role of technology in this research stage was demonstrated to influence participants in their willingness to interact with the myCF pilot. Participants will have a greater tendency to use the myCF pilot implementation if it is familiar technology. It was additionally found that accessing the Internet was not always straight forward for the participants.

Technology use was varied for the participants and this stage found that technology was not currently used for symptom monitoring records. The use of email has resulted in informal record keeping of electronic communication with health care professionals for some participants. Participants frequently used technology for work or school activities however the common form of technology use outside of work or school was a mobile or smart phone. Parent participants varied from avoiding technology use at home, to utilising technology to source information, connect with friends and perform routine activities such as banking or online study. Teenage participants commonly used technology for connecting with friends or gaming activities. Adult participants reflected the parent participants with a greater extreme of technology avoidance and embracing technology.

Finally, an important initial finding was that self-management appears to be driven by a future planning focus rather than incorporated into daily condition management. Treatment and medication are the main components of self-management activities. The concept of a symptom diary is a parent activity undertaken for formal care interactions for younger children.

The initial findings from this stage are:

- myCF accessibility is bounded by Internet access and technology exposure.
- Social connections enable information gathering and emotional support.
- Technology exposure determines the tendency for myCF interaction.
- A symptom monitoring diary is perceived to have different modes of use.
- Symptom awareness for health care appointments is the initial driver for myCF interaction.

- Information and managing the condition is required to be supported by the myCF pilot implementation.
- Ease of use is a complex concept and more than the physical usability of the myCF pilot implementation.
- Self-management is planning focused and limited to medication and treatment.

5.5 CHAPTER SUMMARY

Thematic analysis guided by an inductive approach resulted in the data moving through several iterations of open, axial conceptual coding levels before being abstracted into final level themes.

The focus of stage one – **Foundation Building** was to explore the participants' experience of the introduction of, and the participants' expectations of the myCF pilot implementation. The data collection focused on the experiences of the participants as they were introduced to the myCF pilot implementation, the pre-pilot experience. Each of the seven themes in this stage was presented through the discussion of each connected axial code. The detailed discussion was supported by the use of interview experts, informed by observation and field notes as secondary data sources, and linked back to the concept of each axial code. At the conclusion of each theme, the association back to the overall intent of this stage was discussed. The analysis of this stage resulted in seven themes: *CONDITION, MANAGEMENT, SUPPORT, CONSIDERATIONS, EXPECTATIONS, DEVELOPMENT,* and *BLOCKAGE.*

The initial findings from research stage one – **Foundation Building** that were presented in this chapter are:

- myCF accessibility is bounded by Internet access and technology exposure.
- Social connections enable information gathering and emotional support.
- Technology exposure determines the tendency for myCF interaction.
- A symptom monitoring diary is perceived to have different modes of use.
- Symptom awareness for health care appointments is the initial driver for myCF interaction.
- Information and managing the condition is required to be supported by the myCF pilot implementation.
- Ease of use is a complex concept and more than the physical usability of the myCF pilot implementation.
- Self-management is planning focused and limited to medication and treatment.

The next chapter presents the analysis of research stage two – **Implementation Experience**.

CHAPTER 6   STAGE TWO - IMPLEMENTATION EXPERIENCE

6.1 INTRODUCTION

This chapter describes the data analysis of research stage two - **Implementation Experience**.   The data collection techniques for this stage included semi-structured interviews as the primary data source (see section 4.5.2), and observation, field notes and web-logs as a secondary data source (see sections 4.5.3, 4.5.4 and 4.5.5). The data analysis followed the method detailed in Chapter 4 section 4.6. Research stage two - **Foundation Building** data analysis generated forty-five axial codes and eight themes. The chapter is divided into the following sections:

- Section 6.2 presents the eight themes of stage two - **Implementation Experience**. The eight themes are: *EXPECTATIONS, RELEVANCE, USABILITY, FACILITATION, CONNECTING, CARE, APATHY,* and *LIFE*. The theme is defined and the relation of each axial code to the theme is first described. The axial codes within each the theme is presented with an example of that axial code from the research data. At the conclusion of each theme the initial interpretation is presented.

- Section 6.3 provides a reflection on the interpretation of stage two – **Implementation Experience** and presents the initial findings from this stage.

- Section 6.4 provides a summary of the chapter.

6.2 STAGE TWO – IMPLEMENTATION EXPERIENCE THEMES

This section presents the themes developed as a result of the inductive coding process applied to research stage two – **Implementation Experience**. The focus of this stage was on exploring the myCF pilot implementation experience from the participants' point of view. The analysis of research stage two focused on following up from the participant experience during their pilot participation period (see section 4.4). The following sub sections explore each theme that resulted from the research stage two – **Implementation Experience** data analysis. Each of the eight themes in this stage is presented through the discussion of each connected axial code. The connection of each axial code to the theme is described in relation to research stage two – **Implementation Experience**. This detailed discussion is supported by the use of interview experts and links back to the concept of each axial code. At the conclusion of each theme, the association back to the overall intent of this stage is discussed. The analysis of research stage two – **Implementation Experience** resulted in eight themes: *EXPECTATIONS, RELEVANCE, USABILITY, FACILITATION, CONNECTING, CARE, APATHY,* and *LIFE.*

6.2.1 EXPECTATIONS

> *EXPECTATIONS* refer to recalling the expectations participants held for the myCF pilot implementation and how those expectations were or were not realised.

The expectations include the benefits the system may bring without experiencing the actual interaction of myCF, or the future use of the system. Additionally the theme discusses the comparisons of participant expectations of myCF once they had used the system. The three axial codes that are incorporated into this theme are *Expectations, Theoretical Benefits* and *Future Use.*

Expectations is the matching of the anticipated benefits or issues to the experience in the interaction of myCF. The existence of myCF creates a usage expectation of its own. Participants held a varied range of expectations with the attempt to remain open minded on how the initial use of myCF was experienced. *Expectations* connects to *EXPECTATIONS* through the very nature of the axial code, the meeting of expectations of myCF and how interaction of myCF brings further future expectations.

Theoretical Benefits relates to the anticipation of benefits through the myCF concept, without experiencing the related platform components. The translation of theoretical benefits into reality is a focus of this axial code. *Theoretical Benefits* connects to *EXPECTATIONS* through the theoretical comparison of expectations of benefits, without the actual physical experience of those benefits.

Future Use is concerned with the predicted future use after the experience of the myCF pilot implementation. The axial code has both affirmative and negative aspects to the future sustained use of myCF. The development of myCF interaction into a routine is linked with the possibility of myCF becoming a part of the participants CF management. The frequency

of future use is described as a needs basis. *Future Use* connects to *EXPECTATIONS* through the influence the measurement to current myCF expectations has on the perceived future use of the system.

The axial codes are presented below and supported with extracts from interviews and field notes to illustrate the development of each theme.

EXPECTATIONS

Expectations relate to how the myCF pilot implementation compares to the recalled participant expectations. *Expectations* explores the level of expectations a participant had before participating in the myCF pilot implementation.

> [Particularly if I wanted to do a bit of research or all have a look at some of these other areas.] Adult Participant

Limiting use to the online symptom diary for the myCF pilot implementation is an influencing factor for the successful comparison of expectations. The acknowledgement for expectations to be directly concerned with the myCF pilot implementation provides the participants an opportunity to adjust expectations so that they are realistic.

THEORETICAL BENEFITS

Theoretical Benefits is concerned with the future expectations the participant holds toward myCF through the experienced use of the platform. The perceived potential of myCF is the focus of theoretical benefits and is associated with future use benefits.

> [...because I think that the potential is there for it to be brilliant and you know. And really come in handy.] Parent Participant

The type of benefits possible through further exploration of the platform includes the inclination to see how myCF may be used after the pilot. The belief in the potential of the platform is required in order for *Theoretical Benefits* to be present.

FUTURE USE

Future Use relates to how participants predict their future interaction will be with myCF. This axial code is focused with the sustained use of myCF and the role individuals may play with the sustained use. The existence of myCF demanding future use is additionally explored in *Future Use*.

> [Um it hasn't been useful to me right now but I reckon it will be in the future. We need to use it for something.] Teenage Participant

Future Use raises discussions around the nature of the interaction of the system, in particular the role symptom change has for increased interaction. Symptom increase, or a desire for forward planning, is to be present before interaction is initiated or increased.

[…when we had the computer access, but she was quite fine and so you know like everything is the same it was just, I was just saying to my partner last night. If we had to have been doing it now them um it probably would have been assistance - as moment she has been a bit crook and I would have seen the change.] Parent Participant

The use of myCF during unstable symptom periods is revealed as an interaction mode after the pilot conclusion. The ability to visually track changing symptoms during times of uncertain symptoms provides individuals with a tangible reference to symptom status.

The axial codes in the theme *EXPECTATIONS* focus on the participant comparison of the pre-pilot expectations with the actual experience of myCF. *EXPECTATIONS* is the theme where the potential for myCF sustained use, and methods of future interaction are explored. *EXPECTATIONS* described the axial codes *Expectations, Theoretical Benefits* and *Future Use.*

EXPECTATIONS explored the nature of myCF expectations and how participant expectations are required to be managed in accordance to the level of interaction held with the system during the pilot period. Belief in the potential of myCF to positively impact those who interact with the system reveals the theoretical benefits that may arise from unanticipated method of use. The use of myCF during unstable symptom periods is linked with a strong sense of sustained use. The interaction of myCF during changing symptom periods removes the repetitive nature of symptom entry.

Participant exposure to technology acted as an influence within the theme of *EXPECTATIONS.* The role of technology in the lives of participants was both a facilitator and disabler for this theme. Participants who had knowledge of similar platforms expected a similar user experience whilst participants who did not regularly interact with technology appeared to connect myCF to an information resource.

6.2.2   RELEVANCE

RELEVANCE refers to how myCF can be incorporated with the participant's life events and activities.

The theme includes the fit of myCF's purpose and the participant's perceived purpose of myCF. Additionally, how the participant and the participant's family perceive myCF and the workarounds for use are included in this theme. The four axial codes that are incorporated into this theme are *Barriers to Use, Negative myCF Perception, Relevance* and *myCF Scope.*

Barriers to Use relates to the prevention of myCF use, or the need for workarounds by participants in order to facilitate the preferred interaction methods of myCF. In addition to system usability concerns, miscommunication at myCF introduction sessions and the content of the myCF system are perceived to be *Barriers to Use.* *Barriers to Use* connects to *RELEVANCE* through the ability of the usage barriers to negatively influence the relevance of myCF to participants.

Negative myCF Perception is concerned with how myCF is perceived by participants. The dislike of the system or the content is the basis of this axial code, with a negative emotive aspect. *Negative myCF Perception* connects to *RELEVANCE* through the potential of this axial code to disable the relevance of myCF, particularly to teenage pilot participants.

Relevance is focused on the applicability of the separate myCF system components to participants interaction requirements. Visual display elements enable participants to meaningfully interact with the myCF content. myCF content additionally influences *Relevance* to participants, in particular the content of the myCF pilot implementation questions. Unengaging interaction is perceived to limit the *Relevance* of myCF, regardless of meaningful content and scope. *Relevance* connects to *RELEVANCE* through the direct influence the content and manipulation of information from that content has on prolonged use of myCF.

myCF Scope relates to how the myCF platform is scoped. The axial code includes the scope of interaction in addition to the scope of myCF development. Participants do not see the pilot of the online symptom monitoring diary as reducing the scope of the overall platform. *myCF Scope* connects to *RELEVANCE* through the boundaries placed on the system, and participants, for interaction and the development of perceived benefit.

The axial codes are presented below and supported with extracts from interviews and field notes to illustrate the development of each theme.

BARRIERS TO USE

Barriers to Use is concerned with physical or emotional barriers to using myCF. *Barriers to Use* explores how physical components, such as the use of technology or the Internet, may prevent or discourage use of myCF. The axial code details how the preference of technology use may discourage the use of myCF.

> *[Yeah it does, apart of him coming along and taking the stick out from the side of computer and pinching it so sometimes I have to wait till he goes to bed so I can do it because he comes along to pinch it…] Parent Participant*

The interfering influence of family or other individuals on using myCF and the perceived lack of time is a non-technical *Barrier to Use.* The indication from family members that the required computer use is unacceptable to them includes the physical prevention of accessing the Internet.

NEGATIVE MYCF PERCEPTION

Negative myCF Perception relates to the emotional barriers toward using myCF. The lack of interest or satisfaction with the platform and the underlying reasons for the negative myCF perception are the focus of this axial code.

> *[…can I be brutally honest? – Nothing.] Teenage Participant*

Dissatisfaction with myCF actively removes relevance of the system to the participant. Through the *Negative myCF Perception* participants indicate their preference for no interaction with myCF. The dislike of myCF is not easily attributed to one particular component of the system. Teenage participants link *Negative myCF Perception* with no or little interest in what myCF has to offer.

RELEVANCE

Relevance is concerned with how myCF fits with participants. The relevance of myCF may be linked to the content of the platform or the technology of the platform. The axial code discusses the relevance of myCF when combined with everyday life and the routine of condition management and life activities. Finally, *Relevance* explores the match of diary questions to the symptoms of each participant.

> *[I'm not really a computer person, I rely more on myself than a computer to tell me how I feel.] Adult Participant*

The separation of computer assisted symptom reporting and the participant using him or herself to gauge symptom status indicates a mismatch in relevance of purpose. Participants may use myCF as a confirmation tool or as an alert mechanism when entered symptoms are declining. For some participants, the latter is not preferred.

MYCF SCOPE

myCF Scope relates to the boundaries of the platform. The axial code discusses the focus of the diary for participants and how the content of myCF is scoped by symptoms of CF. Additionally, the axial code discusses how participants perceived the scope of myCF to be unrestricted by the diary component.

> *[…to have his CF, not his habits but whatever has happened to him.] Parent Participant*

myCF Scope explores the perceived limits imposed on the use of myCF due to the diary focal point. The scope of the myCF pilot implementation to capture symptom specific detail is at times too narrow a boundary for preferred interaction, particularly for the parent participants. The scope of myCF is conceptually expanded by participants when discussing interaction of myCF after the pilot.

The axial codes in the theme *RELEVANCE* relates to how well individuals perceive the fit of myCF to their use and interaction requirements. *RELEVANCE* is the theme where the applicability of the myCF platform to the target user groups is explored and described the axial codes *Barriers to Use, Negative myCF Perception, Relevance* and *myCF Scope.*

RELEVANCE includes the requirement for workarounds where participants are unable to interact with the myCF system. It was observed that participants who regularly used myCF during the pilot implementation period were able to provide greater clarity on their chosen discussion topics. Those who did not regularly use myCF during the pilot implementation period focused on the usability and convenience of filling out the diary. The prevention of

use is not restricted to the myCF structure and content but also to other non-technical causes. Relevance is explored as a potential mismatch of purpose between participants and the perceived intent of myCF. Finally, the scoping of the pilot to CF symptoms places restrictions on some of the preferred interaction methods.

The reliance of the Internet acted as an influence within the theme of *RELEVANCE*. A reliable connection to the Internet was not available to all participants and this was highlighted as a barrier to use. myCF would not load correctly or the diary would take an unacceptable time to refresh during participant interaction. The assumption of reliable Internet access for all participants was incorrect and some participants, whilst able to access the Internet at work or school, did not have the Internet connected at home. The relevance of using technology for health information seeking behaviour also influenced participants in how relevant they perceived myCF.

6.2.3   USABILITY

USABILITY refers to concepts of who, how, when, where and what toward the use of myCF.

The theme presents the mode of use, the frequency of use and the motivators for use. The theme explores how the system was accessed, and what were the perceptions of that use of myCF by participants. The axial code includes the need for a wide range of users, and user requirement considerations, to be applied to myCF's actual and perceived purpose. Additionally, how the participant can impact on the usability of the system is included in *USABILITY*. The eight axial codes that are incorporated into this theme are *Degrees of Use, Quick Completion Problematic, Functionality Impaired, Diary Use Barriers, Baseline Important, Input limits Output, Mobile Access,* and *System Balance.*

Degrees of Use relates to how participants interacted with myCF. The axial code includes the method, mode and access points when interacting with myCF. Dual access with children participants provides parents with a self-check mechanism on their child's current symptom status. *Degrees of Use* connects to *USABILITY* through the demonstration of how and why individuals and their families interact with myCF. The innate user-friendliness, and accessibility of myCF is additionally explored through *Degrees of Use.*

Quick Completion Problematic is focused on the perceived lack of engagement for lengthy myCF interaction. The axial code is additionally concerned with the parent perceived lack of child reflection with the quick symptom entry of the myCF pilot implementation. Parents link the length of interaction to the accuracy of entered symptom data. *Quick Completion Problematic* connects to *USABILITY* through the perception of unengaging content on future usability and through the potential for the entered data to be meaningless compared to actual symptoms.

Functionality Impaired is concerned with the ability to perform desired functions in myCF but to an unacceptable level. The functionality of myCF is often achieved through workarounds either at a system level, or user interaction level in this axial code. Concepts of user computer interaction are present in *Functionality Impaired*. *Functionality Impaired*

connects to *USABILITY* through the influence that unexpected task workarounds has on the functionality of myCF.

Baseline Important relates to the bias the baseline of symptoms has upon the symptom reports viewed by the participant. Honest and accurate reflection of their stable symptom periods is required in order for myCF to accurately produce the comparison between daily and baseline symptoms. *Baseline Important* requires the participant to have sufficient awareness of their symptoms in order to set an appropriate symptom baseline. *Baseline Important* connects to *USABILITY* through the flow of effects of a set baseline on the usability of the myCF pilot implementation reports.

Diary Use Barriers is concerned with specific myCF pilot implementation usage issues. These issues revolve around the problematic nature of an electronic diary, incorrect reporting of entered symptoms, the relevance of the online diary questions, and the preference of electronic or paper symptom diary use. The concept of keeping a symptom diary is welcomed. However translating that concept to the active use of a diary is problematic. *Diary Use Barriers* connects to *USABILITY* through the online symptom monitoring diary as focal point of the myCF pilot implementation.

Input limits Output focuses on the influence participants have on the entered symptom data and therefore on the meaningfulness of the symptom reports. Whilst *Functionality Impaired* is the impaired operations of the myCF system, *Input limits Outputs* is the human user contribution to the meaning of symptom data. *Input limits Output* connects to *USABILITY* through the human influence to the functionality of the myCF system.

Mobile Access relates to the portability of the myCF system to mobile devices. The creation of a myCF application for use on smart phones and other mobile devices promotes the preference for interaction with myCF in a mobile and flexible nature. The use of an application of myCF for promoting greater use is additionally explored. *Mobile Access* connects to *USABILITY* through portable use concepts, and the influence these concepts have on the overall functionality of myCF for participants.

System Balance is focused on the broad range of user groups interacting with myCF and the different interaction purposes of those user groups. The balance between ease of use and meaningful data introduces complexities of interface and content design. The age of the participant and role of the individual interacting with CF additionally places requirements on the desired level of interaction with myCF. *System Balance* connects to *USABILITY* through the considerations required in matching the broad range of individuals interacting with myCF, and the purpose of myCF interaction for each individual.

The axial codes are presented below and supported with extracts from interviews and field notes to illustrate the development of each theme.

DEGREES OF USE

Degrees of Use explores the mode of use, the frequency of use and the incentive for use. The axial code reveals the how and why of myCF use. The axial code discusses the status of

myCF use and the workarounds created to prevent usage barriers. The influence a participant's age has on myCF use is explored and the involvement of external support networks using myCF is highlighted.

> *[…where you can have your own account on it or you put in it, like, if you are well and yeah and you can see what websites to look at to find information about CF and some contacts where you can call to see if there's any problems about it.] Teenage Participant*

The ability to interact with as much, or as little, of myCF indicates a freedom of use. Participants interacting with myCF did not necessarily feel compelled to explore the system beyond the myCF pilot implementation. Degrees of use is also concerned with how participants determine the frequency of use through the change in symptoms.

> *[Um, yeah at this point in time because he is well we don't use it as much but if he was unwell or unstable would definitely use it more, but not at this point of time.] Parent Participant*

The desire to use myCF during periods of symptom uncertainty is again focused upon in this axial code. The promise of greater use during periods of unstable symptoms is as yet unfounded.

QUICK COMPLETION PROBLEMATIC

Quick Completion Problematic explores the role of the individual with CF in the interaction with myCF and the speed to which myCF is completed. The axial code is concerned with the negative perception of fast completion of the myCF diary.

> *[All I do know I just thought to be a lot more interactive stuff. That's pretty much it. It took like 30 seconds.] Teenage Participant*

The negative perception is linked to the perceived lack of interactive material on the platform to engage participants in lengthened interaction time. The perception of *Quick Completion Problematic* may stem from the individual using myCF or a parent. The fast completion of the diary additionally holds concerns for the accuracy of the entered symptom data.

FUNCTIONALITY IMPAIRED

Functionality Impaired is concerned with the current functionality of myCF that does not behave in a meaningful or predicted manner. The limited ability to completed tasks has the tendency to introduce frustration to myCF interaction.

> *[I found it very annoying to logout, to go back to home then logout. That really annoyed me and it took me a while to figure it out.] Teenage Participant*

Functionality Impaired includes the ability to perform desired functions in a manner that requires workarounds or is not clearly apparent to the participants. The focus for this axial

code revolves around the incomplete operability of myCF. Participants were aware certain tasks could be completed in myCF however the act of completing those tasks was not straightforward.

BASELINE IMPORTANT

Baseline Important relates to the incorrect setup of the individual baseline which may lead to inaccurate data feedback. This axial code is concerned with the correct setting of condition status quo in myCF in order to achieve reliability tracking information from the entered symptom details.

> *[…just keeping in the center so you start in the center well that everyone can go up and down. But if you baseline is set on low then you can't really going live as a computer won't pick it up, or is giving a good ready when it shouldn't be - not so good reading] Adult Participant*

Baseline Important emphases the requirement for careful consideration of the current baseline condition for the participant. The entry of an inaccurate baseline reduces the meaningful output of symptom data for people living with CF. The baseline is set by people living with CF, requiring objective thought and careful consideration.

DIARY USE BARRIERS

Diary Use Barriers relates to the barriers present when dealing with the diary content, rather than access the myCF platform or other technology concerns. This axial code focuses on the frequency and nature of the diary entry.

> *[I really couldn't do it every day and it almost seemed futile to answer the same question again and again and again...] Parent Participant*

The nature of stable symptoms once again introduces the desire to remove repetitive data entry. The daily nature of the symptom entry is frustrating during periods of stability. The frustration can then lead participants to avoid myCF interaction.

INPUT LIMITS OUTPUT

Input limits Output is the human element of *Functionality Impaired*. Rather than the system restricting the ability to use myCF to the intended functional level, *Input limits Output* is concerned with how the inputted data influences the meaningfulness of the diary symptom output. The concept of using myCF due to pilot requirements and using myCF due to real desire is explored in this axial code.

> *[I think it would be useful, but I think a lot of it would come back and it might not have anything to do with the website. I think unless he's prepared to be brutally honest about whether you know he's taken his tablets and how is it being when he's gone to the tool that it's going to be skewed.] Parent Participant*

The need for honestly when using myCF in order to prevent biased output is present in this axial code and places illustrates the quality of the reported symptoms is only as good as the entered data. The impairment rests with the human user in this axial code, rather than the technology.

MOBILE ACCESS

Mobile Access is concerned with the current portability of myCF onto mobile devices and the creation of the myCF application in order to improve the accessibility. The axial code relates to the high use of mobile devices to access Internet platforms and how the ability to use myCF through such a device may influence the frequency of use.

> *[I didn't like the little – on the small screen on the iPhone, and a lot of the stuff I would be doing my mobile um I didn't, it's not very good on there at all and most most um websites would have a mobile interface.] Adult Participant*

The commonplace use of smart phones is present for those participants who are familiar and posses such technology. Importance is placed on the mobility of the website, as a desktop computer is not always the preferred method of access.

SYSTEM BALANCE

System Balance relates to creating symmetry between the range of individuals interacting with myCF and the content available on the platform. The balance between individual and family use and the data required for meaningful interaction is present as both a restricting and complex factor. *System Balance* additionally explores individual and family inclusion and the potential for increased interaction that may stem from inclusion.

> *[I mean it is hard I suppose when you are trying to get over a broad age group of people. But maybe to pop it into little segments you know, or at the age group is kind of thing.] Parent Participant*

The axial code additionally focuses on the different individuals accessing myCF, and how these individuals will have different requirements for the system, particularly at a parent and child level. The balance between the system's functionality, and the visual presentation of the system is required to be achieved at a number of levels.

The axial codes in the theme *USABILITY* explore how participants perceive the system. The ability for myCF to perform the anticipated functions in the desire manner is of a concern for this theme, with a number of methods, modes and frequencies of interaction present for the myCF pilot implementation participants. *USABILITY* described the axial codes *Degrees of Use, Quick Completion Problematic, Functionality Impaired, Baseline Important, Input limits Output, Mobile Access* and *System Balance.*

USABILITY explored the motivators, methods and frequency of use by participants and is a technology-focused theme. The role of myCF in the parent/child relationship is perceived to act as an additional self-check mechanism. Misinterpretation of the quick use of myCF occurs by the parents of individuals, with symptom entry perceived to be initially without

reflection. It was observed that this misrepresentation could cause conflict between parent and teenager, resulting in annoyance of the teenager. An unengaging system is also attributed to the quick nature of interaction. Incomplete functionality proves a frustration point for those who use the system and additionally appears through the influence of a correct symptom baseline. The nature of the symptom baseline demands a certain level of symptom awareness in order for the interaction to produce meaningful data. The myCF pilot implementation requires participants to be receptive to the nature of the diary. Barriers in keeping the symptom monitoring diary relate to meaningful content and easy, relevant and accessible interaction. The input of symptoms creates the context of how subsequent symptoms will be reported upon, this is the human aspect of impaired functionality. The portability of myCF is linked to the creation of a myCF application. The use of a desktop computer creates restrictions on accessibility in both a technology and physical sense. Finally, the broad range of individuals interacting with the system creates complexities between usable interact and appropriate security and context.

6.2.4   <u>FACILITATION</u>

> *FACILITATION* refers to how participants are able to use the myCF pilot implementation in the manner they desire.

Included in this theme is the achievement of activities through the use of myCF that they could not previously; what has been made easier through the use of myCF; what is required for myCF to facilitate use; and how does myCF help with symptom monitoring and mapping? The three axial codes that are incorporated into this theme are *Enables, Supports* and *Platform Change.*

Enables is the interaction of myCF allowing for the inclusion of a new activity, or the new acquisition of information and knowledge. *Enables* included concepts that allowed for benefits to be provided to individuals that previously were not possible. *Enables* connects to *FACILITATION* through the ability to successfully transfer new information to individuals through interacting with myCF.

Supports includes concepts such as allowing for the provision of support for treatment and care channels. The facilitation of decision-making activities was the major focal point of this axial code. Enhancing condition management activities and the allowance for greater detail in those activities connects *Supports* to *FACILITATION.*

Platform Change relates to the alternative structure of the existing myCF components. The axial code builds on the current myCF content, rather than the ideal platform inclusions. *Platform Change* connects to *FACILITATION* through the conceptualisation of how the current myCF platform can assist participants through improved functionality and form.

The axial codes are presented below and supported with extracts from interviews and field notes to illustrate the development of each theme.

ENABLES

The *Enables* axial code includes concepts that allowed for benefits that assist in the uptake or creation of activities that currently were not possible, and to over-come barriers. The major concept in *Enables* was that of a new activity.

> [Generally, for example – joint pain that one quite surprised me and I suppose that only one I should have mentioned earlier when I think about it, elbows aching you don't think of it and then when that was on there. So all it's all related. Because I haven't had that discussion with medical people before.] Adult Participant

The creation of new knowledge through the interaction of the myCF pilot implementation is perceived as an enabler to inform treatment, or assessment of their daily symptoms. The new activity enabled due to the interaction with the myCF pilot implementation is generally knowledge and information based.

SUPPORTS

Supports includes concepts such as allowing for the provision of support for treatment and care channels. *Supports* additionally includes aspects where current activities may be enhanced. Finally *Supports* relates to functionality that facilitates decision-making.

> [I would probably start doing my job's at that time I really need to. Instead of leaving them until the last minute.] Teenage Participant

The prompting of other CF related activities through interaction with myCF, and enhancing those activities with myCF use, indirectly informs participants for condition decision-making. The decision-making may be better informed through the increasing regularity of treatment compliance.

PLATFORM CHANGE

Platform Change axial code relates to alterations suggested by participants regarding the myCF platform. This axial code is limited to the change of existing available platform and not with desired inclusions as detailed in the axial code *Wishlist.*

> [You should have a little comment but, like they have on Facebook – on the blog, when someone makes an entry you can comment on it. With that having to write another block.] Teenage Participant

The improvement of functionality to enhance the usability of myCF is that it is individualised toward their concept of acceptable function and form. *Platform Change* is centred on knowledge and familiarity with other technology present in the participant's life.

The axial codes in the theme *FACILITATION* explores how myCF facilitates users in the ways they wish to interact with the system. *FACILITATION* is the theme where concepts of

enhancing current management activities, and obtaining new information are explored. *FACILITATION* described the axial codes *Enables, Supports* and *Platform Change.*

FACILITATION reveals myCF's ability to enable access to new information and enhanced condition management. The nature of facilitation is of a positive viewpoint, one where individuals find interaction as value adding. It was observed that participants were surprised at the new potential of information gained from interacting with myCF. Changes suggested to further increase the usability of the system are informed by the individuals current exposure to technology, notably that of social media.

6.2.5 <u>CONNECTING</u>

> *CONNECTING* refers to concepts of reaching out to others, how that is achieved and how it may be blocked.

The theme includes the incentives and conditions for information sharing. The main focus of *CONNECTING* is the non-segregation of information, whether it is CF or non-CF related. The connections discussed may be absent, active or reactive. The seven axial codes that are incorporated into this theme are *Connecting, Consent Rationale, Pre-Pilot Involvement, Provision of Hope, Information Sharing, Closed Environment* and *Isolation.*

Connecting is concerned with reaching out to others for information, support and interaction. The use of myCF in facilitating reaching out is compared to the use of social media by individuals with CF. The axial code explores the current methods of connecting with others, and is not restricted to those with CF. *Connecting* provides a parent perspective on the need to reach out for parent peer support, the awareness of other families introduces a desire to seek assistance from those undergoing similar experiences when parenting with CF. The teenaged participant with CF separates myCF from their use of social media. *Connecting* connects to *CONNECTING* through how myCF may initiate and facilitate an individual's preference for connecting with others.

Consent Rationale relates to the motivation for myCF pilot implementation involvement. The provision of assistance to others is a strong incentive for myCF participation. CF promotion through the myCF pilot implementation is additionally perceived as an activity that will positively influence the CF community of Tasmania. *Consent Rationale* connects to *CONNECTING* through the anticipation of helping others and promoting CF by myCF pilot implementation participation.

Pre-Pilot Involvement focuses on the activities, benefits and relevance for involvement in the design and development of the myCF pilot implementation. The priority of *Pre-Pilot Involvement* is constructed by parents who place their children's involvement as a greater priority than their own. Boundaries are placed for design and development activities, with the preference for initial concept development to be in place before participant involvement. *Pre-Pilot Involvement* connects to *CONNECTING* through the potential to contribute to the myCF pilot implementation and to those who will ultimately interact with myCF.

Provision of Hope is the ability to share positive stories with others in order to improve their emotional state. Rather than the perception of CF as limiting, individuals promote activities achieved in spite of living with the condition. *Provision of Hope* connects to *CONNECTING* through the positive affirmation that the selective sharing of experiences can hold for others with CF.

Information Sharing is the transfer of information. The content of the shared news may be CF or non-CF related and further facilitated by the interaction of myCF. *Information Sharing* may be restricted to the comparison of symptoms, however the scope of shared information may purposefully exclude CF related topics. *Information Sharing* connects to *CONNECTING* through the content of interacting with others and the role myCF may play in enabling that interaction.

Closed Environment is how participants would prefer the myCF pilot implementation to operate. Interaction with myCF, and the potential sharing of information, is restricted to others living with CF. The added aspect of security by defining the approved users of myCF for the child users is perceived as a privacy control by parents. *Closed Environment* connects to *CONNECTING* through the limits placed on individuals connecting with each other through myCF.

Isolation is concerned with the parent's perception of the inability to access support for other parents of individuals with CF. The prevention of cross infection is the requirement that separates individual CF families from physical interaction, which appears to contribute to *Isolation*. The awareness of other parents, but lack of contact connects *Isolation* to *CONNECTING*.

The axial codes are presented below and supported with extracts from interviews and field notes to illustrate the development of each theme.

CONNECTING

Connecting has both a favourable and restrictive focus. The requirement for connecting, whether it is for information sharing and or no real perceived need for connecting with others is present in this axial code. The favourable focus of this axial code is from the parent point of view and desire parenting support from other parents.

> *[So peace of mind ah yeah guess… We could bounce things off each other and say look forgot - what do you or what you think of this one here and yeah we could just talk to each other about it…] Parent Participant*

Connecting has a favourable focus with the opportunities that connecting with others may bring. This connection may be guided by the need for specific CF discussion or the ability to connect with another that has similar understandings of life with CF. Alternatively; *Connecting* includes the dismissal of reaching out to others through myCF.

> *[Just don't think will be used only – not really for talking just get information and stuff.] Teenage Participant*

The restrictive focus of *Connecting* relates to not wanting to associate with other CF individual's. Participants discuss the role myCF may have in connecting with others, limiting the role of myCF to an information source.

CONSENT RATIONALE

Consent Rationale relates to the motivation for participation in the myCF pilot implementation. This component explores the reasons given for involvement and why those reasons hold weight with participants.

> [Well if somebody just come up to me and asked me randomly if I would like to do something like this - I'd says yes because I would understand that I would be like role model to other people…] Teenage Participant

The perception of individual participant by others is an alternative example of providing benefit to other first and the individual second. The desire to convey CF as non-limiting is evident behind this example of *Consent Rationale*.

PRE-PILOT INVOLVEMENT

Pre-Pilot Involvement explores the inclination to participate in the design and development of myCF with the benefit of pilot participation hindsight. The axial code explores the reasons behind the level of involvement preferred and what activities any development involvement may consist of.

> [Um if my involvement was to detract from is my son's involvement then I would encourage him to be involved.] Parent Participant

Parents of participants indicated a greater desire for pre-pilot involvement in the design and development of myCF however this was to be governed through their child's preference. Using the experience of the myCF pilot implementation did not appear to change the majority of child and teenage participant preference for pre-pilot involvement.

PROVISION OF HOPE

Provision of Hope is the emotional impact of connecting with others living with CF. This axial code relates to the ability to provide positive life expectations to those newly diagnosed with CF and to those who are going through periods of hardship. Participants explore living with CF as an un-limiting factor to life achievements. Finally, *Provision of Hope* shares the achievement of others with CF to provide encouragement and uplift.

> […could be handy for someone who is feeling a bit low at I think if so-and-so can get out and climb out Everest well why can't I? To prompt for someone to say no, there is always hope. For the parents as well.] Adult Participant

The supportive element in *Provision of Hope* includes the use of reaching out to others through the sharing of positive life events and information. The *Provision of Hope* can be

deliberate, directly responding to a perceived need, or unintentional – the sharing of positive news that is beneficial to others interacting with myCF.

INFORMATION SHARING

Information Sharing relates to the act of sharing information and the environment in which that information is to be shared. *Information Sharing* focuses on the act of sharing information between individuals and the information content. Finally, *Information Sharing* is concerned with the worth of information sharing between individuals.

> *[…just that be very tempted to click on one of those I'll see, I've got something to say. And because it's Tasmanian focus to it doesn't even have to be CF related it can be who's running the Burnie 10 and then that's an incentive to me to go a look at the forum and I can say I am I am.] Adult Participant*

Tasmanian based information sharing does not require a CF focus in order to facilitate discussion and involvement. Creating relevance outside of the common CF interaction link is perceived to be of interest to those who want to engage more actively with myCF.

CLOSED ENVIRONMENT

Closed Environment is the boundaries of information sharing. Participants explore the reach of information sharing through myCF and indicate the preference for non-CF inclusion. This axial code additionally explores how others may perceive the information outside the CF community.

> *[I don't know that I'd want a share the information with a wider - so people with CF and their immediate families um. I don't know that people would generally want other people to access it.] Adult Participant*

Keeping the reach of information to those with CF, or living with CF enables the control of disclosure of information that is deliberately shared with individuals who interact with myCF. *Closed Environment* relates to the designated social components of myCF. The general information components of myCF do not appear to have such restrictions placed upon them.

ISOLATION

Isolation relates to people living with CF requiring support from others but unable to access that support. The nature of support varies for each participant however it is the lack of ability to access that support that contributes to the feeling of isolation. *Isolation* has a disconnection to others, both as a physical and emotional element.

> *[Because sometimes I feel just a little bit alone so that would help if I've um somebody else was going through the same, and they were in my predicament.] Parent Participant*

The perception of relating to others in similar circumstances is seen to reduce the feelings of isolation. The feeling of loneliness links to the inability to access other parents who are perceived to be in the same situation as the parent.

The axial codes in the theme *CONNECTING* are concerned with the disclosure of information to others interacting with myCF. The conditions and nature of the disclosure is dependent on the participant's interaction methods with the connective components of myCF. *CONNECTING* is the theme where the connecting of individuals and stories are explored and described the axial codes *Connecting, Consent Rationale, Pre-Pilot Involvement, Provision of Hope, Information Sharing, Closed Environment* and *Isolation.*

CONNECTING explores the contrasting need of individuals to connect with each other and the lack of perceived role myCF has in connecting others. Parents wish to engage with other parents for support whilst teenaged participations view myCF as only an information source. For the single parents of participants it was observed that this was a need they felt particularly strong about. Discussion around peer support was passionate and constantly linked back to technology assisting when they could not meet face to face. Participation in myCF is motivated by the perception of helping others, rather than the individual directly. The design and development of myCF was of interest to individuals, with child participation prioritised over parent participation. Limits of design and development were deemed to be necessary in order to ensure meaningful participant involvement. The intentional, or unintentional provision of hope through the sharing of experience is potentially facilitated by myCF. Information sharing, seen to include CF and non-CF aspects, is facilitated by myCF in a closed environment. Finally, isolation is multilayered. myCF can address isolation through the provision of connectivity. The actual interaction and uptake of this connectivity is at this time a theoretical concept.

Participant use of social media and email acted as an influence within the theme of *CONNECTING*. The sharing of news stories and personal information was perceived as an activity that was required to be carefully controlled. It appears that trust of the security of both the technology enabling the process and the people involved in the process is a concern to participants in this theme.

6.2.6   CARE

> *CARE* refers to the care aspects of the CF condition. *CARE* can be seen as two aspects; the formal care and treatment of the disease, and the supplementary elements to care.

The first aspect is concerned with the activities and roles the individuals play out in care. It includes how formal care is accessed and the problems associated with formal care access, activities or attendance. The latter aspect is concerned with the use of non-prescribed treatments and activities to enable care or to make care more lifestyle suited. This theme additionally includes the requirement for memory recall of symptoms. The six axial codes that are incorporated into this theme are *CF Diagnosis, Formal Care, Formal Care Problematic, Alternative Care, Innovation* and *Memory Recall.*

CF Diagnosis is the impact of the condition on life expectancy. The shortened life span of CF is the main concern when defining what it means to have CF. Details around the actual symptoms that may lead to the shortened life expectancy are not explored by individuals. For the individuals, the diagnosis of CF is shortened life. *CF Diagnosis* connects to *CARE* as it is the initiator for an individual to become involved with CF formal care.

Formal Care is the treatment activities and guidance provided by the health care practitioners. *Formal Care* focuses on the activities, frequencies and methods of attendance individuals participate in. The axial code *Formal Care* connects to *CARE* through the source of prescribed care participants receive, usually during clinic visits.

Formal Care Problematic is the difficulties created through the requirement of formal care attendance. Formal care access is considered in this axial code however the focal point of *Formal Care Problematic* is the impact the formal care environment has upon the participants during attendance. *Formal Care Problematic* connects to *CARE* through inability for participants to interaction with formal care in their preferred manner.

Alternative Care relates to treatment and management activities participants may seek outside of formal care boundaries and their own management of the CF condition. *Alternative Care* can be seen to complement formal care activities. However participants may place higher priority on *Alternative Care*. *Alternative Care* connects to *CARE* through the source of alternative care participants may seek out to complement their management of CF.

Innovation focuses on people living with CF enabling greater treatment compliance through the use of games and other non-traditional treatment techniques. *Innovation* is seen as an attempt to reduce the burden of management and treatment of CF from the child, parent or the entire family. *Innovation* connects to *CARE* through the participants attempt to incorporate prescribed treatment into their management of CF.

Memory Recall is concerned with the recall of symptoms to assist with formal care interactions. The axial code is only present when linking to formal care activities and appears to be prioritised to inform health care practitioners rather than the participant. *Memory Recall* connects to *CARE* through the ability to recall symptom status and fluctuations to inform formal care interactions.

The axial codes are presented below and supported with extracts from interviews and field notes to illustrate the development of each theme.

CF DIAGNOSIS

CF Diagnosis is focused on the life expectancy of CF and other factors that influence the individual because of their condition. The participants discuss the implications of shortened life expectancy through periods of illness and formal care consultation.

> *[And as you go through life you know, when you're born the doctors say this is how long you've got] Adult Participant*

Limited life span is a negative perception of adults living with CF. The diagnosis of CF is perceived to be attributed to a limited number of years. The shortened life expectancy frames people living with CF expectations of reaching life's milestones and engaging in life experiences.

FORMAL CARE

Formal Care is concerned about the prescribed elements of CF care. *Formal Care* explores the activities that occur during prescribed care. The perception of the activities completed by people living with CF is of additional focus in this axial code.

> [...when the do lung functions at clinic, I prefer to have it over and done with.]
> *Teenage Participant*

Formal Care is largely a descriptive axial code with access and attendance of prescribed care as inclusions. The mode of prescribed care access defines how the formal care is accessed. The type of prescribed care is focused on what type of care is accessed. *Formal Care* is additionally perceived as 'touching base' with the CF team as periods between clinics can be up to three months.

FORMAL CARE PROBLEMATIC

Formal Care Problematic discusses frustrations and negative perceptions when interacting with formal care. The negative perception of people living with CF is linked to their interaction with the health care practitioner or their attendance to formal care.

> [I hate going to clinic, a hate going on my own I think, more than anything because, so stressful because he runs a muck...] *Parent Participant*

The negative perception of formal care is not only aimed toward the nature of prescribed care but the outcomes of formal care attendance. The influence on child behaviour at clinic attendance is unwelcomed by the parent. The attendance of formal care is not the problem, rather the environment that formal care is set in.

ALTERNATIVE CARE

This axial code compliments *Formal Care* with the non-prescribed care activities participants use to manage the CF condition. *Alternative Care* is concerned with the alternative care options available to individuals and how innovation is used to ensure required care activity compliance. *Alternative Care* relates to the inclination to seek out non-prescribed care and treatment.

> [...and I like just heard a lady say recently she's gone off her antibiotics they aren't helping me and I am trying this miracle medicines.] *Adult Participant*

The perceived effectiveness of alternative treatments compared to prescribed treatments is at times at odds with prescribed care guidelines. The role of *Alternative Care* may move

from supplementary to formal care, depending on the relationship with the formal care team and prescribed care treatment.

INNOVATION

Innovation is concerned with individuals enabling treatment through the use of non-traditional techniques and innovation. The use of games to create interactive physio to improve effort is discussed along with enabling treatment fit with current life events.

> *[I've always thought it would be good to somehow have the actual physiotherapy of linked to some sort of game so became interactive. And so you had to try harder.] Parent Participant*

The use of games and innovation to improve treatment compliance incentives is explored by parents to remove the burden of treatment. Increasing the interactive nature of physio is seen as reducing the reluctance to complete required treatments activities.

MEMORY RECALL

Memory Recall is focused with the recall of symptoms for prescribed care interaction. This axial code draws out the ability to remember relevant condition details when required. *Memory Recall* additionally explores how the introduction of condition change may overshadow the recall of previous symptoms.

> *[Not really no. Um, not that good at remembering.] Teenage Participant*

Finally, this axial code is concerned with the concept of remembering symptoms versus the ability to react to how the participant is currently feeling. The ability to remember CF symptoms when required is not an identified strength for those with stable symptom periods.

The axial codes in the theme *CARE* related to the treatment and formal management of CF. *CARE* is the theme where formal care activities are explored and the enabling of treatment through innovation is seen to drive compliance improvement. *CARE* described the axial codes *CF Diagnosis, Formal Care, Formal Care Problematic, Alternative Care, Innovation* and *Memory Recall.*

CARE is concerned with the prescribed and non-prescribed care elements participants engage with as a part of CF management. Adult participants recall the bleak outlook given by the initial CF diagnosis. During the discussion about the time when their child was diagnosed with CF the parents of participants demonstrated closed body language and subdued vocal tone. Several adult participants confessed to not talking to their parents about their own time of diagnosis, for fear of hurting them or reliving painful memories. Formal care activities include any aspect of care involving a health care practitioner and tend to revolve around clinic appointments. Negative experiences with formal care are limited to the influence of the clinic environment on individuals. The access of alternative care includes prioritising alternative care treatments against prescribed care. Innovation in enabling formal care home treatment activities provides an avenue for reducing the care

burden on individuals, with the use of activities and technology based games to assist with formal care home treatment. Finally, the recall of symptoms is strongly associated with formal care interaction. The role of symptom recall is linked with formal care requirements and is to inform the health care practitioner, rather than people living with CF.

6.2.7 <u>APATHY</u>

> *APATHY* refers to the lack of participant CF knowledge and the lack of drive to acquire that knowledge.

This theme additionally deals with the individual's avoidance of dealing with their condition or condition changes. The two axial codes that are incorporated into this theme are *Condition Knowledge Lacking* and *Knowledge Re-enforcement Problematic.*

The lack of CF knowledge is a concerning factor in *Condition Knowledge Lacking*. The lack of knowledge is not identified as a new occurrence and is highlighted to be a consistent state – particularly when interacting with formal care. *Condition Knowledge Lacking* connects to *APATHY* through the low levels of CF knowledge as of occasional concern. Participants do not always attempt to add to their current knowledge base. The perception of the lack of knowledge is through dealing with formal care, rather than the knowledge of individual symptoms.

Knowledge Re-enforcement Problematic connects to *APATHY* through how known symptoms are re-enforced. This reinforcement may be through other family members but is largely in the terms of myCF reporting. The presentation of symptoms through myCF is not usually a surprising outcome of system use. *Knowledge Re-enforcement Problematic* is divided into the representation of symptoms that are already known, creating a repetitive view of symptoms and into family members expressing concern over symptoms that the participant is aware of, but not concerned by. The lack of concern for symptom change additionally connects to *APATHY.*

The axial codes are presented below and supported with extracts from interviews and field notes to illustrate the development of each theme.

CONDITION KNOWLEDGE LACKING

The knowledge level of participants, and the participant's families was explored in *Condition Knowledge Lacking*. Insufficient knowledge, and the continued state of the perceived lack of knowledge without initiating changes forms the basis of this axial code.

> *[At the moment I'm feeling a little bit, I know nothing so I don't know what to expect, Because I seem like I know nothing about CF…..] Parent Participant*

The reinforcement of their lack of knowledge is present through interaction with myCF. The axial code of *Condition Knowledge Lacking* displays two levels of knowledge insufficiency; a lack of perceived knowledge and a lack of desire to create knowledge. The

disregard for their symptom status, and the lack of desire to monitoring symptoms relevant to their condition is also present.

> *[…I don't even have a blood sugar diary and I've got diabetes!] Adult Participant*

The confession of non-compliance with condition records can be presented as a status of independence. The no care attitude of their condition is at odds with the requirement of daily entry for the myCF pilot implementation.

KNOWLEDGE RE-ENFORCEMENT PROBLEMATIC

This axial code had two aspects to the problematic nature of re-enforced knowledge. The first area is concerned with how myCF reported what they already knew about their condition, or what their family knew about their condition. The repetitive nature of the perceived condition status and the system illustrated system status was not something that was found helpful, or inclined to react to.

> *[um just because it basically like, just every day - It was just telling me what I already knew pretty much. But just in a graph form and stuff. Um - it just over it - a bit boring for her think because she was like – she'd fly through the questions and they were the same answers as yesterday yeah] Parent Participant*

The reception of repetitive information could be potentially transferred to complacency of data entry. The second area of the axial code related to the unwillingness to deal with the re-enforced knowledge provided to the participants.

> *[…my partner wants to bring me to hospital because she thinks I'm really sick and I don't think I'm really sick, but this is was happening. Um coughing up a cup of blood every morning and I am not worried…] Adult Participant*

The second area of the axial code related to their daily condition, or their changing symptoms. The participant experiences changing symptoms however the reaction between the participant and the family is mismatched.

The axial codes in the theme *APATHY* have described a lack of CF knowledge and the lack of desire to attain that knowledge. *APATHY* is the theme where participants discussed the impact of known symptoms displayed through the myCF symptom diary and described the axial codes *Condition Knowledge Lacking* and *Knowledge Re-enforcement Problematic.*

APATHY is demonstrative of a lack of perceived knowledge and lack of desire to create knowledge. The lack of desire to create knowledge is perceived by some participants as separating themselves from CF. Observations support this through the participant body language and tone of voice. The conversation is often quickly changed to a non-related topic to demonstrate their lack of interest. Record compliance is at odds with the pilot trial requirement of daily symptom entry. Repetitive data entry can lead to compliancy, disabling reflection of symptoms. Finally, *APATHY* reveals the response to myCF re-enforcing changing symptoms varies between the adult participant and surrounding family.

6.2.8 LIFE

LIFE refers to the concept of dealing with life and the behaviours, decisions or activities that are driven by or demand consideration by their CF.

The theme explores the behaviours that CF may drive them to exhibit, and the overlapping of CF onto their daily life. The included concepts are largely unstable, and may need reconsideration at a daily or even, hourly basis. The nine axial codes that are incorporated into this theme are *Balanced Management, Normalisation Needed, Condition Awareness, Condition Consequences, Model Behaviour, Family Isolation, Positive Feedback Sought, Condition Determines* and *Technology Use.*

Balanced Management is focused on balancing the potential competing interests of condition management and life activities. The axial code is concerned with how people living with CF chose to prioritise the condition activities with other life activities. *Balance Management* provides the parent focus of how and if parents chose to inform their children of the details of CF and how the parent encourages the child to comply with the management activities. The determinants and prevention of risks toward stable symptoms is also explored in this axial code. *Balanced Management* connects to *LIFE* through the placement of CF management in life activities and the considerations required achieving that placement.

Normalisation Needed is the avoidance of special treatment due to their diagnosis of CF. The provision of pity is unwelcomed by individuals from those outside the CF community. The idea of 'just getting on with things' is linked into *Normalisation Needed.* *Normalisation Needed* connects to *LIFE* through the need to normalise their daily activities to those without CF.

Condition Awareness is focused on the individual, family and public awareness of the CF condition. The level of awareness is considered to be both a deliberate act to either be aware or unaware of symptom status, and the non-deliberate act in not understanding how symptoms are connected to CF. The axial code additionally explores the concept of condition ownership and the influence upon *Condition Awareness. Condition Awareness* connects to *LIFE* through the link between CF condition awareness and the resulting influences the awareness has on life activities.

Condition Consequences is the consequences experienced by people living with CF. The impact of CF on participants, and the treatment considerations are explored in this axial code. The enabling of life activities through medication and treatment create a continuous requirement of some level of compliance with these treatment activities. The influences of symptom status and change toward life activities are of additional concern in this axial code. *Condition Consequences* connects to *LIFE* through the repercussions of living with CF.

Model Behaviour relates to participants attempting to understand the formal care perception of acceptable behaviour during formal care interaction. The axial code arises during formal care interaction and does not appear to govern other family behaviour. The conforming to *Model Behaviour* is specifically for the purpose of formal care contact.

Model Behaviour connects to *LIFE* with the considerations of conforming to behaviour formal care approves of. This behaviour may then influence the choice of life activities and interaction with myCF.

Family Isolation is concerned with the inability to connect with other families when the desire to do so is present. The perceived isolation is experienced through both a physical and emotional sense, with some participants unsure on how to initiate access to peer support. Isolation from others in a physical sense is a requirement to prevent cross infection between people with CF. *Family Isolation* connects to *LIFE* through the perceived lack of peer support that is equipped to relate to CF influenced concerns.

Positive Feedback Sought relates to the requirement for participants to receive and focus on the positive symptom changes. The colour coded symptom summaries in the myCF online diary are attributed to positive and negative values. The positive values are sought by participants. *Positive Feedback Sought* connects to *LIFE* through the encouraging influence toward the participants emotional state when symptoms are indicated to be improving via myCF.

Condition Determines is the determination of life event participation by CF symptoms. The focus people living with CF place on symptom monitoring and management can be rendered irrelevant when the individual is physically unable to engage in preferred activities due to changed symptoms. During periods of unstable symptoms, individuals may be required to change their plans without notice. *Condition Determines* connects to *LIFE* through the potential of frequent condition reflection that may dictate daily activities and/or changes daily activities.

Technology Use is the use of technology by participants. The type and frequency of technology access is determined through work functions, school functions or recreational activities. For individuals with constant exposure of technology in daily life, incorporating ICT enabled monitoring is preferred through current technology sources. *Technology Use* connects to *LIFE* through the current status of technology in everyday life and how that technology may support the myCF platform or something of a similar nature.

The axial codes are presented below and supported with extracts from interviews and field notes to illustrate the development of each theme.

BALANCED MANAGEMENT

Balanced Management is centred on three aspects. *Balanced Management* explores how balance is needed between focusing on the individual's CF and the remaining aspects of their life. This axial code is additionally concerned with how the participant desires to be interacted with without focus on their condition. Finally, *Balanced Management* explores the awareness of the CF condition from an internal and general public perspective.

[It's probably made me, in a good way focus on a more but I can see the tendency maybe that you might dwell on some of things now because you've been – you're having to reflect on them all the time. So I think that has to, you have to be aware of it may be more than anything.] Adult Participant

Balanced management is concerned with achieving a sense of balance between their daily lives and the management of their condition. The make-up of that balance is largely individual and is determined by their current life priorities. The tendency to overthink symptoms is concerning, but perceived to be manageable. The aspect of continuous reflection requires people living with CF to determine when deliberate or routine response is required toward symptom make up.

NORMALISATION NEEDED

Normalisation Needed relates to how each participant attempt to remove the CF focus from interactions with others. This can be to either protect family members or to protect how they currently experience life interactions. The protective element extends to both others and the individual.

[…but not that I'd want him to be aware I have all those sort of symptoms and things like that – I'm just Mum] Adult Participant

The avoidance of pity, from other family members and those outside the family, is desired by the participant in order to draw focus away from the CF condition. Consideration of others is desired however that consideration should not include unnecessary detail of symptoms and treatment.

CONDITION AWARENESS

Condition Awareness is concerned with awareness of CF by individuals and the larger community. This axial code explores the awareness that individuals, children in particular, have of CF. The public awareness of CF, and how this awareness may be improved, is additionally of focus.

[…that you still get other students that go you know what is cystic fibrosis? Is that just banging on the back and I think you know we really need to raise the profile] Parent Participant

The existing profile of CF in the greater community is seen to be lacking by participants. Participants have a desire for greater public awareness in order to fundraise and to help develop the appreciation of the daily regimen that most individuals go through in order to manage their CF. This aspect of the axial code does contrast with the axial code *Normalisation Needed.*

CONDITION CONSEQUENCES

Condition Consequences explore the repercussions of living with CF, either as the affected individual or the surrounding support network. The bottom line of living with CF from a

diagnosis and lifestyle point of view presents individuals with a daily impact. The consequences of living with CF are additionally present through formal care interactions.

> *[I went to doctor you know whenever I was sick you know they would tell my parents you know, take him home and this is how long you've got left now and there is nothing positive about it...] Adult Participant*

Historically, the adult participant recollects the negative outcomes linked to CF and the constant referral to limited time. While a shortened life span is still possible with the diagnosis of CF, the meeting of a greater number of adult milestones is something that individuals place emphasis upon.

MODEL BEHAVIOUR

Model Behaviour is the tendency to gauge acceptable behaviour through health practitioner guidance. This axial code is focused on the placement of boundaries on behaviour by prescribed care, rather than people living with CF creating boundaries.

> *[I don't know how far he is allowed to run amok before I start growling and things like that.] Parent Participant*

The uncertainty in parent authority during formal care interactions is created through the parent appearing to require guidelines from the health care practitioner. Two power hierarchies appear in *Model Behaviour*, the parent-child and the health care practitioner and parent.

FAMILY ISOLATION

Family Isolation relates to people living with CF requiring support from others but unable to access that support. The nature of support varies for each participant however it is the lack of ability to access that support that contributes to the feeling of isolation.

> *[There's a lot of us out there are suppose so it's nice to – because you don't meet anyone they don't like to mingle all that sort of thing because of the bugs that but down the line it could be...] Adult Participant*

Family Isolation has a disconnection to others, both as a physical and emotional element. The requirement for physical distance to be maintained due to cross infection fears is understood, but a source of frustration for parents. The automatic inability to interact physically contributes to the feelings of isolation, in addition to the knowledge of the existence of other families that could be a potential source of support.

POSITIVE FEEDBACK SOUGHT

Positive Feedback Sought is concerned with receiving positive symptom feedback through the interaction with myCF. The preference for improved symptom response and how positive feedback symptom feedback motivated for greater focus of management is a focal point.

> *[Yeah and we didn't see any green and I like green. I think. Green is a good sign.] Teenage Participant*

Attributing a preference for the green symptom output attaches an emotional value to the symptom data. The preference for the indication of symptom improvement underlies the emotional value. The absence of green symptom output has the potential to reduce myCF interaction, rather than increase condition management.

CONDITION DETERMINES

Condition Determines explores the nature of planning around the CF condition. This axial code is demonstrative of the tendency for the symptoms of CF to determine behaviour or life events. *Condition Determines* relates to the overlap of CF onto the daily lives of people living with CF, regardless of how CF management is prioritised. Finally this axial code explores the ever-changing nature of decisions or activities that are driven by or demand consideration by the condition.

> *[I'm always getting in to trouble in doing too much. That takes my mind off, so I'd just go and do it.] Adult Participant*

The measurement of acceptable behaviour levels and the matching of a participant's behaviour to those levels is not always in sync. The participant does not always follow through with the guidance of daily activities through the CF condition, with the continued involvement in preferred activities acting as preventing over bearing condition focus.

TECHNOLOGY USE

Technology Use relates to the use of technology in the participant's life. The axial code explores the familiarisation of technology when associated with planned tasks and the impact the introduction of new technology use may have. *Technology Use* is additionally concerned with the positive or negative perception participants may have with the use of technology.

> *[…because, most people these days have iPod touches, – which would be a lot easier for an iPod user with CF, and myCF app.] Teenage Participant*

The disseminated technology within the CF community includes mobile devices such as smart phones and iPods. Providing incentive and ease for use is indicated through the provision of a mobile application that enables one touch access to the myCF website. The traditional use of desktop computers does not always fit with the current use of technology.

The axial codes in the theme *LIFE* is concerned with concepts of dealing with life and the behaviours, decisions or activities that are driven by or demand consideration by their CF. *LIFE* is the theme where the broader intersections of life activities and the CF condition are explored and described the axial codes *Balanced Management, Normalisation Needed, Condition Awareness, Condition Consequences, Model Behaviour, Family Isolation, Positive Feedback Sought, Condition Determines* and *Technology Use.*

LIFE explores the nature of balanced CF management for individuals, and how the definition of balance can prove to be very individualised. Participants wish for the avoidance of pity due to CF however they desire the profile of CF to be raised for fundraising and greater levels of public understanding. Historically, adult participants were exposed to concepts of limited time and a bleak future. The power hierarchy of the parent/child, and the health care practitioner/parent is explored to find some boundaries blurred with the requirement for certain behaviours during formal care interaction is present for parents of CF individuals. The isolation of families is contributed by the inability to interact with other families physically. This can be then translated to an emotional feeling of isolation. Participants require green symptom data outputs to add to feelings of satisfaction with symptom status. Syncing behaviour to condition limits is not always achieved nor a concern to participants. The un-synced behaviour is additionally used as an avoidance technique. Finally, technology in some form is evident in everyday life with varying degrees of use and acceptance. Observations of technology at the homes of each participant reflected the level of technological interaction described by each participant.

6.3 STAGE TWO – IMPLEMENTATION EXPERIENCE INITIAL FINDINGS

The initial findings from research stage two – **Implementation Experience** indicate the complete myCF pilot implementation concept did not completely match the design requirements of the participants. The range of individuals who can potentially interact with the myCF pilot implementation requires finding and maintaining a balance between functionality and form. Despite this, it is evident that participants believe the specialised CF health care professionals accurately captured the basic concepts of an online symptom monitoring diary.

Parents were expressive of the desire to connect with others. Teenagers with CF view myCF as more of an information portal rather than a communication tool. Isolation concepts were strongly linked to the combination of knowledge and access. Parents were aware of other families living with CF but they are unable to access those families for support and education. The perceived isolation was interestingly connected with the family of the participant, rather than the individual themselves.

The recall of symptoms had a strong link to formal care activities. Formal care interaction appeared to also influence the power hierarchy of the parent/child and the parent/CF specialist health care professional. For participants with stable symptoms, the repetitive nature of stable symptom data was problematic and may lead to compliancy with data entry. The lack of desire to create knowledge for CF management was viewed as separating the participant from the CF condition. The new behaviour of keeping a symptom diary was at odds with the current lack of diary use. The highlighting of changing symptoms by the myCF pilot implementation reports had mixed reactions, with the increased awareness of symptoms not always resulting in proactive condition management.

CF management was viewed at three distinct levels. Participant self-care included the daily maintenance of health from a general point of view. Condition management of CF was

identified to be unremarkable and routine. Self-management had more of a planning approach, to prevent sickness. An important initial finding for this research stage was that the participant did not always initiate self-management activities. Additionally participants rarely explored self-management as a separate element from treatment and medications.

The influence of family on the duration of the myCF pilot implementation interaction appeared to be a restricting factor, particularly for those who are parents with more children than just the child with CF. The restriction is found in the attraction for the other children to use the computer, making it difficult for the parent and child with CF to use the myCF pilot implementation without interruption. The excitement of the other children leads to a tendency to not to want to use the myCF pilot implementation, as the parent finds it difficult to assist the child using the computer, and to distract the other children, who want to use the computer.

Accessibility of the myCF pilot implementation was not concerned with the Internet but rather with the technology used to access myCF. The myCF pilot implementation was revealed to be easy to interact with for all participants involved in the pilot. The easy interaction was translated into two ways and reflects the irony that the easy use of the myCF pilot implementation is a complex issue. The first interpretation is that the easy interaction was an enabler that allowed participants to use the myCF pilot implementation in their preferred manner without hassle. However, there is evidence that the easy interaction impaired the time available for participants to reflect upon their symptoms, leading to automatic input of symptom levels.

Technology was present in the participants' life with varying roles and use priorities. The participants who currently used technology and were comfortable in using that technology were more inclined to use the online symptom monitoring diary during the pilot. The participants with current technology exposure were additionally more inclined to see a future use for the myCF pilot implementation.

The relationship between life events and the use of the myCF pilot implementation is multifaceted. For those with stable symptoms, the influence of life is an order of priorities. During periods of unstable symptoms, it appeared the focus moved from the greater life concepts to the participant's condition. It appears that the family of the participant can influence the frequency and length of the myCF pilot implementation interaction.

This research stage illustrated that participants placed limits on when and how the myCF pilot implementation was to be used. The influence of stable symptoms was apparent through both the perceived and actual use of the CF pilot during the pilot period. Other influences such as life and family did have some impact towards the use of the myCF pilot implementation. The existence of stable symptoms was the predominant cause of lower interaction levels and perceived helpfulness.

It was found that the lack of predictable access was a deterrent for interacting with the myCF pilot implementation. The influence of the entered symptom baseline adds to this frustration however this is a human controlled component, rather than the incomplete functionality of the system. When participants used the myCF pilot implementation reports

they either became frustrated with the obvious information begin reported to them or the participants reflected on their current condition management strategies. Aligning with the frustration of the entered baseline is the participants experience with the traffic light reporting from the myCF pilot implementation. The traffic light reporting was not compatible with participants who experience a high symptom baseline. This research stage found that participants attributed subjective meanings to the colours of the traffic light system. The colour green was linked to positive feelings, participants welcomed the colour green and it appeared to re-enforce their current condition management status. Participants aimed for green and this was at times difficult for those on a high baseline. If a participant was on a high baseline, the opportunity for symptom improvement was small; therefore the likely colours to be returned via the traffic light system were either orange or red. Participants did not appear to focus on the colour orange, for those with either stable or unstable symptoms it was an indication of neither improving nor declining. Finally, the returned colour of red was linked to not only symptom decline but also to the participants feeling that their current condition management strategies were not 'correct'. There is a concern that the participant could be managing their condition appropriately and still receive the reported red symptom indicator. The participants perceived the traffic lights to be a quick and visual way to view the status of the daily entered symptom against the logged baseline symptom. The use of the baseline as the comparison point emphasises the importance of correctly implementing the traffic light reporting system.[5]

Finally, the participants' measurement of perceived usefulness was not dependent on the physical use of the myCF pilot implementation. The interaction of the myCF pilot implementation appeared not to be required for benefits to be gained. The range of participants introduced a number of different criteria for which participants judged the myCF pilot implementation on it's perceived helpfulness. The criteria included how symptom awareness was impacted, how easy the system was to access and interact with, and the meaningfulness of the information retrieved from the myCF pilot implementation. The judgement criteria additionally included emotive elements of inclusion, control, and accessibility of information.

The initial findings from this stage are:

- Influences for using the myCF pilot implementation are symptom focused and the creation and sharing of information.
- Connectivity is required as a concept but not as an activity.
- The development of participant monitored symptom records is clinically focused and scoped to periods of unstable symptoms.
- The family of the participant influences interaction with the myCF pilot implementation.
- The influence of mobile technology is conducive to routine management.
- Stable symptom periods are perceived to lower symptom monitoring benefits.

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[5] There is a need for further insights to be gathered on the impact of traffic light reporting implementation, and the relationship between symptom baseline and reported symptom outline, however it is not the focus of this research.

- Symptom monitoring leads to increased awareness of symptoms.
- Technology initially enables interaction with the myCF pilot implementation and moves to block or provide impaired myCF pilot implementation access.
- Participants subjectively interpret objective symptom reporting by the myCF pilot implementation.

6.4 CHAPTER SUMMARY

This chapter has presented the data analysis and initial findings of stage two. Stage two– **Implementation Experience** explored the myCF pilot implementation as experienced by the participants. The data collection focused on the myCF pilot implementation with a view on exploring the implementation and pilot experience from the participants' point of view. Each of the eight themes in this stage was presented through the discussion of each connected axial code. The detailed discussion was supported by the use of interview experts, informed by observation, field notes and web-logs as secondary data sources, and linked back to the concept of each axial code. At the conclusion of each theme, the association back to the overall intent of this stage was discussed. The analysis of this stage resulted in eight themes: *EXPECTATIONS, RELEVANCE, USABILITY, FACILITATION, CONNECTING, CARE, APATHY,* and *LIFE.*

The initial findings from research stage two – **Implementation Experience** that were presented in this chapter are:

- Influences for using the myCF pilot implementation are symptom focused and the creation and sharing of information.
- Connectivity is required as a concept but not as an activity.
- The development of participant monitored symptom records is clinically focused and scoped to periods of unstable symptoms.
- The family of the participant influences interaction with the myCF pilot implementation.
- The influence of mobile technology is conducive to routine management.
- Stable symptom periods are perceived to lower symptom monitoring benefits.
- Symptom monitoring leads to increased awareness of symptoms.
- Technology initially enables interaction with the myCF pilot implementation and moves to block or provide impaired myCF pilot implementation access.
- Participants subjectively interpret objective symptom reporting by the myCF pilot implementation.

The next chapter presents research stage three - **Life Context.**

CHAPTER 7 STAGE THREE – LIFE CONTEXT

7.1 INTRODUCTION

This chapter describes the data analysis of research stage three – **Life Context**. The data collection techniques for this stage included unstructured interviews as the primary data source (see section 4.5.6) and observation, field notes and web-logs as a secondary data source (see sections 4.5.3, 4.5.4 and 4.5.5). The data analysis followed the method detailed in Chapter 4 section 4.6. As detailed in chapter four, section 4.4 stage three focused on the development of rich case studies. The data analysis of this stage generated twenty-four axial codes and four themes. The data gathered from research stage three – **Life Context** was complemented by data from research stage one – **Foundation Building** and research stage two – **Implementation Experience**. The developed case studies provide both an individual and collective viewpoint of the myCF pilot implementation experience and the patient participant's current life situations. Each case study is presented in the following manner:

- o General introduction of the case study
- o Table presenting the demographics and myCF pilot implementation web-logs
- o Insights gained from the unstructured interviews held with the participant enriched with observation data to create the participants story
- o Presentation of how the case study compares to the overall analysis of research stage two **Implementation Experience**.
- o Reflection of the case study towards the research.

In this chapter nine case studies are presented. The chapter is divided into the following sections:

- Section 7.2 outlines the four themes of stage three – **Life Context**. The four themes are: *ATTITUDE, TRYING TO BE NORMAL, CONDITION AND SOCIAL INTERACTION,* and *CF KNOWLEDGE*.

- Section 7.3 presents Case Study A. Dennis is a 20-month old child who lives with him mum, dad and older brother. This case study is written from his mother's point of view.

- Section 7.4 presents Case Study B. Iain is a 5-year old child who lives with his mum and dad. This case study is written from Iain's and his mother, Nikki, points of view.

- Section 7.5 presents Case Study C. Keir is a 3-year old child who lives with his mum. This case study is written from his mother's point of view.

- Section 7.6 presents Case Study D. Jarrett is a 14-year old boy who lives with his mum and dad. This case study is written from Jarrett's and his mother, Jenny, points of view.

- Section 7.7 presents Case Study E. Nate is a 12-year old boy who lives with his mum, dad and older brother. This case study is written from Nate's and his mother Mary's, points of view.

- Section 7.8 presents Case Study F. Saxon is a 15-year old teenager who lives with his mum, dad, twin sister and younger sister. This case study is written from Saxon's, his mother Jacqui's and father Sebastian's, points of view.

- Section 7.9 presents Case Study G. Wallace is a 52-year old male who lives with his wife and two cats. This case study is written from Wallace's point of view.

- Section 7.10 presents Case Study H. Martin is a 45-year old male who lives with his wife, three boys, two dogs, cockatiel and about 10 cars. This case study is written from Martin's point of view.

- Section 7.11 presents Case Study I. Nyda is a 36-year old female who lives with her husband and two boys. This case study is written from Nyda's point of view.

- Section 7.12 presents the case study comparisons with each other and with the stage one – **Foundation Building** and stage two – **Implementation Experience**.

- Section 7.13 provides a reflection on the interpretation of stage three – **Life Context** and presents the initial findings from this stage.

- Section 7.14 provides the findings that emerged from the integrated interpretation of the concept map.

- Section 7.15 provides a summary of the chapter.

7.2 STAGE THREE – LIFE CONTEXT THEMES

The focus of stage three – **Life Context** was to develop a rich description of the myCF pilot implementation participants, their lives and the impact of CF. The analysis of stage three data enabled the development of the individual case studies used to present the four themes of *ATTITUDES, TRYING TO BE NORMAL, CONDITION AND SOCIAL INTERACTION,* and *CF KNOWLEDGE.*

ATTITUDES refer to the positive and a negative perception of CF by the participant or by others. The theme included aspects of positive thinking, negativity and indifference to CF and how it impacted on life activities. *ATTITUDES* were perceived by the parents of the teenagers as a something that was required as the teenager moved into adulthood. Parents of teenaged participants thought it was important for their children to have the appropriate attitudes regarding CF, in order for the successful transition of the management for CF from the parent to the child. *ATTITUDES* were perceived as a matter of priority between CF managed or life priorities. *ATTITUDES* were dependent on how the participant viewed their life activities. When participants regarded CF as a low priority the condition frustrated the participants when it limited what they wanted to do.

TRYING TO BE NORMAL refers to achieving 'normality'. This was an unsurprising theme as participants felt that it was important that they were not know for their CF. It was more important for participants to be involved with their life activities despite their CF. An interesting part of this theme was the participants sometimes wanted people to know they had CF, to show they could achieve their goals no matter their health status. *TRYING TO BE NORMAL* was a complex theme and did not only concern the participants. The participants support networks appeared to assist the participant when they wanted to promote or deflect their CF.

CONDITION AND SOCIAL INTERACTION refers to socialisation. This theme was strongly connected to the parents involved in the myCF pilot implementation. The responsibility of parenting decisions that connected to CF condition management was the main part of this theme. The dilemma of wanting control over the parenting and socialisation of their child, and complying with the required CF condition management was reflected in *CONDITION AND SOCIAL INTERACTION.* The theme appeared to be of greater concern to parents and children. The parents of younger children particularly wished for their child to have access to a peer support network.

CF KNOWLEDGE refers to the CF knowledge that was perceived by participants. This theme included the participants, their support networks and the general public. Participants placed their own judgements on the level of CF knowledge they held and compared this to what the participants perceived was appropriate. The measurement of CF knowledge appropriateness was obtained from the specialised CF health care professionals involved in the participants care, or the opinions of the participants support network. *CF KNOWLEDGE* included aspects of frustration as people did not appear to understand what it was like to live with CF. Teenaged participants wished for more awareness of CF but at the same time did not want attention drawn to themselves or commit time to condition management.

7.3 CASE STUDY A

The rich and detailed discussion of data presented in this section details the individual case study Dennis. This case study is written from the points of view provided by Angie, Dennis' mother. The data used for the development of the case study was collected and analysed as described in chapter 4.

Sex	Male
Age	20 months
Location	Northern Tasmania
Rurality	Suburban
Parent Involved	Yes – Angie
Method of myCF use	Parent
Internet Access	Broadband - Home
Diary entries	31 out of 42
Blog activity	2
User view activity	3
Contact/clinic view activity	8
Useful links activity	2
Stable symptoms during pilot	Yes

7.3.1 DENNIS

Dennis is a 20-month old child who lives with his mum, dad and older brother. Dennis lives in a suburb of one of Tasmania's major cities. Dennis was one of the younger participants in the project. Dennis attends a local childcare five days a week. His older brother is six and is in primary school. Dennis' father is self-employed and his mother works part time and is at university full time, completing her nursing degree. Dennis is the only participant enrolled from this postcode.

Dennis is an energetic little boy who loves diggers and trucks. He is loud, lovable and his energy is contagious. Dennis' grandparents live interstate but keep in touch with regular phone calls. Dennis' parents and brother are his main form of family support. His older brother is fiercely protective of Dennis when out in public. When at home they are both usually engaged in rough and tumble play. His grandparents are kept up to date with their grandson's activities and Dennis' current health status. The family's daily life is busy and quiet periods are rare. During the myCF pilot implementation period Angie was in her second last semester of her university studies with the examination period approaching. Exams for Angie place greater time commitments on her studies, with family time precious and fleeting.

Dennis was born with a bowl obstruction, which led to his CF diagnosis. When he was three days old he was transferred to the Royal Hobart Hospital by air ambulance. Angie perceives Dennis' case of CF to be currently mild and does not interfere with his daily play and social activities. Dennis is on daily antibiotics and enzymes and physio is incorporated into play. For most part, Dennis accepts the medication treatment of his condition without complaint, unless it is interrupting his play activities. Compared to other children of his age, Dennis appears to be both developmentally similar, with no current limitations on his physical abilities.

Dennis' mother has a lot of exposure to technology through her university studies and through her work. Angie has limited interaction with social media, namely Facebook, and has recently joined a Facebook parenting group for Tasmanian parents with CF children. Angie also owns a smartphone and uses it to make phone calls, send SMS's and take photos. Angie is comfortable with both her smartphone and laptop and considers herself to be proficient in using her laptop to get tasks completed. Dennis and his older brother as also exposed to the laptop through their mother's use. Both Dennis and his older brother enjoy using the computer for their games and videos.

During the interviews with Angie and Dennis throughout the myCF pilot implementation, the following insights became apparent. Angie sees a positive outlook for Dennis in regards to his CF. His diagnosis should not limit him in activities or future aspirations. Dennis is aware he has daily treatment however his age prevents a real knowledge of what his condition is. Dennis' older brother knows a little more of CF. Dennis' older brother is a very good at promoting CF awareness by telling everyone they meet that Dennis has CF.

> [You know what I mean? If your time is up, then your time is up. How much can you wrap them up? You don't. You plan for the worst and expect the best]

Angie requires Dennis to be perceived as a typical child. According to Dennis and his older brother, he is a typical child. Dennis has not known otherwise. There are outside influences that at times make the positive attitude difficult to maintain. The current round of health care cuts is impacting on the CF care support in the north of Tasmania has direct implications to Dennis and his family. The current public perception of CF is another influence that Angie feels Dennis will be exposed to as he grows up.

> [We get the... I knew someone who had that, or that's really sad and sorry. But there is nothing sad and sorry about our little monster so...] Angie

Dennis is referred to as 'their little monster' and this term is used to describe her youngest son's enthusiasm for life and food. Angie and her husband both work, on top of Angie's full time university studies. Sometimes maintaining a balance between the working and family aspects of life is difficult. A quite moment is rare and their house ranges from neat and orderly to 'something like the Wizard of OZ.' The main focus is Angie's life at the moment is to complete her university studies.

[I don't know about order but yeah, I am doing a summer subject as I may have failed one unit – I worked 3 to 11 the night before, 'husband' has been working away for the last five to six weeks and I got to the exam and it was like some kind of drug trip…] Angie

Family life is busy with all family members involved in work, school, childcare and sport activities. Evenings are the main time when all family members are under the one roof, unless Dennis' father is working away. During these times it is up to Angie to shoulder the responsibility of parenting for both boys.

Dennis's older brother loves his Lego set and Dennis is permitted a few small items when his older brother is playing. Dennis loves diggers and trucks, as well as playing on his scooter. He is also prone to jumping on the furniture, a source of angst for Angie.

[and the jumping off the couch – we are bound for A & E soon.] Angie

Dennis' health so far has been stable and without remarkable changes. Angie acknowledges there may be tough times ahead but uses Dennis as proof that CF does not mean the individual is sick or helpless.

[He's brilliant, he's really good – we call him Teflon, nothing seams to sick…] Angie

Having an older brother is a positive influence through Angie's eyes. Dennis and his older brother play well together, with bouts of rough and tumble play.   Angie's mother comments that she never experienced the busyness of two boys, as Angie has a sister. Angie perceives her two boys relationship as very different from the one she had with her sister when growing up.

[I think it will toughen him up… when they go out they are very protective of each other. They push each other around, on the floor but heaven forbid someone come overs to my youngest son when they are out…] Angie

The parenting of Dennis is becoming interesting as he gets older and learns from others around him, including his older brother. The parenting of Dennis is sometime a source of amusement for Angie, as she described his older brother as the quieter one. Parenting issues that crop up with Dennis have not been encountered before with his older brother.

[…my son swore the other morning – in the right context. He's never done that before. Couldn't help myself – I laughed. I didn't know what to do, I was so flabbergasted. It was just – I didn't know what to do!] Angie

Angie has recently returned from a CF conference on the Australian mainland where she was introduced to a Facebook group supporting parent's and guardians of children with CF. Through the Facebook group Angie has been introduced to a couple of local parents and is planning to catch up with some of these parents in the near future. The focus of this catch up is on the parents of the children.

[I think it will be parent's only, I think we'll keep the kids away.] Angie

Dennis is restricted in mixing with other CF children due to cross infection controls. Angie doesn't perceive Dennis to be deprived of friends; he is a sociable little boy and enjoys his time in childcare. In the Christmas period he is one of the children invited to the Special Children Christmas Party. This invite was a source of discussion on the Facebook page, with many parents upset at receiving the invite. Angie has taken Dennis in previous years however her studies prevented it this year.

> [We all got invited to the Christmas party – on Facebook there were Mum's saying – the hospital should know better – they know we shouldn't mix but my opinion is that it is up to me, that's my decision as a parent to decide. I would be upset if the hospital didn't send the invite.] Angie

The role the hospital plays in Dennis' treatment is purely for the treatment of his CF, Angie draws the line at formal care involvement for parenting concepts and how to parent her child. Dennis' condition may require greater consideration as he ages, but Angie sees no reason to unduly restrict him in his experiences at this point of time. Dennis is in childcare five days a week and due to his stable condition, has been able to enjoy childhood much like his older brother. Angie attributes Dennis' stable health to both his diagnosis and luck. The initial diagnosis period was confronting and Angie recalls being in a daze for the first couple of weeks. Using technology to build on Dennis' parent's limited knowledge at the time added to the stress.

> [once we heard about his diagnosis we got to a computer and typed in 'cystic fibrosis' and all this scary stuff turned up.] Angie

In the years since Dennis' birth, Angie has been active in attaining knowledge about his condition. She attributes this to both a natural thing as a parent and something that aligns with her university studies. Angie has an active relationship with the paediatric CF co-ordinator and likes to keep up to date with the current issues facing the CF population.

> [I was away – I was in Melbourne for the Cystic Fibrosis concert – conference, concert sounds better doesn't it?] Angie

Angie is continuously interested in updating her knowledge. The social aspect in connecting with others is something she welcomes and can now do through the Facebook group. It is only since joining the Facebook group she has met with other parents in the local area. Angie has known about these other parents for quite some time. She is willing to catch up and socialise but has never before initiated a parent catch up.

7.3.2 COMPARISION OF CASE TO STAGE TWO ANALYSIS

The following is a summary of how this case study contributes to the stage two analysis. The contributions are based on Angie's and Dennis' myCF experience.

Angie approaches Dennis' CF treatment and management at a relaxed and flexible manner. Daily medications are required and physio is integrated into Dennis' play activities. Angie doesn't keep a formal symptom diary of Dennis' symptoms however she does keep all his medical records, email correspondence and other CF related documents in an electronic and

physical folder. This was particularly helpful when the hospital lost Dennis' records for a period last year. Angie has frequent email and phone contact with the paediatric CF coordinator. Dennis has yet to experience a major period of unstable symptoms and Angie admits she deals with Dennis' CF in a routine manner. Angie can detect symptom change in Dennis but rarely places a high focus on the changing symptoms, attributing it to other causes rather than CF. Angie has a high desire to attain more CF knowledge and likes to maintain independence, alongside the support of her husband and parents.

Angie expresses a desire for improved social contact through Facebook or the social pages of myCF however she does not perceive herself to be isolated. The lack of contact is attributed to their busy schedules and her low levels of motivation to seek ways to initiate contact. myCF is perceived to be an information portal for Angie, a source of trusted information for when Dennis is reaching a new milestone. myCF is also a way for her to track his symptoms when she desires. The ability to link medical test records with myCF is an additional wish list item. Angie uses technology similar to myCF to access her university material and prefers a laptop when using the Internet.

Angie's experience of the myCF pilot implementation was a largely positive one. During the pilot Angie and her family went through a period of illness that prevented Angie from recording Dennis' symptoms regularly. Angie's work and university schedule additionally created a barrier to use. Dennis' symptoms remained largely stable during the pilot period and Angie also attributes this to reasons why myCF was not interacted with everyday. In contrast to this, Angie is on the computer regularly and sees no reason to why she could not easily incorporate the use of myCF into a daily routine.

myCF was revealed to have more of an individual focus for Angie, rather than the community approach she was expecting. The role of myCF is for formal care interaction, to have a record of symptoms to print off and present to the health care practitioners. The benefit of using myCF is in building a history of Dennis' symptoms. For Angie, the ability to think more clinically is enhanced by myCF and is not a negative aspect of use. Angie feels the use of myCF brings a greater focus towards Dennis' symptoms however she has not changed her response to those symptoms.

For the future of myCF Angie would like to see a Facebook type forum that allows flexible interactions between myCF members. The ability to add medical records and diary notes would improve the usefulness of the symptom monitoring diary for Angie and Dennis. Angie uses myCF with Dennis observing and would like to continue in this way until Dennis is able to complete the diary himself. The promotion of CF in the larger community is a more abstract benefit that Angie feels is possible for myCF, by linking in it through fundraising activities.

7.4 CASE STUDY B

The rich and detailed discussion of data presented in this section details the individual case study Iain. The case study is written from the points of view provided by Iain and his mother Nicki. The data used for the development of the case study was collected and analysed as described in chapter 4.

Sex	Male
Age	5 years
Location	Southern Tasmania
Rurality	Rural
Parent Involved	Yes – Nicki
Method of myCF use	Parent with child
Internet Access	Broadband - Home
Diary entries	13 out of 42
Blog activity	4
User view activity	1
Contact/clinic view activity	2
Useful links activity	1
Stable symptoms during pilot	No – common cold

7.4.1   IAIN

Iain is a 5-year old child who lives with his mum and dad. Iain lives in a rural area in Tasmania's south. Iain is the oldest boy in the paediatric myCF pilot implementation group. Iain goes to kindergarten 3 days a week and childcare one day a week. Iain's mum and dad are both registered nurses and work full time. Iain is one of two participants enrolled from this postcode.

Iain is an independent boy who loves Ninjago and Ben Ten. He takes piano lessons and no one is allowed to talk when he is giving recitals at home. Iain's Nan Nan says that he is much like his mum when she was young. Iain also goes to a trampolining club on the weekends and attends a music group once a week. He is one busy boy! Iain's grandparents live close by, with Nicki's mum and dad regularly looking after Iain due to shift work. Iain's dad is constantly searching for alternative treatments to support Iain's formal care and Niciki's mum supports him in this. Iain loves reading and is able to read books by himself.

Iain was not diagnosed with CF until the results of the heel prick test taken at birth were returned to the GP. Iain was around 6 weeks when the heel prick test and sweat test indicated he may have CF. Further tests that were returned a few weeks later confirmed

Iain had CF. Nicki feels that Iain's CF is relatively stable and so far enzymes and a daily antibiotic is all the medication Iain requires. Nicki and Iain don't usually do formal physio but use the trampoline, bubble blowing and running to help 'clear out the muckies'. Iain has a very basic understanding of CF and recently has started to ask if other children need to take enzymes. Nicki does have contact with other CF families through Facebook and has been showing Iain pictures of the children.

Nicki has a lot of exposure to technology, through her work and previous studies. Nicki also owns a smart phone and uses it for Facebook, web searching, as a camera and for phone calls. She also has several games on her smartphone but Iain likes to play his DS (hand held game console). Nicki is fairly confident with computers and likes to use a laptop, rather than a desk PC. Iain can also use the laptop by himself to play his games and reading eggs. Nicki uses Facebook through her smartphone, as it is usually with her all the time. During her night shifts the computer at work is used to complete work activities and for accessing the Internet and Facebook during slow periods.

During the interviews with Nicki and Iain throughout the myCF pilot implementation, the following insights became apparent. Nicki and Iain live greater than 35kms from where Nicki works and Iain's school and piano lessons. Life seems to be always spent in the car. Nicki brought a new car last year and she remembers the look of surprise the mechanic had when she brought it in for the 10,000km service only 8 or so weeks later! Shift work is sometimes difficult to manage, especially if Iain's parents are working the same shifts or opposite shifts.

> *[it can be difficult, I work shift work so three nights in a row and I just want to sleep. There's only so many times I can say, go play the DS without feeling guilty. It's better now he's at school, pressures off me a bit!] Nicki*

Iain started school this year and enjoys kindergarten. He reads very well and Nicki can no longer spell simple words when she doesn't want Iain to know what she is talking about. Iain likes playing piano and has just started putting on shows for his family. Iain goes through periods of shyness and outrageousness. One minute he's hiding behind his mum, the next he's chatting up a storm to whoever will listen. Iain likes things to be just so, and frequently bosses his family around so things are to his liking. He has firm opinions on many things and it is engaging to watch how engrossed he can get with a particular subject.

> *[We were at Mum's and he wanted to put on a show for us. So we are all siting down and we were not allowed to speak, not a word. He very seriously played Mary had a little Lamb and then told us we could clap.] Nicki*

Iain's Nan Nan and Pop Pop are a large part of his life. He sees them at least weekly and enjoys spending the night. Iain also has his dad's mum still alive, but she is older and he sees her only occasionally. As an only child, Iain is Nan Nan and Pop Pop's only grandchild. He is spoilt for choice around birthdays, Christmas or just because. Nicki's parents are semi self-employed and also do a lot of volunteer work, so they often are able to help out with little notice. Nicki relies on her parent's for this extra support, due to both her and Iain's Dad working shift work.

[Mum and Dad help out a fair bit. Iain has sleepovers there. Night shift I sleep there, we have been known to spend a few days up there, after only asking for a few hours.] Nicki

Iain loves his DS and seems to be able to use any type of technology without too much hassle. He has his own file on the laptop for his games that he can access without any help from his mum. Iain is also into reading eggs, a reading program from the Internet. He can use reading eggs without help from Nicki and she is careful of limiting Iain's access of the Internet to sites she is sure of. Nicki's smart phone is another source of entertainment for Iain, although he does prefer the games on his DS.

[He can use my phone better than me. This is my second phone, the first kept on shutting down. So there's Ben 10 on it now. I'll give it another chance before going back for another rant.] Nicki

Iain's health has so far been stable. Daily antibiotics have only become a regular thing in the last year, as he is now going to school. Nicki is aware of Iain's current mix of symptoms but so far they have been what she considers mild and stable.

[…with worsening symptoms or anything. Which there hasn't been so far.] Nicki

Iain has a wide group of friends from childcare, school and playgroup. As he is an only child, Nicki likes him to have many play dates. Iain also enjoys sleepovers with friends at his house, he is yet to venture out to one of his friends houses for a sleep over. Some of his friends also have chronic conditions but none have cystic fibrosis. Iain is starting to ask Nicki about other people with CF and wanting to meet them. Nicki treats this as natural curiosity and uses Facebook to help her, and another friends daughter, to meet others with CF.

[I know a few people with CF and another mum and I are friends on Facebook. Both our kids have been asking about CF and if other kids have it so we have been showing them photos of each other. We'll get around to making a Skype call no doubt.] Nicki

Nicki uses Facebook to contact other parents whose children have CF. She has only recently started to do this now that Iain is starting to ask more questions about people with CF. Nicki has a close circle of friends that provide life, family and parenting support.

7.4.2 COMPARISION OF CASE TO STAGE TWO ANALYSIS

The following is a summary of how this case study contributes to the stage two analysis. The contributions are based on Nicki's and Iain's myCF experience.

Nicki has a flexible approach to Iain's treatment and Iain is now responsible for taking his enzymes when he needs them. Iain knows if he doesn't take his enzymes his tummy hurts and he spends a lot of time of the toilet. Iain has not yet had a period of unstable cystic fibrosis symptoms and symptom monitoring is an informal and background activity. Nicki only focuses on symptoms when Iain has a cold or is otherwise unwell. Contact with the CF clinical team is usually only through clinic attendance although Nicki knows how to contact

them if required. Nicki, as a parent, has found that some formal care relationships are best maintained at a distance.

Nicki does not keep a symptom monitoring diary of Iain's symptoms and does not currently feel there is a need to. Iain's stable symptoms are the main reason behind the low priority placed on a symptom monitoring diary. Nicki and Iain do not appear to be isolated from support and friends; Nicki does know a few other CF families through Facebook, this appears to satisfy Iain's curiosity about his condition. myCF appears to be beneficial as background support that is easy for both Nicki and Iain to use. Nicki feels that some symptom monitoring may not be beneficial when you are going through a tough period. The faces on the diary appeal to Iain and he uses myCF with Nicki supervising him. Iain and Nicki use both laptop and smartphones to access the Internet, with the laptop being the first choice.

The myCF pilot implementation was straightforward for Nicki and Iain. At the start of the pilot Nicki and Iain used the symptom monitoring diary everyday. This tapered off after the first week or so. Iain's symptoms remained fairly stable during the pilot period despite catching a common cold. Nicki felt that reflecting on his own symptoms was beneficial to Iain, but not as a daily occurrence. Shift work also was a barrier to myCF use, as the entry for the day could not be completed in retrospect once Nicki came home from night shift.

The easy use of myCF meant that Iain could use the platform by himself, with his mum watching him. myCF met Nicki's expectations in terms of the symptom monitoring diary. Nicki felt that the questions were appropriate but it would also be helpful if notes could be put into the diary. Nicki feels myCF will be important for Iain to use once he is older, so that he can have more ownership of his condition. Nicki additionally feels the myCF concept is helpful, even if it is not used everyday.

Nicki would like to see the pilot feedback incorporated into myCF but does not think the platform needs a social focus. The inclusion of news and events in the myCF platform would also suit Nicki, as the CF Tas webpage does not seem to be updated regularly.

7.5 CASE STUDY C

The rich and detailed discussion of data presented in this section details the individual case study Keir. The case study is written from the points of view provided by Kate, Keir's mother. The data used for the development of the case study was collected and analysed as described in chapter 4.

Sex	Male
Age	3 years
Location	Southern Tasmania
Rurality	Metro
Parent Involved	Yes – Kate
Method of myCF use	Parent
Internet Access	Prepaid USB - Home
Diary entries	12 out of 42
Blog activity	16
User view activity	34
Contact/clinic view activity	6
Useful links activity	4
Stable symptoms during pilot	Yes

7.5.1   KEIR

Keir is 3-years old child who lives with his mum. Keir lives in a metro area in Tasmania's south. Keir is too young for school and is looked after by close family friends when his mum is at work. Keir has an older sister who is 21 and she also helps to look after Keir from time to time. Keir's mum works part-time and has recently managed to swap her Saturday shifts to during the week. Keir is one of two participants enrolled from this postcode.

Keir is a cheeky little boy who loves Batman and the Teenage Mutant Ninja Turtles – particularly Leonardo. Keir and Kate try to go to a children's library session every week but sometimes Kate has to work. Kate has her daughter and a close family friend help out with Keir. Keir calls Kate's friend 'Aunty'. Aunty spoils Keir rotten, often stopping round with treats and new toys. Keir's big sister would do anything for Keir but sometimes he can be naughty for her. She often gets frustrated with Keir, as he likes to play the repeating word game. Kate and Keir do not have any other family members close by.

Keir was diagnosed with CF with the heel prick test done in hospital after he was born. Tests carried out by his GP and the Royal Hobart Hospital later confirmed this when he was a few months old. Most days Kate doesn't think Keir has CF at all as he appears to be well

the majority of the time. Kate and Keir try to do some physio and Keir takes daily enzymes. Keir doesn't seem to know he has CF and Kate sees Keir as a healthy little boy.

Kate uses a computer for work and owns a basic mobile phone. They have a basic desktop computer at home and Kate connects to the Internet through a pre-paid USB. Kate occasionally sends emails and uses the Internet to search for information and to play some games. Keir prefers his shows on the TV and doesn't like his mum spending too much time on the computer. If Keir feels Kate has had enough computer time he will come along and pull out the USB stick or turn off the power points. Kate doesn't feel confident when learning new things on the computer. Keir prefers his toys to technology!

During the interviews with Kate and Keir throughout the myCF trial, the following insights became apparent. Kate and Keir live close to where Kate works. Kate depends on her job so it sometimes seems that work dictates what they can do. Aunty and Uncle look after Keir while Kate is at work and she can usually get Keir to most activities through their help or her daughter's help. This year's Special Children's Christmas party was the first Kate attended.

> *[I couldn't go last year. We planned to but I got called into work so his big sister took him for me.] Kate*

Keir spends most of his time with his mum or his Aunty. Kate likes to try to take Keir to the playground or the library for reading time. Kate and Keir live just up the road from their local library, so the walk is good to get out of the house for a while. Keir has just started to show an interest in books and the library was a good way to give Kate and Keir an activity to do together.

> *[He likes his books, sometimes. So we have been to the library but I can't manage that anymore] Kate*

Keir is a cheeky little boy who keeps his mum on her toes. He is shy around strangers, which can be embarrassing for Kate as she thinks he is being rude when he doesn't want to say hello. Once he gets over his initial shyness he constantly has toys to show off, and telling his mum which one she needs to play. This usually involves a bit of dress up. When asked about his favourite superheros he is quick to choose Batman.

> *[Turtles, batman – Spiderman. He is Leonardo! Loves transformers. I was living with Batman for a few days…] Kate*

Superhero work is where Keir sees his future; he wants to be a Ninja Turtle. Kate is not sure where the Ninja Turtles came onto Keir's radar, as he doesn't watch them on TV. At only three, Keir has high level of superhero vocabulary and plays make believe often. Kate's plans for Keir at this point are getting ready for school, which he will start in 2014.

> *[He wants to be Michelangelo, from the turtles] Kate*

Aunty, Uncle and big sister make up Keir's family support. Aunty and Uncle look after Keir when Kate is at work. Keir's big sister helps out if Aunty can't babysit or just to play with her little brother. Keir's big sister dotes on him but finds his cheeky nature sometimes hard to

deal with. Kate's parents are no longer alive, and she doesn't have a good relationship with her sisters. Close friends are considered family.

> [We don't really have anyone, my mum and dad are passed. I have my sisters but I don't see them much, they are too bossy, typical big sisters. So it's just us really, and Aunty and Uncle. But we're going to Christmas dinner with my ex-in laws. We still get on well and they love Keir] Kate

Kate feels guilty, as she doesn't play a lot of emphasis on Keir's CF treatment and management. She doesn't make him complete physio when he wants to play with his toys and feels that her laid back attitude to CF is because he is always well.

> [I wish I took it a bit more seriously, but it's hard when he's so good. I should be a bit more responsible.] Kate

Keir's current health is stable and he has not had any complications due to his CF. Keir does not take any medication apart from his enzymes. Keir sleeps in just his nappy as he sleeps hot and sweats a lot.

> [Yeah really, really good. I walk around thinking there's nothing wrong with him. He does a little bit of his physio…] Kate

Keir doesn't meet a lot of children and because of the big age gap between him and his sister, spends the majority of the time alone with Kate or Aunty. Keir will be starting school in a years time and Kate would like him to get used to other children otherwise she fears Aunty will have to join Keir in the classroom! Kate and Keir attempted playgroup sessions but Kate's work made it difficult for them to go weekly.

> […because he's with Aunty or me 24/7 there's only a certain amount of children he knows and he's got to get used to being with other kids so I'm going to book him into childcare like one or two days a week.] Kate

Kate's friends and workmates know Keir has CF but they think it is something to do with his muscles. Kate wants to take some material to her workplace so people have a better understanding of Keir's condition. Kate didn't know what CF was before Keir was diagnosed and she thinks that the more people know about CF, the more can be done for Keir and others.

> [A lot of my friends here – they think it's Cerebral Palsy still – oh no he looks alright, he's not walking funny. And they just don't – I don't know what they think but a lot of people still don't' understand what CF is.] Kate

Kate thinks Keir's CF is mild but has read other stories of people waiting for a lung transplant or in constant ill health. Kate reads 'That's Life' and 'Take 5' where more and more people are sharing stories about CF. Kate is saddened by the number of stories she reads but says that not all of them are doom and gloom. More CF stories means more people will know about CF.

> [It's never a good news story but it's good to see more awareness.] Kate

Aunty and Uncle are very involved in Keir's life and are constantly on the look out for ways to help Keir with his CF. Uncle has recently found an alternative therapy that he thinks will be good for Keir but Kate's Internet searches for more information has been unsuccessful. Kate is willing to give anything a try but feels that if it were good for Keir the health care practitioners would have already told her about it.

> [...they've heard of this thing called 'Silverwater' – it's supposed to kill bacteria. It's used in cancer patients and things like that. I don't know whether to ask about it – but I can't find anything about it on the 'net – I keep on getting pages to Silverwaters Resort.] Kate

Kate enjoys using myCF and thinks the platform has everything she needs for Keir's CF. She would like more information about CF to be able to print out and take to work to give to her boss. The symptom monitoring diary is easy to interact with and covers all of Keir's symptom requirements.

> [... so I've been onto that and it's great. I love it. It's got everything I want on it.] Kate

Kate feels her CF knowledge is basic but isn't too worried, as Keir appears to be healthy and well. Outside of Aunty and Uncle, Kate has a few friends who she would contact for help and advice. Keir's contact with other children is through Kate's small friend group or her workmates.

7.5.2   COMPARISION OF CASE TO STAGE TWO ANALYSIS

The following is a summary of how this case study contributes to the stage two analysis. The contributions are based on Kate and Keir's myCF experience.

Kate is very laid back about Keir's treatment and management. Kate doesn't keep a symptom diary but has attempted to write notes for formal care, and loses them before the appointment. Kate is hesitant about contacting the CF team, as she doesn't want to waste time or ask silly questions. Kate feels her CF knowledge is basic and she would like to improve it if she can.

Kate feels quite isolated and would like to be able to talk with other parents to make friends. Kate only has a few close friends but doesn't feel she can talk to them about Keir's CF. myCF is perceived to provide Kate with a way of tracking symptoms between clinic visits, to improve her CF knowledge and to contact other families. Kate has a desktop PC she can use to access the Internet but Keir dictates when she can go on. Kate uses a computer at work but new technology situations are confronting for her. Kate does not want to appear silly when interacting with formal care and relies on formal care for the appropriate treatment and management of Keir's CF.

Miscommunication initially prevented Kate from using myCF on a daily basis but she found accessing and entering symptoms into the symptom-diary easy. Her computer was moved into the lounge room so that she didn't have to go into the hallway to use myCF once Keir had gone to bed. Keir had no symptom change during the myCF pilot implementation. Kate

used myCF without Keir, as he preferred her not to be on the computer. Kate refers to myCF as a friend, despite the low number of diary entries.

Kate is unsure how to act during formal care interactions, as she feels out of place to parent Keir if he is misbehaving. Seeking alternative treatment is a bit of embarrassment as Kate feels that the health care practitioners will already know what is going to help Keir. Kate uses Uncle and her daughter's boyfriend to help her with any computing issues and doesn't feel confident in learning new things. The myCF use guide was very helpful to Kate as she could follow the instructions step by step.

Kate would like to see more information about CF included in the future platform of myCF. She would also like to be able to contact other parents but does not currently use social media. Kate thinks the current layout of myCF is easy to use and like the way the symptom monitoring diary is laid out.

7.6 CASE STUDY D

The rich and detailed discussion of data presented in this section details the individual case study Jarrett. The case study is written from the points of view provided by Jarrett and his mother Jenny. The data used for the development of the case study was collected and analysed as described in chapter 4.

Sex	Male
Age	14 years
Location	Southern Tasmania
Rurality	Suburban
Parent Involved	Yes – Jenny
Method of myCF use	Self
Internet Access	Broadband - Home
Diary Entries	19 out of 42
Blog activity	19
User view activity	3
Contact/clinic view activity	6
Useful links activity	10
Stable symptoms during pilot	Yes

7.6.1   JARRETT

Jarrett is a 14-year old boy who lives with his mum and dad. Jarrett lives in a suburban area in Tasmania's south. Jarrett is the second oldest child in the teenager myCF pilot implementation group. Jarrett goes to high school, which is about a 10-minute car ride away from his house. Jarrett's dad works full-time and his mum works part-time. Jarrett is the only participant enrolled from this postcode.

Jarrett is an active teenager who is interested in sport, his iPod and Facebook. His current passion is long boarding but this can change on a weekly basis. Jarrett has many previous interests including trampolining, choir, squash, AFL, rugby, cross-country, and triathlons. The list keeps on getting bigger and he occasionally goes back to visit a previous passion! Jarrett's parents encourage whatever activities he is interested in and try to make sure he can take part in whatever activity has his current interest. Jarrett's mum works part time with some volunteer work at his school, this helps when she is required to play taxi.

Jarrett was born with meconium ileus – blocked bowel. He was operated on the day after his birth and the surgeon gave his parents a short list of possible causes, including CF. Jarrett's parents had not heard of CF before. 11 days after Jarrett was born he was

diagnosed with CF. Jarrett is meant to take enzymes each day, as well as daily antibiotics. Jarrett does not like taking his enzymes and this leads to loud discussions between Jarrett and his mum. Jenny thinks physio is a lost cause on Jarrett at the moment but as he is very active he makes up for it during sport. Jarrett has another friend with CF and goes to school with another CF teenager. They are not allowed to play with each other or be in the same classes.

Jarrett is constantly on technology, namely his iPod. His school is introducing iPads next year and Jarrett can't wait. Desktop PC's are too slow for Jarrett, and are too bulky. Jarrett's iPod never leaves his hand and when at school it's in his pocket. Jarrett is very possessive about his iPod, his mum is not allowed to touch it. Jenny feels this is a general state of being 14, protective about their possessions and generally uncooperative to anything outside of his iPod. Jenny prefers the desktop computer to mobile technology and does not own a smart phone. Jarrett makes it very clear he is not a nerd. His iPod is used for mainly Facebook, chatting with his Facebook friends.

During the interviews with Jarrett and Jenny throughout the myCF pilot implementation, the following insights became apparent. Jarrett doesn't care about CF, he feels that he doesn't need to seek more information on his condition. The daily requirement of medications is another sore point for Jarrett. He goes through periods where he doesn't take his enzymes at all.

> [It sucks – I hate taking medicines. I don't really care about CF.] Jarrett

Jarrett does not like taking medications and he appears not to care about CF. This can be hard for Jenny who would like Jarrett to take his medications so that he does not have to spend hours on the toilet. If Jarrett took his enzymes he would also get all the required nutrients. Jarrett is also not interested in learning more about CF, he feels that he knows all he needs to know. Jarrett generally appears not to care about CF or about learning more about his condition.

> [I just go to nobody – well I don't really care about the information, I know all I need to know] Jarrett

Jenny is unsure on how to deal with Jarrett's mixture of indifference and negativity towards CF. She attributes to the general state of a teenager, CF isn't the only thing he's not interested in at the moment. Jarrett is only interested in satisfying what he wants; CF is not one of his top priorities.

> [It's probably a hard age I guess – it's probably 16 or 17 before they start to taking it all on themselves. Yeah it's a hard age – he sort of, doesn't care about it at the moment. But just – he's not interested, you know, in anything. Not just related to the CF] Jenny

Jarrett is involved in a variety of sports; the one of choice at the moment is fun runs. Jenny usually provides the transport for these activities and encourages Jarrett to be active. Jarrett is also a part of the inter-school cross-country team.

[I'm doing the Mark Webber Adventure Run, the Run the Bridge and the 5km Cadbury Marathon.] Jarrett

Jarrett also enjoys long boarding, skateboarding on a longer skateboard. When talking about potential user names, he enjoys mixing up his opinion of himself with his long boarding status. Jarrett enjoys creating different usernames for his various games he plays through Facebook.

[Sexy Long Boarder. Me – Sexy. I ride a long board.] Jarrett

Jenny has been witness to many of Jarrett's activities. Last week it was scooter and building them up with all the 'bling'. Next week she is sure it will be something else. Jarrett enjoys activities that are popular with his friends at school and it seems his group of friends have frequently changing tastes.

[For this week anyway…] Jenny

The initial introduction to CF was confronting and lacked information. The CF team were away when Jarrett was diagnosed and the main source of information the family found was from the Tasmanian Public Library, dated in the 1970's. Since then Jenny has kept up to date with all the CF information she could possibly find and is actively involved in the CF Association of Tasmania.

[It must have taken about 11 days for the diagnosis to come through, he was born with a blocked bowel – the doctor who operated on him mentioned CF – we'd never heard of it before. The information we could source at that time was very bleak and out dated - this was only 14 years ago and we weren't even sure if he would make it home with us. So, very confronting.] Jenny

Jarrett frequently is frustrated with CF as he switches between not caring and caring that people don't know what CF is. Jenny can understand some of Jarrett's frustrations as the daily upkeep is not easily recognised or understood.

[It's a very frustrating disease. Because they look, and act, and do –what everybody else does. It frustrates – as a parent, it frustrates because the upkeep is quiet intensive] Jenny

When Jarrett was first born, the lack of physical markers of CF was a relief for Jarrett's parents. For Jenny, Jarrett would be judged as a person first, not his condition. But as Jarrett has got older, Jenny can appreciate how Jarrett sometimes switches between wanting people to know everything about CF, to not caring about the disease at all. Jarrett does not want-forced reminders about his symptoms but wants to choose when he wants to know about, and promote CF.

[It's a catch 22 you know. When he was first diagnosed, we sort of said well thank god he's got something where people don't automatically look and go 'oh'. At least he's got the opportunity for people who don't know he's got CF to you know, to get to know him as him and then, now that's he's older if he wants to tell people he can. But so yeah, it's a double-edged sword I think.] Jenny

Parenting a fourteen-year-old is Jenny's source of frustration. Jarrett is on Facebook constantly and Jenny finds it challenging to let Jarrett have enough freedom using social media and making sure he is safe while using it. The topic of checking up on Jarrett with Facebook is a reoccurring issue.

[You always log on to check on my Facebook.] Jarrett

[I haven't checked your Facebook for ages.] Jenny

[Good then – don't.] Jarrett

Jarrett is constantly connected to his iPod. He doesn't seem able to leave it alone for more than a couple of minutes. During school he must keep it in his pocket. His iPod is how he connects to Facebook, or downloads music; his current interest is rap music. Jarrett likes to make it very clear that he is not a nerd. According to Jarrett iPod's are an extremely common technology with people his age. Jenny gets cross with how dirty the iPod screen can get, since Jarrett seems to be always eating. Jenny has wondered if Jarrett uses the iPod in his sleep.

[You are on technology all the time – it (iPod) never leaves your hand!] Jenny

Jarrett thinks Jenny and his CF care team place too much emphasis on CF, and what he needs to do to manage his CF. Life is Jarrett's current focus, and that means his iPod, long boarding and chatting to his friends on Facebook. School is not interesting to him, even though he's on the student representative council.

[I have a life. I don't care about CF.] Jarrett

Jarrett is interested in raising money for CF when he is running his triathlons and marathons. Jenny supports him by designing T-shirts for him to wear. Jarrett is proud of these slogans and puts on the appropriate funny voices when telling people the slogans.

[It was Mum's idea for that, with the T-shirts that say 'I've got CF!, I'm coming for yooooou!'] Jarrett

Fundraising is a way for Jarrett to raise the profile of CF as he feels people don't think it's as important as some other life threatening diseases. Jarrett is very open with his friends about having CF and gets upset when they don't seem to respond to his attempts to make CF more visible. He doesn't want to talk about his CF to his friends at a personal level but he wants more people to care about CF as a disease.

[Because nobody's gives two bobs worth about it. I put a think up on Facebook the other day, 60 likes in 60 minutes if you wish CF didn't exist. I got 22 likes. But then I said, I knew I never was gonna get 60 likes because nobody gives a s*** about CF and it's just as important as cancer. And then I reckon I got about 50 comments on that] Jarrett

Jarrett has a circle of friends at school and Jenny has been friendly with another CF mum since both their boys were very little. Jarrett is happy for people to know he has CF. Jenny thinks that Jarrett was more accepting of his CF when he was little, as everything thing seems too hard now. His group of friends are mainly from his school, or weekend sports.

[When Jarrett was younger, we were leaving from somewhere and breaking the rules. Jarrett and another friend with CF were siting in the back of the car and his friend turned to Jarrett and asked 'How are you going with your CF?' and Jarrett replied 'It sucks. I hate taking tablets'. It was so nice, that he had that someone to go – this sucks. I mean they were only little but for them to have that – a bit of a vent.] Jenny

Jenny thinks that the teenage years are generally hard, as they don't relate to what other kids are going through unless it directly affects them. This can be hard for Jarrett when he wants to talk about CF to his friends, usually by Facebook. Jenny also thinks it is related to the general well being of Jarrett. Because he is so active and does not look different, this can mean other kids don't understand what CF is.

[It's hard sometimes – kids aren't always that understanding, and at his age they are a bit um – in their own world. So if they don't understand it – if they aren't going through it then – it doesn't matter. And it's not restricted to CF.] Jenny

Jenny has regular contact with the CF care team as she tries to find ways to get Jarrett to take his enzymes. While Jenny may not always agree with some of the formal care opinions, she is careful to consider their point of view before deciding what to do. Jarrett's parents found the initial diagnosis period confronting and Jenny recalls her mum trying to find information at the Tasmanian State Library. The information was terribly out-dated and the outlook for children very bleak.

[I was in NICU and they handed me a green book, I will never forget that green book. The nurse said to me, just read the first chapter. Well of course, I didn't do that. No one survived. It was a nightmare until the CF team came back.] Jenny

Jarrett doesn't use a desktop computer for his usual interactions with technology he prefers an iPod. He does use laptops at school, during class times. Jarrett likes instant log on and easy navigation to where he wants to get to, so the applications on his iPod are ideal. He thinks he's too busy to find a computer, to enter the address of myCF and then to log on.

[It take's up too much time, find a computer, type in all that – www.cystic_fibrosis_self_management.org.] Jarrett

Jenny doesn't own a smart phone and prefers the use of a desktop PC. She likes the current layout of myCF but would also like to have greater control on some of the information children under 18 can access. Jenny does not currently access social media but is kept up to date with CF information as she volunteers with CF Tas Association.

[I think it's fine, I find it a good tool.] Jenny

Jenny is happy with her current CF knowledge but is often frustrated that Jarrett does not appear to care about CF or how to look after and manage his condition. Jenny is currently responsible for looking after Jarrett's condition and she feels that at 14 it should be starting to move over to him. Jenny also knows that 14 is an age where teenagers don't seem to care about anything unless it's a current interest. Jenny does not feel isolated but she would like to be able to talk to more parents about strategies on CF and teenagers. Both Jenny and Jarrett are active in raising money and awareness for CF.

7.6.2   COMPARISION OF CASE TO STAGE TWO ANALYSIS

The following is a summary of how this case study contributes to the stage two analysis. The contributions are based on Jarrett and Jenny's myCF experience.

Jarrett is not concerned by his CF and does not always comply with his treatments and medication. Jenny still maintains condition ownership for Jarrett, organising formal care and monitoring his symptoms. Jarrett does not have any symptom focus, although he is away of some symptoms when he does not take his enzymes. Jenny views the CF team as approachable and is in regular contact with the CF paediatric co-ordinator. Jarrett has had several hospitalisations but these have been for routine 'tune ups'. So far he has had moderately stable symptoms. Jenny does keep a symptom diary of Jarrett's symptoms and uses it for formal care interaction.

Jenny does not feel isolated but would sometimes like advice on how to deal with Jarrett's unwillingness to participate in his CF treatment. Jarrett is connected to his friends through Facebook and by attending high school. Jarrett is unsure what benefits, if any, myCF will give him. Before participating in the myCF pilot implementation he was unsure on what to expect. Jarrett did not appear to be concerned by the potential usability of myCF and was interested in the blog section of the site.

The myCF experience was a confusing one for Jarrett, his symptoms never seemed to report correctly. He also lost interest halfway through the pilot. Jenny was disappointed by Jarrett's lack of diary entries but thought the misreported symptoms played a large part in Jarrett losing interest. Jenny would like to be able to access myCF as a parent, so she can enter his daily symptoms on Jarrett's behalf. Jarrett disliked the web-based platform while Jenny preferred this layout. Jarrett would like myCF to be available as an application, so that he can use it on his iPod. Until myCF becomes more mobile Jarrett is not interested in logging on daily.

Jarrett did find the myCF pilot implementation easy to use, despite the incorrect symptom feedback. This symptom feedback frustrated Jarrett. Jarrett sees no benefit in using myCF

to track symptoms, gain information or connect with other CF individuals. He is not interested in using the platform or monitoring symptoms. Jenny thinks myCF will be helpful in recording Jarrett's symptoms for formal care interactions. She also found the information on myCF to be relevant and helpful, compared to her family's initial introduction to CF.

Jarrett is indifferent to the future of myCF but Jenny would like to see a parent diary that will allow her to enter symptoms for Jarrett. Jenny additionally feels up to date and accurate information about CF in the myCF platform will be helpful to existing and new families. Jenny sees using myCF to give Jarrett evidence that he needs to take his medication. While Jenny does not think Jarrett is isolated, the ability to vent to other teenagers with CF could be beneficial. Jarrett switches between not caring about CF, and wanting others to be more aware of the disease.

7.7 CASE STUDY E

The rich and detailed discussion of data presented in this section details the individual case study Nate. The case study is written from the points of view provided by Nate and his mother Mary. The data used for the development of the case study was collected and analysed as described in chapter 4.

Sex	Male
Age	12 years
Location	Southern Tasmania
Rurality	Metro
Parent Involved	Yes – Mary
Method of myCF use	Self
Internet Access	Broadband - Home
Diary Entries	38 out of 42
Blog activity	5
User view activity	3
Contact/clinic view activity	17
Useful links activity	4
Stable symptoms during pilot	Yes

7.7.1 NATE

Nate is a 12-year old boy who lives with his mum, dad and older brother. Nate lives in a metro area in the south of Tasmania. Nate is the youngest teenager participant in the myCF pilot implementation. Nate attends his local primary school. His older brother goes to an independent high school. Both of Nate's parents work as teachers, his mum part time and his dad work full time. Nate is the only participant enrolled from this postcode.

Nate is a quiet and considerate boy who loves cricket and soccer. He is passionate about his schoolwork, taking his subjects seriously. Nate's parents and his older brother are his main form of family support. He sees his grandparents occasionally, usually during the school holidays. Both Nate and his brother have sport during the week and on the weekends. Nate and his brother catch the bus home from school and Mary meets them at home. Nate has a dog called Muppet and loves him dearly. Nate worries about Muppet as he has run away from home a few times and they live on a busy road.

Nate was diagnosed with CF at birth. Nate has had relatively stable symptoms, with only two hospitalisations since birth. One hospitalisation was for a treatment 'tune up' where they have 14 days of daily physio and intravenous antibiotics. Nate is on daily antibiotics,

nebuliser treatments and enzymes. Nate also does daily physio, with the help of his mum. Nate considers his physio and treatment to be his jobs, something he needs to do. Mary says Nate is pretty good at remembering what he needs to do for his CF.

Nate and Mary have a variety of technology in their home. They have a desktop PC, a laptop, Nate has his iPod and Nate's dad has an iPad. Nate likes to play Angry Birds on the iPad. Mary mainly uses technology at work, with only sending the odd email or playing a game on the computer at home. Nate uses computers at school and doesn't really have a preference for the iPad or the desktop PC. He thinks the games are better on the iPad. Nate and Mary don't use any form of social media. Nate did prefer using myCF on either the iPod or iPad.

During the interviews with Nate and Mary throughout the myCF pilot implementation, the following insights became apparent. Nate has a positive attitude towards his CF and wants to be there for people who may be feeling down and not having an easy time with their CF. Nate also wants to show people that having CF doesn't mean you cannot do what you want to do. It is very important for Nate to be seen as a good role model.

>   *[I really want to be somebody that's a role model to other people with CF so they know what they can reach, even if they have a bit more of a disability than others.] Nate*

Nate likes soccer and cricket, and plays in a footstool game, a fast paced version of soccer. Nate is soft spoken until he gets onto a subject he is interested in, then it is hard to get a word in. As Christmas is approaching, Nate takes an opportunity to remind Mary of one of his present requests.

>   *[I like drums, I just like the beat with Bongo Drums, with the high and low sounds.] Nate*

The family also own a dog called Muppet and Nate is very protective of him. Nate has taught Muppet a few basic tricks, to sit and to fetch his ball. Muppet has managed to escape a few times and this causes Nate to worry where Muppet is whenever he is in the backyard.

>   *[I just wonder where he is all the time, because he's run off a few times. If he hadn't I'd be okay with it.] Nate*

Nate would like to work in a sports area once he's grown up. At the moment he would like to become a sports physio, as the physio's he knows are nice and seem to enjoy their jobs. Nate wants a job that will be fun and one that he can help children. Again, Nate is keen to be a role model for others with CF.

>   *[Yeah, I guess I'd – well I'm not wanting to do stuff in the offices with physiotherapy but sort of getting out and helping the kids more. Like a sports physiotherapist sort of…] Nate*

Nate enjoys his friends at school and missed them during his last tune up. He now plays footstool because of his friends. He likes to help out his friends with school projects and regularly has his best friends over to play after school. Nate is sociable and seems to be able to fit in with whatever his friends are doing.

> [My friends played it and I wanted to join so I did.] Nate

> [His best friend plays it, they are inseparable. Usually I have both of them here a couple of times a week.] Mary

Nate doesn't mind who knows about his CF. His friends are the ones that ask the most questions but Nate's whole class is aware he has CF. Nate is keen to be a role model for CF and so the more people who know about it the better. At Nate's age he is lucky to have stable symptoms, and doesn't appear to be frustrated by his treatment activities.

> [Pretty much everyone in the class knows.] Nate

Nate likes to improve his CF awareness. He is currently working on a school project and has chosen CF for his topic. He was going to do cricket but thought more people would like to know a bit about the history of CF. Nate likes myCF as he can read about CF and understand the information on the platform. Nate believes that the more he knows about CF the better he can help himself.

> [Well knowing what it's, what it's all about will help you with your understanding of CF and make you know what you need to do to help your CF symptoms.] Nate

Both Nate and Mary think that myCF has a lot of potential for raising public CF awareness. Mary is supportive of Nate wanting to know more about CF but also tries to be careful about what information he can access. For a 12 year old, Mary feels that some information on CF is not yet appropriate for Nate. Mary thinks the information on CF would be good to have as public access, so that registered users are not the only ones to benefit from CF information.

> [I definitely think my family, if they want to access it and know more, I think myCF will be great for that. I think the language that is used is really good, for both adults and children.] Mary

Mary and Nate do not use social media. Mary and Nate think myCF may be a good way for people with CF to connect with each other in a safe manner. Mary thinks the main parts of myCF should be restricted to those with CF, with access given by the CF health care practitioner team.

7.7.2   COMPARISION OF CASE TO STAGE TWO ANALYSIS

The following is a summary of how this case study contributes to the stage two analysis. The contributions are based on Nate and Mary's myCF experience.

Mary and Nate manage the treatment of Nate's CF at a routine level. Nate completes his treatments tasks at a particular time each day. Mary is confident in Nate's ability to take his

medications and do his treatments and just likes to make sure things are done right. Mary doesn't keep a formal symptom diary of Nate's symptoms. Both Nate and Mary use their memory as records. Nate has weekly contact with formal care for his physio, which his mum also goes to. Nate and Mary both feel the CF team are approachable, aside from the regular physio sessions they usually only contact the team for clinic appointments. Mary sometimes contacts the formal care team via email.

Nate and Mary do not perceive themselves to be isolated. Nate has his friends at school that he feels he can talk to. Mary thinks myCF may give Nate another avenue to talk about his CF to people who are going through what he is going through but doesn't think he is suffering because that is not currently an option. Mary also thinks that myCF will be able to show Nate when he has forgotten a treatment and they can plan for that not to happen again. Nate thinks myCF will be somewhere that he can record his symptoms and others can see how he is going with his CF. Mary feels the information that will be available through myCF will be helpful for Nate when he wants more information.

Nate and Mary's experience of myCF was a positive one. Nate preferred to use myCF on the iPad or iPod. Both Nate and Mary found myCF easy to use and Nate enjoyed the visual feedback of his symptoms. The baseline was a concern for both Nate and Mary, as Nate's high baseline and stable symptoms meant that green symptom reporting was difficult to aim for. Mary was concerned that only receiving orange and red feedback was not a good thing for Nate, especially when his symptoms were stable and not declining. Nate completed myCF during his evening treatments and sees no reason why he cannot continue to use myCF as part of his daily treatment routine.

myCF matched Nate and Mary's expectations. Mary would like to be able to connect Nate's formal care medical tests to his myCF diary so the record can be used at the clinic. The main role of myCF is for formal care interaction. However both Nate and Mary like the ability to access information and the potential to chat to others. Nate feels he copes quite well with his CF, he doesn't let it hold him back. Nate thinks he could be a positive influence to others who might not be as accepting of their CF. Both Nate and Mary feel myCF gives a better focus to symptoms but the reaction to changing symptoms remains largely the same. Mary likes Nate to use myCF when he is going through a low period, to keep an eye on his otherwise stable symptoms.

Nate and Mary think the future of myCF has a lot of potential. Mary feels that myCF will help Nate take more responsibility of his condition management so she can start taking a step back. Nate feels that myCF will help track his symptoms but let him be a role model to other teenagers with CF. Neither Nate and Mary feel they are isolated but Nate would like to connect with others as a positive influence. Overall, Mary and Nate feel myCF has lived up to their expectations. Nate is interested in learning all he can about CF and promoting CF to other people.

7.8 CASE STUDY F

The rich and detailed discussion of data presented in this section details the individual case study Saxon. The case study is written from the points of view provided by Saxon, his mother Jacqui and his father Sebastian. The data used for the development of the case study was collected and analysed as described in chapter 4.

Sex	Male
Age	15 years
Location	Northern Tasmania
Rurality	Suburban
Parent Involved	Yes – Jacqui and Sebastian
Method of myCF use	Self
Internet Access	Broadband - Home
Diary Entries	40 out of 42
Blog activity	3
User view activity	4
Contact/clinic view activity	11
Useful links activity	3
Stable symptoms during pilot	Yes

7.8.1   SAXON

Saxon is a 15-year old teenager who lives with his mum, dad, twin sister and younger sister. Saxon lives in a suburban area in Tasmania's north. Saxon is the oldest teenage participant in the teenager myCF pilot implementation group. Saxon goes to high school, in grade eight. Saxon's parents both work full time. Saxon is the only participant enrolled from this postcode.

Saxon is a reserved teenager who loves to read, play his computer games and avoid any kind of sport! He does not play sport by choice and enjoys war craft games on his computer. He will soon be able to take his learner driving test and keeps reminding his mum about getting behind the wheel. Saxon's grandparents live interstate. Saxon and his family used to live on the mainland, near his grandparents and clinic visits meant a cooked roast on the way home. Saxon's dad and grandfather are constantly trying to build new physio devices, this started out to stop arguments but is now to make physio more interesting.

Saxon is a twin and was diagnosed with CF when he was a few years old. His twin sister does not have CF. Saxon has relatively stable symptoms and takes a mixture of daily antibiotics, nebuliser and enzyme medication. He also has daily physio activities he does at

home. Once a week he goes to formal physio. In order to gain extra computer time Saxon also clocks up the kilometres on the treadmill, something he does under sufferance. Saxon has a good understanding of what CF is. After agreeing to be in the myCF pilot implementation Jacqui and Sebastian had a chat with Saxon to find out his level of CF knowledge and found that he has a good understanding of things they hadn't really talked about before.

Saxon is on computers a lot. His dad has a smart phone and the family own an iPad. Saxon prefers to use his laptop or desktop PC because that where his games and programming software are located. Saxon is very confident with computers and values quality of information over the prettiness of the display. Saxon and his friends are on a Facebook embargo, vowing never to join that form of social media. If Saxon had his own way he would always be on a computer, much to Jacqui's disgust. Sebastian enjoys technology just as much as his son, designing new physio games to help with Saxon's treatment.

During the interviews with Saxon and Jacqui throughout the myCF pilot implementation, the following insights became apparent. Saxon enjoys school, mostly in the areas of graphic design, gaming and programming. He likes to experience new things, as long as it isn't sport! Saxon enjoyed Business Week as the extra bonus as he missed out on the school sports week, something he calls a 'happy coincidence'. Saxon enjoyed Business Week and their imaginary business was to help raise money for rural youth with a branding company. Saxon and his group won Business Week with their idea. Jacqui lists that as a 'proud mum moment.'

> [We did Business and Enterprise like um, just a couple of weeks ago. You know Business Week? It's the Young Entrepreneurs Challenge – it's a part of Business Week. So we design our own business and stuff – and we actually won this but…] Saxon

Saxon loves his computers and quite happily calls himself a nerd. Jacqui would like him not to spend so much time on the computer but he uses myCF time to his advantage. Saxon does not like many sports, he states he's been scared for life by the hurdles and splinters. He does run on the treadmill for extra computer time but would much prefer to be with his friends, on his computer or reading books.

> [I do, I am, I am a bit of a computer nerd. No Mum's like, you can do your CF thing and that's it!] Saxon

> [Too much time on the computer otherwise.] Jacqui

Saxon is doing a higher level maths at high school and will need to do exams for that subject. He doesn't normally have to do any exams for his other subjects. Saxon and his classmates find higher maths both amusing and frustrating. At the moment they are covering quadratic equations which Saxon finds frustrating. He says he puts himself through this misery as he wants to do graphic and game design, and you need to have a good understanding of maths to do that.

> [Yeah, graphics and games – that's where the maths comes in.] Saxon

Jacqui reminiscences on how quickly Saxon has grown up and how the next steps are a bit daunting. Saxon is very confident about his future driving abilities but Jacqui isn't too sure. She wants to know where all the time has gone, as it was only yesterday she was seeing him off to school for the first time. Jacqui does think that Saxon is a pretty reasonable teenager on the whole and Saxon agrees that Jacqui doesn't nag at him too much. Jacqui would like to get that comment on tape as they have days where she feels she is always on Saxon's case. Learning to drive will be the next bargaining chip.

> *[…it's the driving part that's scaring me now. Get my L's soon mum, get my L's soon mum! Its gone from starting school to this!] Jacqui*

Saxon has a background focus to his symptoms, they are not at the top of his mind all day, every day. He thinks outside influences, like a cold, are more to blame to symptom decline, rather than his CF.   Using the online symptom monitoring diary in the myCF pilot implementation meant that Saxon paid more attention to his symptoms. Jacqui thinks this is both a good thing and a bad thing. When Saxon is feeling good, his symptoms should really be in the background. If he's becoming unwell then Jacqui thinks it's appropriate he thinks a bit more about them.   Missing his enzymes does bring his symptoms to his attention. Jacqui says the whole house knows when he has not had his enzymes!

> *[I – as such, never really thought about my symptoms unless you know, I miss my enzymes and you – I'd think about it then. But just day to day and stuff I wouldn't really pay too much attention, wouldn't think about it too much] Saxon*

Saxon has a close group of friends and appears to get along with the majority of his classmates. Saxon decided to do Business Week because one of his friends wanted to do it. Jacqui is quick to point out that it was his girlfriend. Like most teenagers, doing subjects with your friends is so much more fun. Saxon finds his mum's delight with his girlfriend embarrassing.

> *[No, actually the only reason why I did it was because one of my friends like, you know…..] Saxon*

> *[His girlfriend was doing it!] Jacqui*

Saxon does not tell everyone he has CF. He only tells his close friends, other class members don't know about his CF diagnosis. The friends that do know have asked Saxon for more details. Some have gone and found some information themselves and then asked Saxon about it. Jacqui was impressed when she found out his friends went and found more information for themselves. She values Saxon having friends he can rely on. Jacqui was worried that some of the information would scare some of his friends, especially about the life expectancy. Saxon just shrugs his shoulders. He doesn't say what his friends thought of some of the scary stuff.

> *[I really – my close friends know that I have it, and some friends know what it is and stuff. A mixture of what I have told them and what they have gone and found out and stuff.] Saxon*

Saxon, Jacqui and Sebastian all think myCF will help the CF Tasmanian community in some way. myCF has a clinical focus for Saxon and he was disappointed when they couldn't use it during his last clinic visit. The immediate benefits are not clear to the family but they still think myCF will be useful to them in some way.

> *[Yeah I think it's has the potential to be helpful, I haven't actually had the chance to use it in clinic or relied on it yet or anything but I reckon in the larger situation it could be useful] Saxon*

The information pages on myCF appeal to Saxon as he could use them to explain what CF is to people, particularly his friends. Jacqui liked that she could trust the information on the site as it was from the health care practitioner CF team. The information is not restricted but Jacqui also wonders about the sensitivity of some information for younger people with CF. Saxon thinks the information on myCF is already available through the Internet in some way, you just don't know the quality of that information.

> *[Most of the stuff on there I already knew – that sort of information you could freely find on other sites and stuff. It would be handy if you want to explain what CF is to someone.] Saxon*

When Saxon and his parents were talking about the information sections of myCF, Saxon described it as 'good, basic information to introduce CF to someone with no other knowledge about CF'. Saxon prefers quality of information, even if the presentation of the information is basic.

7.8.2   COMPARISION OF CASE TO STAGE TWO ANALYSIS

The following is a summary of how this case study contributes to the stage two analysis. The contributions are based on Saxon and Jacqui's myCF experience.

Jacqui and Sebastian prefer that Saxon manage his condition treatment in a regular and planned nature. Saxon's parents think Saxon has a mature approach to his CF treatment and feel they can trust him to complete the majority of his treatment. Saxon doesn't think changes in symptoms are because of his CF, he usually blames it on a cold. Saxon's parents have regular email contact with the formal care team.

Saxon and his parents do not keep a symptom monitoring diary. The benefits of myCF are seen for formal care use and for helping parents with CF related parenting dilemmas. Jacqui and Sebastian give serious consideration to formal care guidelines however the lack of resources when attending clinics does frustrate them. Saxon does not appear isolated because of CF and he admits that beside treatment times he rarely thinks about his diagnosis.

The myCF pilot implementation was straightforward for Saxon and his parents. Saxon used the symptom monitoring diary daily, expect for a weekend the family went camping. Saxon likes using myCF on a desktop PC as he can play his games once myCF is finished. Jacqui would like Saxon to spend less time on the computer and more time doing exercise. Saxon thought myCF was quick and easy to use. Jacqui didn't think Saxon could complete the

diary as quick as he could but when she watched Saxon she noticed he did reflect on his symptoms.

Saxon found the appearance of myCF pleasant and easy to navigate. Saxon did notice some bugs in the symptom monitoring diary but he values the quality of data reported back to him. Saxon would prefer a quality clunky system to something that looked pretty but returned useless data. Saxon thinks myCF could also be good if you wanted to explain to people what CF was, using the library resources. Sebastian likes the idea of creating a myCF app so that it can be portable, and would like some of the features from other symptom tracking apps. Saxon feels myCF needs to be used for something, now that it has been piloted. The family is unsure of the benefits that myCF will give them but do feel there are some benefits to be gained. Saxon and his parent's attempted to use myCF at their last clinic visit but the consult room was not very big and there was no computer.

Saxon and his parents would like to see myCF be developed into an application for an iPod or smart phone. myCF will be helpful for Saxon to track how his symptoms are going and to share his symptoms during formal care interactions. Jacqui feels the easy use of myCF may not let Saxon reflect on his symptoms enough to give accurate tracking. Saxon and his parents think that myCF has potential but they do not see a direct benefit for Saxon at the moment.

7.9 CASE STUDY G

The rich and detailed discussion of data presented in this section details the individual case study Wallace. Wallace provides his own points of view for this case study. The data used for the development of the case study was collected and analysed as described in chapter 4.

Sex	Male
Age	52 years
Location	Southern Tasmania
Rurality	Metro
Parent Involved	N/A
Method of myCF use	Self
Internet Access	Broadband - Work
Diary Entries	17 out of 42
Blog activity	16
User view activity	7
Contact/clinic view activity	7
Useful links activity	5
Stable symptoms during pilot	Yes

7.9.1 WALLACE

Wallace is a 52-year old male who lives with his wife and two cats. Wallace lives in a metro area in Tasmania's south. He is the oldest participant in the myCF pilot implementation. Wallace works full time as a finance officer in the public sector. His wife is retired and they don't have any children. Wallace enjoys running, which can be a hazardous with Tasmania's weather! He is part of a running group that claims it's a drinking group with a running problem! Wallace is the only participant enrolled from this postcode.

Wallace enjoys gardening, cycling and spending time with his wife. He has just started a new veggie garden and hopes he manages not to kill this one with kindness. They have recently moved from a rural costal area and they have noticed the difference in travel time. Weekend drives are now a pleasure, not a necessity. Wallace has a sister and brother-in-law who live on the mainland, they travel over occasionally to visit. They like to catch the ferry and make a drive of it. Wallace currently works full time but is moving to a 9-day fortnight as he is starting to find it a bit hard to get up each morning.

Wallace was diagnosed with CF as a young child. He thinks his CF is a mild case and he is one of the luckier ones. He has not been greatly affected by his CF but as he is getting older he is finding that his symptoms are slowly declining. Wallace feels that it is to be expected

and other have it worse off. Wallace is on daily antibiotics, enzymes and nebuliser treatments. He is starting to have greater contact with the CF physiotherapist for physio but his running helps him out. Wallace is not sure if his running is not more like walking on some days but he enjoys it anyway.

Wallace uses a computer daily for work, and they also have one at home. He also has a mobile phone but he is not very confident with using it for anything but phone calls. Wallace is confident in using his computer and can manage to work out new experiences. Wallace uses his desktop PC at work for email and work. They do have the Internet on at home for email and general searching. Wallace does not use social media.

During the interviews with Wallace throughout the myCF pilot implementation, the following insights became apparent. Wallace thinks his condition is deteriorating but he doesn't focus too much on his declining symptoms. Everyone else has issues to deal with and so he does not dwell on the bad days.

> [I mean, everyone has problems of their own. Some you can see, some you can't.] Wallace

Wallace works full time and is approaching retirement. He wants to spend some more time with his wife and lately it seems harder to get up five days a week to go to work. Wallace has managed to work out a 9-day fortnight. He hopes they will be able to take a few more driving trips around Tassie. Wallace's wife also has a chronic condition and he is her carer.

> [I've just been given to go ahead to change to a 9-day fortnight, so it'll give me a break. Hopefully I can make it a Friday. You work and work and work and you start getting to the stage where you're thinking about retirement and oh god! All I've done is work.] Wallace

Wallace enjoys social running and runs every week with his running club. He is not very fast but the social aspects make up for it. They run in all types of weather and this can be interesting in Tassie. His running group occasionally raises money for charity and participate in fun runs.

> [Went for a run on Monday, got caught in the rain actually. Wasn't too bad but glad that doesn't happen too often!] Wallace

They have recently moved house and are now closer to Wallace's work. The garden has needed some work; some thing Wallace enjoys but does not always have success with. The veggie garden is going well this time, he is hopeful he doesn't manage to kill it with love!

> [Got the veggie garden going well – its looking better this time so fingers crossed.] Wallace

Wallace has family that live interstate; he and his wife enjoy visiting them regularly. During the hustle and bustle of Christmas he enjoys the holidays with his wife and cat.

> [It's pretty quiet when - It's just us, don't have any kids, grandkids, nieces or nephews.] Wallace

Wallace's symptoms are starting to decline, this hasn't stopped him from doing his normal activities but he is more aware of his different symptoms now. He considers his CF to be mild and this is why he has been able to live life without too many restrictions. Wallace figures he's had a good run and now he just has to slow down a little bit.

> [I'm struggling a bit – to be honest, yeah I guess I make the best of what I've got now – it just makes me a bit more aware...] Wallace

Wallace's approach to his condition management is routine and something he views as unremarkable. He feels his age gives him valuable experience in dealing with CF and this means he rarely needs outside help.

> [Well I've been living with it for 40 – 50 years so yeah. I've got my routine sorted really.] Wallace

 His use of myCF was easy but he did forget to enter his symptoms on some days. Wallace thinks myCF is very straightforward to use and the majority of people would not have trouble in using the online-symptom monitoring diary. His participation in the pilot meant he had to complete the diary. Wallace is apologetic but now the pilot is over he has forgotten about the diary.

> [It's easy enough to follow through, so um – it's all pretty straight forward really. But I went through and did it because I had to in a way, and now well – to be honest I've just forgotten about it] Wallace

Wallace does not use social media and is not interested in contacting others with CF. He does like to keep in touch with the CF community news and events.

7.9.2 COMPARISION OF CASE TO STAGE TWO ANALYSIS

The following is a summary of how this case study contributes to the stage two analysis. The contributions are based on Wallace's myCF experience.

Wallace manages his CF with a background focus. As he gets older his symptoms are becoming a little harder to ignore. Wallace complies with his medication as he finds it harder to get through the day otherwise. When Wallace has stable symptoms his management of CF becomes routine. Wallace has regular contact with the CF team, usually initiated by the health care practitioners. Wallace feels his symptoms are starting to decline but this is to be expected, he doesn't let this stop him from his gardening and running. Wallace's partner also has chronic conditions and he tends to focus on her well being first.

He does not keep a diary of his symptoms. Wallace feels that myCF will help older individuals with CF educate younger people; he doesn't see a direct benefit for him. Wallace prefers to use myCF at work, rather than his home computer. Wallace does not feel he is isolated but he feels he has lived long enough with CF to know what he is doing.

The myCF pilot implementation was straightforward for Wallace. He used his work computer to fill in myCF, the days he worked were the days he entered. Wallace forgot to

use the diary some days, but felt it was because he knew his own body; he relied on himself rather than a computer to tell him how his symptoms were. Wallace feels that myCF would be helpful when you were going through symptom decline but again thinks the benefits are for others, rather than him.

Wallace found myCF easy to use, which he found helpful, as he is not always confident with computers. He would like the clinics to be able to see his symptoms remotely, rather than just at clinic visits. Wallace feels myCF should be aimed at children and teenagers, as adults have lived with CF for some time and know what they are doing. myCF made him more aware of his symptoms but he is not sure that was helpful to him. Wallace found that some of his symptoms were reported back to him incorrectly but figured it was just a part of the pilot experience.

Wallace feels myCF is beneficial for formal care interaction but he does not see a direct benefit from him using it. He would like to see more games and interactive material to help teenagers use myCF to better understand their condition. Wallace found myCF easy to use and quick to interact with and liked that he did not have to use the other links in the site. He could just use the online symptom monitoring diary if he wished.

7.10 CASE STUDY H

The rich and detailed discussion of data presented in this section details the individual case study Martin. Martin provides his own insights for this case study. The data used for the development of the case study was collected and analysed as described in chapter 4.

Sex	Male
Age	50 years
Location	Southern Tasmania
Rurality	Rural
Parent Involved	N/A
Method of myCF use	Self
Internet Access	Broadband - Home
Diary Entries	41 out of 42
Blog activity	7
User view activity	4
Contact/clinic view activity	5
Useful links activity	3
Stable symptoms during pilot	No

7.10.1 MARTIN

Martin is a 45-year old male who lives with his wife, three boys, two dogs, cockatiel and about 10 cars. Martin lives in a rural area in Tasmania's south. He is the second oldest participant in the myCF pilot implementation. Martin is self-employed in the hospitality industry and spends most weekday mornings at work. The afternoons are for his cars and other around the house jobs. Martin's wife is a schoolteacher at a nearby primary school and works full time. Martin is one of two participants enrolled from this postcode.

Martin enjoys working on restoring his cars with his boys and going to car shows, both local and interstate. Martin's parent still live close by and he sees his mum nearly everyday, as she likes to come and walk the two dogs. Martin's eldest son is a third year apprentice and enjoys football. Martin's youngest sons are twins, in grade eight at the local high school. The elder twin likes to work on the cars with his dad. Martin's younger twin is cricket mad. Martin's mum also feeds his cockatiel, yet the bird will only let Martin touch him. Martin thinks it is funny, everyone else looks after the bird and he is the only one it will talk to. His cockatiel can get noisy when visitors come over, so the cage is on wheels to lock him in the cupboard!

Martin was diagnosed with CF when he was a child and remembers that doctors visits were not a positive thing, particularly if he was unwell. His parent's were told to take him home and enjoy him, as they were only going to have a small number of years. Martin thinks that framed his teenager years – he managed to get into a fair bit of trouble as he thought he only had a short time. 'Here for a good time, not a long time' was his motto. Martin thinks his CF is mild and does not worry too much about symptom changes – he is blaming old age and nothing else! His wife disagrees and is constantly reminding him to check up on his symptoms, take medication or get in contact with the clinic.

Martin will reluctantly use computers but prefers to leave that all up to his sons and wife. The only time he will willingly use the Internet is when he is searching for car parts. He has a mobile phone but tries not to give out the number, as he does not like using it. A good day is when he has not been on the phone or the computer! The family owns a number of laptops and connects wirelessly to their home network. Martin does not own a smartphone but his wife does. According to Martin, computer use is done 'under protest'. His sons all use Facebook but Martin wants nothing to do with it!

During the interviews with Martin throughout the myCF pilot implementation, the following insights became apparent. Martin and his family live in a rural coastal area. His wife and boys have to travel 20kms to attend school but Martin's business is local and this means he can work in the mornings and come home in the afternoons to spend time with his boys. Owning your own business can be time consuming but Martin feels they have finally ironed out all the bugs – this means he does not have to spend every weekend working.

>   [We have every second weekend off now, yeah.] Martin

Martin's boys have a wide circle of friends and interests. There always seems to be something happening at the home, or they are heading out somewhere. The Christmas period gives the family a welcome break, especially since Martin closes the business for a few days. Camping is the number one choice, with lots of fishing!

>   [Three or four days off, it's a good. We'll go down to the farm, recharge. Back
>   into it. Never stops!] Martin

Martin restores cars in his spare time (which he tends to make every afternoon) and likes to travel around to the different car shows. His wife usually goes with him to make sure they do not bring another one home. His current car belongs to a friend, they are restoring it to take it over to the mainland for a road trip.

>   [We're going to Chrysler on the Murray in three months, so it's going to be a big
>   job. We'll drive it up there, hang around for the weekend and then drive back on
>   the boat.] Martin

Cars are Martin's passion – they frustrate him and give him delight at the same time. He has just finished working on a car with his eldest son and now has started another with his mate. He is also looking for another car that he and one of his younger sons can start on. His mate's car was thought to be in good condition, until they stripped the old paintwork back.

[Then my mate – we were working on the car… the rust has come up right through the bodywork – she needs stripping right back. Argh! Labour of love!]
Martin

Martin was diagnosed at a time where the outlook for CF was bleak. He says that only really started to change recently, adults with CF used to attend child clinics in Tasmania until a few years ago. CF services were for children, as children were the only ones living with CF.

[It was only 6 years ago that they started the adult clinics, it was always you went to the kids CF clinic in the Royal.] Martin

Martin's family keeps him busy. He enjoys having his younger boys on school holidays as his eldest son works. Due to their busy schedules, early mornings and late evenings are when everyone is home. Holidays are the time to spend together.

*[Boys finished today and **wife** finishes next Thursday. So we'll go camping to the farm, hang out.] Martin*

Martin does not use technology unless he has to. The exception to this rule is when he is working on the cars. myCF has given him the confident to use the internet to find car parts, colours and inspiration. He avoids his mobile phone and gets his wife to handle the emails and bill payments.

[Doesn't make much of a difference to me, I'm not into them that much, yeah. Just that I can hop onto it and do it. Now that I've finished the latest car I don't need to touch it. It'll be a couple of months before I have to do that again. But the other day I was working with a mate on a car, needed a part – I said, come on mate – found the site. So now I can just, bang – straight on, get what I need.] Martin

Martin has fairly regular contact with the CF care team and has recently been in hospital due to pseudomonas (a type of bacteria that does not sit well with people with CF). The treatment was necessary but he does not like sitting around doing nothing, especially in hospital.

[Been in hospital with a bug, god that's boring – hooked up to the bottle. Waste of a week…] Martin

Martin does not focus on his chronic conditions if he can help it. He likes being busy and aside from the daily condition management tends to brush off symptoms until they stop him from doing what he wants to do.

[I don't have time to worry about CF. I've got bigger things to worry about these days – kids – car- work – wife! When's the next car start?] Martin

Martin has a large circle of friends and the majority know he has CF, he does not mind people knowing but he does not make an issue of it. One of their friends is a foster parent and fosters a child with CF. Martin and his wife are used as a support base when their friend is uncertain.

[She looks after foster kids, she has a child with CF. That's why she took him on, knew she had us…] Martin

Martin does not use social media, but his wife and children use Facebook. Martin's family and friends are his support base, with his wife giving him the most support in relation to his CF.

7.10.2 COMPARISION OF CASE TO STAGE TWO ANALYSIS

The following is a summary of how this case study contributes to the stage two analysis. The contributions are based on Martin's myCF experience.

Martin has a very laid back approach to his treatment and symptom monitoring. He is aware of what happens when treatment is not followed but he tends to blame symptom change on things other than CF. His wife tends to manage treatment by giving him reminders, or as Martin describes it 'nagging'. Martin's response to symptoms remains very much in the background, only focused on when he is unwell. The CF health care practitioner team maintain regular contact with Martin, he has regular phone contact and goes into the clinic fortnightly.

Martin does not keep a symptom diary for his CF or for his other chronic conditions. Martin's symptoms appear to impact him on a daily basis but he is not interested in tracking them. Martin does not appear to be isolated; he has a large amount of family and friend support. Martin is not sure how myCF will benefit him; he is participating to help others. Martin does not use computers and using myCF will require him to change this. He owns a mobile phone but tries not to use it.

myCF was easy for Martin to use during the pilot period. Despite his laid back attitude to symptom monitoring he missed only one day of data entry. Martin is pleased he managed to enter his symptoms nearly everyday. Martin did experience some decline in his symptoms during the pilot that was shown in the symptom monitoring diary. He did contact the formal care team as a result of the reported data. Martin feels that his response to his symptoms hasn't changed due to myCF but it has decreased the time it would normally take for him to act. Martin used myCF in the evenings; he liked that as it 'kicked the kids off the computer for bed time.'

The easy use of myCF meant that Martin could enter his symptoms quickly and without hassle. myCF met Martins expectations but he was not sure what to expect. He thinks myCF places a greater focus on his symptoms and that made him more aware of what was going on. For him this was a good thing. Another benefit of myCF was improving his confidence in using the Internet; he now can search for car parts with more confidence. Martin isn't sure if he would use myCF regularly but thinks it will be good for him and other people with CF. Martin thinks his wife would use myCF to keep an eye on his symptoms.

Martin thinks myCF in its current format is suitable for his needs. He would like the diary questions to be broken up into night and day segments as he has different symptoms during the different day parts.

7.11 CASE STUDY I

The rich and detailed discussion of data presented in this section details the individual case study Nyda. Nyda provides her own points of view for this case study. The data used for the development of the case study was collected and analysed as described in chapter 4.

Sex	Female
Age	36 years
Location	Southern Tasmania
Rurality	Rural
Parent Involved	N/A
Method of myCF use	Self
Internet Access	Broadband - Home
Diary Entries	41 out of 42
Blog activity	8
User view activity	32
Contact/clinic view activity	5
Useful links activity	2
Stable symptoms during pilot	Yes

7.11.1 NYDA

Nyda is a 36-year old female who lives with her husband and two boys. Nyda lives in a rural area in Tasmania's south. She is one of the two females in the adult myCF pilot implementation group. Nyda works as a part time teacher at a government college. Her husband works full time shift work in the public service. Her eldest son is in grade two and her youngest son starts kindergarten next year. Nyda is the only participant enrolled from this postcode.

Nyda enjoys spending her spare time with her family, preferably somewhere sunny. She has a room dedicated to scrapbooking at home but rarely gets a chance to sit and enjoy it. If she is not working she is chasing around her two boys with their sporting activities or helping out some of her students after hours. Nyda likes to be organised and has been known to have her Christmas shopping sorted in July! She does not do sport but says that being a mum to two young boys is enough sport for her. Both Nyda's and her husband's parents live close by and visit regularly.

Nyda was diagnosed when she was 6 years old but does not know a lot about her time of diagnosis. The few conversations she has had with her parents about that time were very emotional and she does not want to put them through unnecessary pain. Nyda does know

her parent's were told not to expect her to live past 10 or 12. Nyda has a moderate case of CF and has been in hospital at least once a year due to infections, usually picked up from her school. Nyda was advised not to have children but did so anyway, she thinks you cannot let these things rule your life, otherwise what's the point. Nyda is on daily medications, including nebuliser treatments, antibiotics and enzymes. She goes swimming with her sons to help with physio.

Nyda is frequently on technology at work and home. The family have a desktop PC and an iPad. The iPad is loved by all her boys, big and little. When her husband is home, her son's have little chance of playing games on it! Nyda uses Facebook to keep in touch with her family and friends. She is confident with computers and uses email and the Internet frequently. Nyda also owns a smartphone that she uses as a camera, as well as make phone calls and send text messages.

During the interviews with Nyda throughout the myCF pilot implementation, the following insights became apparent. Nyda and her family live in a rural area about 30kms from their workplaces. Their children attend the local childcare and primary school. Nyda husband works shift work so some weeks Nyda is left holding the fort. The end of the year is a busy time for them all. Nyda really enjoyed the latest family holiday but it is hard arranging schedules so they all have the same time off.

> *[Getting to the business end of the year, kids are getting ratty. My youngest has been up and down since the holiday – we're just getting busier. Need another one but arranging that is just impossible.] Nyda*

Nyda is always busy but since her eldest son has started school the time really started to fly. She wonders what it will be like when her youngest son starts kindergarten next year. The holiday season seems to come around fast each year and this year it took her by surprise.

> *[Christmas is coming up and so we need to start thinking about that. We went up to the local shopping market and I was surprised to see the decorations up – but it is now November I guess…. Where's that gone?] Nyda*

Nyda takes her youngest son swimming each week. Her eldest son does AusKick and Nyda's husband has made footy goals in their front yard, something the boys love! Nyda enjoys time with her youngest but is not so fond of getting in the pool.

> *[We go swimming every week, I'll be looking forward to the day I don't have to get into the pool with him.] Nyda*

Nyda loves to scrapbook but is finding it difficult to finish off projects. They have only recently moved into their house, which they built. Her husband organised a scrapbook corner and she really hasn't used it yet.

> *[I have this wonderful scrapbooking corner and I've not touched it since it was finished – I still haven't finished off my eldest sons book yet and how old is he? Opps.] Nyda*

Nyda does not want her children to know the greater details of her condition. She does not want them to worry on her behalf. She feels she is big enough to worry for them. She knows where she can get help if she needs to and does not want them fearing for what the future may bring.

> [I don't want my children to know the in's and out's of CF. They know I have it but they don't need to know the details.] Nyda

Having two young boys brings it's own set of parenting challenges. Sharing toys is one area that brings constant trouble. Her eldest son has recently saved up some pocket money to buy a toy and doesn't always let his younger brother play with it. Nyda sometimes wants to step in and sort the boys but she makes herself step back.

> [I just think, let him have turn – but no no, stay out of it, they will sort it out.] Nyda

Nyda has mostly stable symptoms but has periods during the year that she knows are going to be difficult. The end of winter and the start of summer are usually difficult times for her. Winter is hard for everyone but she thinks the start of summer is because they have been so busy for so long and then everything stops. Once she is resting her body starts to play up.

> [You've sort of been going on that treadmill for so long. It just starts to wear by the time term is over.] Nyda

Nyda uses Facebook to keep in touch with family and friends. She doesn't feel the need to contact other people with CF for support but would like to offer support to people with newly diagnosed children, or young children. She feels it is important for them to know that you can still live a full life with CF. No one is ever normal, Nyda does not like using that label. If we were all normal life would be boring.

7.11.2 COMPARISION OF CASE TO STAGE TWO ANALYSIS

The following is a summary of how this case study contributes to the stage two analysis. The contributions are based on Nyda's myCF experience.

Nyda has a planned approach to her condition treatment and management so she can get it done around her family activities. She has a background focus to her symptoms but makes sure her treatments are done in order to be able to keep up with her boys. Nyda currently does not have a lot to do with the CF care team but know she can contact them for assistance at anytime. She is guided by medical advice but is not always driven by it. Nyda can predict when her symptoms decline, usually in the middle and end of the year. Her workplace means she is constantly exposed to whatever is currently going through the student population.

Nyda does not keep a symptom diary of her symptoms and responds to symptoms as they change. Nyda does not appear to be isolated but can imagine that the younger families and newly diagnosed may want to talk to others to get more information. She also feels it would be important for parents of young children to realise there is life after a CF diagnosis.

Nyda is participating in the myCF pilot implementation because she was asked to and wants to help out. She is unsure of the benefits myCF might give her and feels that myCF may be more relevant for others.

The myCF pilot implementation was straightforward for Nyda. The symptom monitoring was easy to use; Nyda liked the faces as prompts for symptom status. Nyda was in hospital during the pilot period for a tune up, the hospital did not have Internet access so she had her husband enter her symptoms for her at home. Nyda felt that reflecting on her symptoms was helpful, as over time you may start to see patterns in the reported data that you would normally not notice. She did think a balance was needed between reflecting on symptoms and dwelling on symptoms. Nyda is aware that the wide range of users may make it hard for myCF to suit everyone.

The easy use of myCF meant that Nyda though her eldest son could use it but she protects them from her condition as she does not want to be anything other than mum to them. myCF met Nyda's expectations. She feels that in the future it would be a great way for parents, patients and doctors to interact. She liked the ability to either use the diary or stay on the site and explore the other areas. Nyda liked to be able to look up the other users of myCF and viewing the blog comments.

Nyda feels myCF will be important to help young families be exposed to the positive side of CF and to gain support from others who have been in similar situations. Nyda feels that while her family may be interested in looking at myCF, it would cause more worry about her symptoms, something she wants to avoid. The inclusion of news and events in the myCF platform would be beneficial to the CF community, letting others know what people with CF have achieved.

7.12 CASE STUDY COMPARISIONS

The theme *ATTITUDES* was found in all the teenager case studies (cases D, E and F). The theme *ATTITUDES* included a positive and a negative perception of CF by the participant or by others. *ATTITUDES* was perceived by the parents of the teenagers as a something that was required as the teenager moved into adulthood. Parents of teenaged participants thought it was important for their children to have the appropriate attitudes regarding CF, in order for the successful transition of the management for CF from the parent to the child. *ATTITUDES* were perceived as a matter of priority between CF managed or life priorities. *ATTITUDES* depended on how the participant viewed their life activities. When participants regarded CF as a low priority the condition frustrated the participants when it limited what they wanted to do. One parent in the paediatric case studies (case A) and one adult (case G) also demonstrated this theme. Both case studies were identifying the need for positive perception towards CF and the impacts it may have on life activities.

TRYING TO BE NORMAL was present in all case studies. This is unsurprising as participants felt that it was important that they were not know for their CF. It was more important for participants to be involved with their life activities despite their CF. An interesting part of this theme was the participants sometimes wanted people to know they had CF, to show they could achieve their goals no matter their health status. *TRYING TO BE NORMAL* was a complex theme and did not only concern the participants. The support network of the participants demonstrated a need to maintain the participants sense of normality. This included assisting the participant when they wanted to promote or deflect their CF.

CONDITIONAL AND SOCIAL INTERACTION was connected to the parents involved in the myCF pilot implementation. Interestingly, this theme also appeared in an adult case study (case H). The theme in case H represents how CF can be used within a social circle to provide support to others. *CONDITION AND SOCIAL INTERACTION* illustrates that CF may take part in the decision making to take part in life activities. The responsibility of parenting decisions that connected to CF condition management was the main part of this theme. The dilemma of wanting control over the parenting and socialisation of their child, and complying with the required CF condition management was reflected in *CONDITION AND SOCIAL INTERACTION.* The theme appeared to be of greater concern to parents and children. The parents of younger children particularly wished for their child to have access to a peer support network.

Finally, *CF KNOWLEDGE* includes the participants, their support networks and the general public. Participants placed their own judgements on the level of CF knowledge held by themselves. The judgement placed on their CF knowledge was compared to what the participants perceived was appropriate. The measurement of CF knowledge appropriateness was obtained from the specialised CF health care professionals involved in the participants care, or the opinions of the participants support network. Frustration was often expressed as people did not appear to understand what it was like to live with CF. Teenaged participants wished for more awareness of CF but at the same time did not want attention drawn to themselves or commit time to condition management. This theme did not appear in one of the paediatric cases (case B) or two of the adult cases (H and I). It is

unclear to why these cases did not include *CF KNOWLEDGE* however each of the three cases did exhibit a strong support network.

Using the research stage three themes, the individual case studies can be expressed in the following table. Table 7.1 shows the presence of each of the research stage three themes across each individual case study. The double check mark indicates a strong presence of the theme for that individual case study.

Table 7-1 Stage three-theme presence in individual case studies

	Attitudes	Trying to be Normal	Condition and Social Interaction	CF Knowledge
Case A	+	++	+	+
Case B		++	+	
Case C		++	+	++
Case D	++	++	++	+
Case E	+	++	+	+
Case F	+	++	+	+
Case G	+	++		+
Case H		++	+	
Case I		++		

The following tables illustrate how each individual case study compares to the stage two data analysis, providing a holistic viewing of the individual case study themes. This comparison also allows the individual voice to be placed on the stage two themes, developed from the whole individual and family viewpoint. For case studies D to F, P means the theme was present for the individual with CF, PP means the theme was present for the parent of the individual and B means the theme was present for both the individual and parent.

Table 7-2 Comparison of individual case study to Stage one - Foundation Building themes

	Stage One – Foundation Building								
	Case A	Case B	Case C	Case D	Case E	Case F	Case G	Case H	Case I
Condition									
Symptoms	✗	✗	✗	B	B	B	✗	✗	✗
Symptom Response						B			✗
Symptom Memory				PP					
Symptom Decline				PP	P	B	✗		✗
Treatment Considerations	✗	✗		PP	B	B		✗	
Medical Condition	✗	✗	✗	PP	B	B	✗	✗	✗
Management									
Routine Fundamentals					P		✗		
Care Accessibility	✗	✗	✗	B	B	B	✗	✗	✗
Care Continuity	✗					PP			
Support									
Care Communication	✗	✗	✗	PP	PP	PP	✗	✗	✗
Seeking News							✗		
Individual Management	✗	✗	✗	B	B	B	✗	✗	✗
Diary Status	✗	✗	✗	B	B	B	✗	✗	✗
Considerations									
Life Priorities	✗		✗	B	P	P		✗	✗
Life with CF								✗	✗
Isolation			✗	PP					
Family Perceptions				PP		PP		✗	
Sustainable Use	✗					P			✗
Condition Ownership		✗		PP	PP	B			✗
Child Manipulates						PP			
Consent Rationale	✗	✗	✗	PP	B	B	✗	✗	✗
Expectations									
Wishlist						PP	✗		✗
Benefits of Participation	✗	✗	✗	PP	B	B	✗	✗	✗
Expectation of Issues									
Expectation of Benefits	✗	✗	✗	PP	B	B	✗	✗	✗
Interactions			✗						
Development									
Pre-Pilot Knowledge	✗	✗	✗	B	B	B	✗	✗	✗
Predicted Functionality	✗	✗		B	B	B	✗		✗
Development Involvement	✗	✗	✗	B	B	B	✗	✗	✗
Project Experience			✗						✗
Blockage									
Model Responses			✗						
Attention Negative							✗		
Barriers to Use		✗						✗	✗
Computer Literacy							✗	✗	
Communication Issues				P					
Accessibility	✗	✗	✗	B	P	P	✗	✗	✗

As shown in table 7.2, the axial codes of *Care Accessibility, Individual Management, Diary Status, Pre-Pilot Knowledge,* and *Development Involvement* were all present in each individual case study. It is unsurprising as the questions asked by the researcher were related to the concepts of these axial codes. The axial code *Medical Condition* was answered by all but a teenage participant – this was not a direct question however the majority of participants included elements of CF or their CF diagnosis during the pre-pilot semi-interviews. *Symptom Memory* is only present in case study D, by the parent of a teenaged participant.

The research stage one – **Foundation Building** axial codes present in the individual case study place a formal care focus on the perceived use of myCF. *Care Communication* was present for the adult's in the case studies, either those as parents or the adult participants. The *Seeking News* aspect to communication was only present in the adult case study G. *Isolation* is present in the case studies from the parent point of view. The expectation of myCF was largely positive, with the axial code *Expectation of Issues* absent from all the individual case studies.

Model Responses was present in the paediatric case study C, by a parent. The axial code *Barriers to Use* was present in three of the case studies, by one parent and two adults. The axial code *Attention Negative* in case study G is concerned with gaining attention from the formal care team, contacting the formal care team was a sign of not coping. *Computer Literacy* was also found in two adult case studies, G & H. These adults were the oldest myCF pilot implementation participants. Finally, accessibility was present in all case studies but not by all participants. This is not surprising as *Accessibility* was largely a result from a direct question regarding Internet and computer access.

Table 7.3 shows the comparison of research stage three - **Life Context** to research stage two – **Implementation Experience**.

Table 7-3 Comparison of individual case study to research stage two - Implementation Experience themes

	Stage Two – Implementation Experience								
	Case A	Case B	Case C	Case D	Case E	Case F	Case G	Case H	Case I
Expectations									
Expectations	✗	✗	✗	B	B	B	✗	✗	✗
Future Use	✗	✗	✗	B	B	P	✗	✗	✗
Relevance									
Barriers to Use		✗	✗	P			✗		✗
Negative myCF Perception				P					
Relevance	✗	✗	✗	B	B	B	✗	✗	✗
myCF scope	✗	✗			B	B	✗		✗
Usability									
Degrees of Use	✗	✗	✗	B	B	B	✗	✗	✗
Quick Completion Problematic						PP			
Functionality Impaired		✗		B	B	B		✗	
Baseline Important							✗	✗	
Diary Use Barriers		✗	✗	P					✗
Input Limits Output				PP					
Mobile Access				P		B			
System Balance	✗			PP	PP	PP	✗		✗
Facilitation									
Enables	✗	✗	✗	PP	P	B		✗	
Supports	✗	✗		PP	P	B	✗		✗
Platform Change	✗	✗		B	B	B	✗		✗
Connecting									
Connecting	✗		✗	PP		P			✗
Consent Rationale	✗	✗	✗	PP	P	P	✗	✗	✗
Pre-Pilot Involvement	✗	✗	✗	B	B	B	✗	✗	✗
Provision of Hope							✗		✗
Information Sharing	✗	✗	✗	PP	B		✗		✗
Closed Environment		✗			PP	P	✗		✗
Isolation			✗	PP		PP		✗	✗
Care									
CF Diagnosis								✗	✗
Formal Care		✗			B	P		✗	
Formal Care Problematic	✗		✗			B			
Alternative Care									
Innovation						B	✗		
Memory Recall	✗		✗	PP	B	P		✗	✗
Apathy									
Condition Knowledge Lacking			✗						
Knowledge Re-enforcement Problematic		✗							✗
Life									
Balanced Management	✗	✗		PP	B	B		✗	✗
Normalisation Needed				B					✗
Condition Awareness	✗			PP	B	B	✗	✗	✗
Condition Consequences	✗	✗	✗	PP	B	B	✗	✗	✗
Model Behaviour			✗						
Family Isolation			✗	PP				✗	
Positive Feedback Sought			✗		B	PP			
Condition Determines		✗		PP	P			✗	✗
Technology Use	✗		✗	P	PP	P	✗		

As shown in table 7.3, the axial codes *Expectations, Relevance, Degrees of Use* and *Pre-Pilot Involvement* were present in all the individual case studies. *Expectations* and *Pre-Pilot Involvement* are present as the result of direct questions during the post-pilot semi-structured interviews. *Relevance* and *Degrees of Use* are the concepts gathered from the response to several questions but are also unsurprising due to the purpose of the stage two **Implementation Experience** interview questions. *Future Use, Consent Rationale* and *Condition Consequences* were present in all the individual case studies but were not answered by all the pilot participants.

Negative myCF Perception was from the teenage perspective and was concerned with the nature of the technology myCF used and the focus it placed on CF symptoms. This was further added to by the teenager experiencing incorrect reporting of symptom data by myCF. *Quick Completion Problematic* was a parent perception and they connected the easy use of myCF to their child not reflecting on their symptoms when completing myCF. *Diary Use Barriers* was present in three case studies and was attributed to life factors, rather than the myCF platform itself.

Isolation and *Family Isolation* was again present in this stage, expressed by the parent's of CF individual or the adult participants who were speaking for parents of CF individuals. *Memory Recall* is present in all but two individual case studies, and is not restricted to parents, teenagers or adult participants. In stage one – **Foundation Building** *Memory Recall* was limited to the parents of participants.

7.13 STAGE THREE – LIFE CONTEXT INITIAL FINDINGS

The initial findings from research stage three – **Life Context** illustrated that participants found the emotional attachment of the myCF pilot implementation to be of comfort to them, even when they did not physically interact with the myCF pilot implementation. Despite the way participants used or did not use the myCF pilot implementation they perceived the myCF pilot implementation as something that was reassuring to have. This initial finding adds complications to the participants' evaluation of the myCF pilot implementation as the likeability and helpfulness of the myCF pilot implementation did not necessary translate to participant use.

It was found that the role of symptom information was dependent on if the participant was a parent or the person with CF. Parents used the information from the myCF pilot implementation to gain control of their child's CF symptoms and to improve knowledge of those symptoms. People with CF interacted with the myCF pilot implementation to assist them to report symptoms to either the specialised CF health care professionals, their significant others or their parents. It was found in this research stage that parents used the symptom information to gain control whilst participants with CF used the symptom information to comply with significant others or their specialised CF health care professionals.

An important finding from research stage three is that self-management is a group activity and not something that is solely undertaken by the person with CF. An important boundary to this finding is the nature of the group approach to self-management of CF. From this

research it is the family of the person with CF who play a significant role in the self-management of the participants CF. For the older participants the behaviours of self-management may be an individual event but the lead up to those behaviours is influenced by their family and significant others. There is both an internal and external focus to the participants self-management of CF. Participants understand self-management as taking greater control of their CF so they can do the things they need or want to do. As they age, self-management behaviours also allow participants to reduce family worry or to be able to experience family milestones. This research stage has also indicated that the specialised CF health care professionals involved in with the person with CF can be also considered a significant person. As the participant ages the role of the specialised CF health care professional may change but they are still a factor during times of unstable CF symptom periods. This is an important initial finding as the myCF pilot implementation allows singular participant interaction but it is lacking the family approach evident from this research.

It was found in this research stage that stable symptoms lower the participants' focus on the myCF pilot implementation. Symptom monitoring was found to have a background focus for the participants for the majority of the time. During the myCF pilot implementation the participants generally experienced stable symptoms with minimal exacerbations. Their CF symptoms did not cause them to divert or cancel life activities during the myCF pilot implementation. It was perceived by the participants that during times of unstable symptoms the myCF pilot implementation would assist them in understanding the changes in their symptoms and planning their condition management.

Finally stage three found that symptoms provided a prompt for the participant to interact with the myCF pilot implementation. It was found that the participant's perception of the myCF pilot implementation technology dictates the nature of interaction once symptoms have prompted participants to use the myCF pilot implementation. The technology improves the perceived helpfulness of the myCF pilot implementation for the participants. This initial finding also illustrates that the myCF pilot implementation technology is something that both enables and frustrates the participants. For some participants the myCF pilot implementation technology is something that is familiar and experienced in their daily lives. The participants' familiarity with technology allows the participants to experience quick and easy navigation when using the myCF pilot implementation. The quick and easy navigation is at times frustrated by the perception that the symptom entry is not well thought out. Quick interaction is perceived to not allow participants to enter symptom data that is reflective or reflected upon. In addition to this the enabling nature of the myCF pilot implementation technology frustrates some participants as the mobile friendly nature of the technology has limited functionality on some mobile platforms.

The initial findings from this stage are:

- The myCF pilot implementation concept provides benefit to participants.
- The requirements for CF management is individual and depends on if the person has CF or is providing care for someone with CF.
- The myCF pilot implementation is helpful for participants, regardless of interaction.
- The technology used to access and host the myCF pilot implementation determines the relevance of the myCF pilot implementation for each participant.

7.14 RESEARCH FINDINGS

Each of the initial findings was mapped to develop the initial findings into research findings that reflected both the individual and collective perspectives present in this research. The relationships in each research stage and between each research stage are now apparent. A representation of the concept map used in the interpretation of the twenty-three initial findings can be found in Figure 7.1. A readable A3 concept map is found in Appendix E. Appendices F – M contain each a concept map of the eight findings that form the complete concept map.
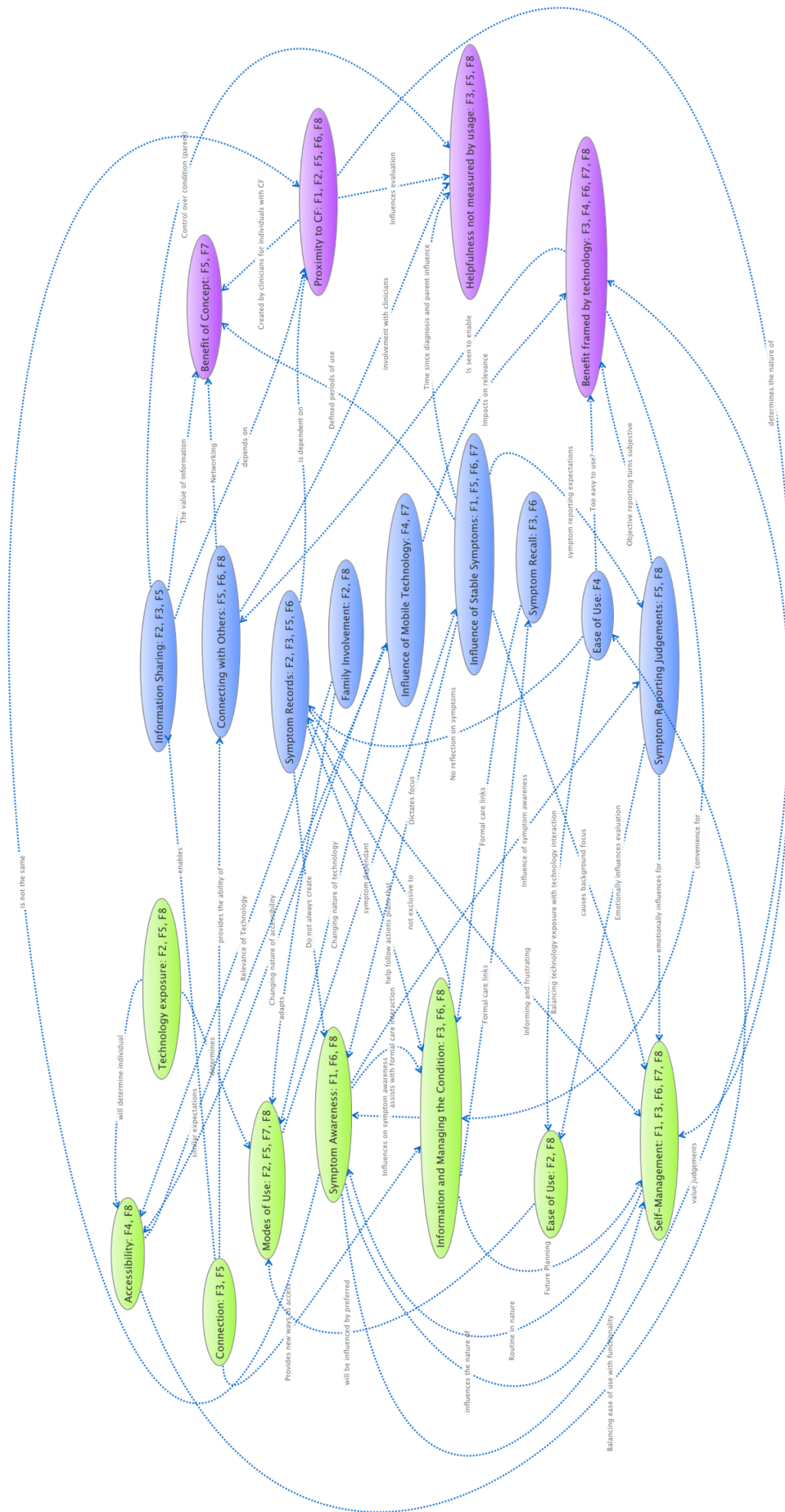
Figure 7-1 Concept map of the interpretation of the initial findings of this research

Participants view symptom monitoring as a way of gaining control of CF. The activity of symptom monitoring is a end result of the participant wanting to gain control, or being directed to gain control by a person of influence. This draws in the relationships the participants have in their life with the health care system and their family, as the completion of the myCF pilot implementation appears to be an activity that is not done in isolation.

It was found that ease of use is a complex concept and is more than the physical usability of the system. This initial finding was a mixture of enablers and frustrations. The myCF pilot implementation was easy to use and quick to navigate. The ability to quickly complete the online symptom monitoring diary was perceived to be unsupportive of adequate symptom reflection by the parent participants. The participants did not find the online symptom monitoring diary threatening in presentation or in the questions that were included. Whilst the questions were not threatening, it was evident that the meaningfulness of the questions was difficult to maintain for all participants.

It was evident that the barriers to use the myCF pilot implementation moved from the participants' level of computer literacy to family, life, time and symptom influences. The exposure to the online symptom monitoring diary during the pilot meant the usability of the myCF pilot implementation became more than just accessing the technology supporting it. If the information gained by using the myCF pilot implementation was perceived to be meaningful by participants then the supporting technology lost focus and the importance of accessing the information gained focus. The dilemma present is that the meaningfulness of the accessed information plays a role in the participant evaluation of the myCF pilot implementation. Participants initially viewed symptom entry objectively. As the pilot progressed the symptom information was viewed subjectively and with emotion. The subjective nature of the symptom reports appeared to influence the participants' decision to continue to use the online symptom monitoring diary. Additionally, the participants place emotional judgements on the online symptom monitoring diary reports. For the teenage participants the emotional judgements became competitive, trying to aim for the green symptom feedback.

The development of participant symptom records primarily assisted with formal clinic appointments with the specialised CF health care professionals. The symptom data from the myCF pilot implementation does not include a mandatory reporting of data to the specialised CF health care professionals. The myCF pilot implementation was designed to be a self-contained symptom monitoring system. Participants prefer to control how they share their symptom data and this illustrates another form of control participants were taking of CF.

Self-management was perceived as taking greater control of CF so life activities could be completed. Self-management was condition focused, and in response to planned treatment plans developed by their specialised CF health care professionals. As they grew older, self-management behaviours allow participants to reduce family worry or to be able to experience family milestones. The myCF pilot implementation assisted participants in their condition management of CF by increasing symptom awareness to allow symptoms to be managed accordingly.

It was found the participant evaluation of the myCF pilot implementation was multi-faceted. The participants judged the myCF pilot implementation by the technology used to access the online symptom monitoring diary and by the meaningfulness of the information that was given to them through their use of the myCF pilot implementation. The initial use was concerned with the supporting technology and then moved to what purpose the accessed information was serving for the participant. The perceived helpfulness of the myCF pilot implementation was additionally not dependent on the use of the online symptom monitoring diary. An emotional judgement was not only placed on the traffic light reporting participants received but also on the myCF pilot implementation's existence. It was evident that the emotional impact of symptoms and symptom data reporting did influence the participants evaluation of the myCF pilot implementation.

Finally, the combined initial findings from research stage one and two demonstrated that the perceived helpfulness of symptom monitoring is dictated by the participant's symptom status and the perception of the technology used by the myCF pilot implementation. Symptoms will prompt for symptom monitoring and the technology supporting the myCF pilot implementation will govern how symptoms will be monitored and for the length of time each log on will occur for.

The combined analysis and interpretation of the three research phases resulted in the following research findings:

F1: Requirement for symptom monitoring reduces as knowledge of CF improves.

F2: Parents continue to monitor symptoms regardless of their child's ability to recognise their symptoms.

F3: Participants understand self-management however demonstrate only compliance.

F4: Expectations of the myCF pilot implementation usability do not alter between mobile and computer based platforms.

F5: The myCF pilot implementation is perceived to be helpful even when not used.

F6: Online symptom monitoring tool provides symptom support during unstable symptom periods.

F7: The myCF pilot implementation supports daily condition management.

F8: The evaluation of the myCF pilot implementation is dependent on if the person has CF.

7.15 CHAPTER SUMMARY

The analysis of research stage three – **Life Context**, developed a rich description of the myCF patient participants. Nine individual case studies have been presented in this chapter, discussing a myCF participant in terms of their demographical and family details, the stage three data analysis themes and how that case relates to the stage two data analysis.

The chapter presents a tabular comparison of the stage two themes to each individual case study, in addition to the presence of each stage three theme in each individual case study. These tables inform the next stage of the research, the exploration of the inter-relationships in the data.

This chapter concluded with the findings that emerged from the integrated data analysis and interpretation conducted across the three research stages initial findings.

The next chapter discusses the significance of these findings in relation to the current literature and in answering the research objective and questions.

CHAPTER 8   DISCUSSION OF FINDINGS

8.1 INTRODUCTION

This chapter discusses the findings from all stages of this research (see Chapters 5, 6 and 7) in relation to the current literature. The discussion refers to the myCF pilot implementation and is not limited to those case studies presented in chapter 7. The chapter is structured into the following sections.

- Section 8.2 discusses the findings which emerged from the analysis of all the research stages (see sections 5.4, 6.3, 7.13, and 7.14).

- Section 8.3 re-introduces the research questions and the associated research objectives.   This section provides answers to the research questions and the associated research objectives by presenting the key findings from this research. The section details how the myCF pilot implementation supports individuals with the self-management of their CF.   It concludes by discussing the role that lifestyle choices have on individuals when managing their condition.

- Section 8.4 presents the outcomes from this research.   The key findings for this research are:

    o **KF1: Without a transition from self-management 'understanding' to self-management 'knowledge' it is not possible for an online symptom monitoring diary to provide self-management support.**

    o **KF2: Symptom monitoring is a background activity for those with CF, and a focused activity for those who care for people with CF.**

    o **KF3: Evaluation methods that focus on use of electronic tools for self-management support are not able to holistically capture all aspects of perception of helpfulness.**

    o **KF4: Lack of consistency in user-interface design directly impacted on perceptions of satisfaction during interaction and overall evaluations of the entire online symptom monitoring diary**.

- Section 8.5 provides a summary of this chapter.

8.2 FINDINGS

This section provides a discussion of the findings in relation to the current literature. The discussion is a result of the interpretation of the concept map (see Appendix E) that presented the initial findings from the three stages of the research. As shown in sections 4.6 and 4.7 the data analysis resulted in nineteen themes that were developed into twenty-one initial findings after the initial interpretation. The further interpretation of the initial themes through concept mapping has resulted in eight research findings (see Appendices F – M). The eight research findings were used to answer the research questions and research objectives (see section 1.3.2) and the final interpretation produced four key research findings (see section 8.4). The eight findings are presented below.

8.2.1   FINDING ONE

Requirement for symptom monitoring reduces as knowledge of CF improves.

This research has found that symptom monitoring, in this case using an ICT tool, is not a regular part of CF condition management. When symptom monitoring did occur it was performed only by the parents or carers of children with CF. Specifically, the parents of young children with CF undertook symptom monitoring on a regular basis. Symptom monitoring was the parent's way of trying to experience second hand their child's CF symptoms. The parent had to understand what symptoms the child was experiencing and how those symptoms affected the child, in order to manage how CF impacted on their child. The symptom information provided by the online symptom monitoring diary enabled the parent to understand their child's CF and helped them establish a baseline for symptoms monitoring.

> *[You know when he first got sick - we said we should write everything down*
> *– at the start it's information overload. There was a lot of things we needed*
> *to do] Denis' Mum*

Children with CF grow up with their parents monitoring their symptoms and being guided by their parents on the required condition management. As the children age, the nature of symptom information moves from the parents' observations and keeping a symptom diary to the physiological experience of the symptoms. Symptoms are acknowledged and responded to or dismissed as the participant creates priorities between symptom management and current life activities. Children with CF are experiencing the symptoms and do not appear to have a desire to record the symptoms. The child learns from the way the parents have managed the child's symptoms and therefore are able to link this information when experiencing the symptoms. The parent of the child can only continue to gain information about the symptoms through monitoring and recording. This activity may become difficult as the child ages and starts to choose what symptom information they wish to share with their parents. The children are starting to be independent and this draws in the discussion of parental control. The changing nature of parental control over children as they age is a well-known topic but for this research it is important as it is the child who has CF and not the parent. The parent is going to have to give up symptom monitoring for their

child at some point. This presents two questions - does the child have to take up symptom monitoring? and what role will an ICT tool have if they do?

Interestingly, during the myCF pilot implementation period, teenagers and adults logged a higher average number of interactions when compared to the parents of child participants. Parents of child participants interacted with the online symptom monitoring diary an average of 15 times during the 6-week period, teenagers demonstrated an average of 38 times and adults interacted an average of 32 times. There is a conflict between the perceptions of the participants and the actual logged online symptom monitoring diary interactions. Two parents of the participants experienced computer difficulties during the online symptom monitoring diary 6-week period. The average number of logged interactions of those without computer difficulties was 19 times. For parents of participants the biggest barrier to using the online symptom diary was the lack of retrospective entry. It was perceived that if they had the ability to enter a previous days entry, the online symptom monitoring diary would be used more. The perception of participants does not match the experience of the parent of the participants. This indicates that something else is preventing their interaction with the online symptom monitoring diary, regardless of their perception that symptom monitoring through the online symptom monitoring diary helps them improve their knowledge of their child's CF symptoms. Teenagers attributed parental reminders and activity trade off for their high interaction rate. The teenagers wanted to avoid the parents 'nagging' them to use the online symptom monitoring diary, or they were offered a trade off to complete the diary. Adult participants linked their high interaction rates to their commitment of agreeing to be a part of the myCF pilot implementation.

This finding highlights the limitation of symptom monitoring for the parents of children with CF and the importance of the symptom monitoring processes when learning to manage the CF condition. Symptom monitoring is a focused activity for those caring for people with CF, and a background activity for those living with CF. This is a conflicted finding as the perceptions of the participants do not match the logged interactions during the myCF pilot implementation period. The conflict may be better understood through the exploration of the influence of stable symptoms, technology exposure, and life style priorities.

8.2.2 FINDING TWO

Parents continue to monitor symptoms regardless of their child's ability to recognise their symptoms.

It was evident that the parents of participants, rather than the participants themselves undertake symptom monitoring activities.

> *[I rely more on myself than a computer to tell me how I feel.] Wallace*

The specialised CF health care professionals linked symptom monitoring activities with improved self-management behaviours during the development of the myCF pilot implementation. The current level of participant symptom monitoring records is low and this was reflected through the logged interactions of the online symptom monitoring diary. The teenage and adult participants are aware of their symptoms but they feel they do not

need to record symptoms to understand what is occurring within their body. The parents of participants understand their children's symptoms by symptom monitoring and by recording those symptoms. The use of the online symptom monitoring dairy provided some assistance in creating those records.

Parental symptom monitoring occurs as it is the sole method of gaining symptom information from their child while they are young. As the parents do not experience the symptoms, they can only get information about their child's symptoms through symptom monitoring. People with CF gradually learn their symptoms and start to self-adjust as they age. For those with CF, experiencing the symptoms in addition to parent behaviour gradually removes the need for deliberate and continuous self-monitoring.

> *[… when he was little because he couldn't tell me things, so I sort of had to record everything.] Jarrett's Mum*

Benefits such as improved symptom awareness and reporting accuracy, increased access to information, and improved communication can be gained through interaction with ICT self-management tools (Cummings et al., 2010, Atkinson and Gold, 2002, Cox et al., 2012, Roehrer et al., 2011, Neuhauser and Kreps, 2010). The main benefit of symptom monitoring for the parents is during unstable or new symptom periods. The focus of parent symptom monitoring was found to be in the creation of symptom records that would assist with formal care interactions. The use of the online symptom monitoring diary initially assisted with symptom record keeping however as the pilot implementation progress other barriers to use became apparent.

Symptom monitoring activities change focus as the participant ages and the different ways that each participant age group used the online symptom monitoring diary reflected this. Symptom monitoring is central to assisting in gaining symptom experience and information during childhood, and under the care of a parent. Self experience and observations of their parents reduce the need for symptom monitoring as participant enters their teenage and adult years. The participants become symptom aware without the need for deliberate monitoring. Deliberate symptom monitoring becomes a priority once more during times of unstable symptoms.

Two ways of understanding symptoms have been identified, experiencing symptoms and monitoring symptoms. Experiencing symptoms is only possible for those with CF, however, those with CF can also monitor their symptoms. Parents are restricted to monitoring symptoms and their child can supplement this. The discussion of symptoms between the parent and the child results in more detailed symptom information than parental monitoring alone (Hafetz, 2010). Difficulties can arise when parents and children have different understandings of their condition, leading to parents being reduced to the monitoring role and the child experience lower adherence to parental symptom monitoring (Modi and Quittner, 2006, Zindani et al., 2006). During the adolescent development period, child disclosure may cease as the child seeks independence and to fit in with their peers (Modi et al., 2008). Child disclosure for symptom monitoring is also influenced as the child experiences their CF symptoms and observes their parents reaction to those symptoms.

8.2.3 **FINDING THREE**

Participants understand self-management however demonstrate compliance.

As the research progressed it became evident that the participants' perceptions of self-management was based in treatment and medication activities.

> *[That you take your enzymes, do your nebs, take care of yourself.] Nate*

Participants perceived self-management to include responding to symptoms and tailoring their treatment activities to their lifestyle. Self-management is perceived as a matter of priorities. The participant nature of responding to symptoms is reactive, with minimal evidence of forward planning and symptom anticipation. This reactive, treatment based conceptualisation of self-management was present for all the participants in this research. Participants did not undertake self-management activities in isolation from their health care professional team. The participants used pre-determined courses of action to take when symptoms stated to deteriorate. The pre-determined treatment actions were largely prescribed by the health care professional, with some input from the participant. The adult participants initiated conversations regarding treatment action plans for symptom deterioration.

> *[I mean I might start on antibiotics but that's usually when I have asked the Doctor, when I get an exacerbation, when I get sick, what antibiotic should I go on next. So I already know.] Wilson*

The tailoring of treatment activities involved choosing what treatment suited the participant and how other activities could provide the same treatment benefits. Participants determined their own likelihood to comply with prescribe treatment activities and demonstrated self-reflection in planning how they would undertake their treatment activities. The participant commitment required to undertake the treatment activities is indicative of the processes for Cognitive Participation, as per Normalisation Process Theory (see sections 3.3.2 and 8.2.6). Participants perceive self-management as the internal bargaining between what has been prescribed and what they wish to do. Self-management is complying with treatment to prevent symptom decline and parental reminders for the teenage participants. The parents of teenage participants view teenaged self-management as an indicator for the transfer of condition ownership and responsibility.

> *[That he'll take responsibility for managing his own illness and keeping himself well.] Saxon's Dad*

Self-management support was required to be relevant to the participant's perception of self-management. Self-management support assisted participants with decision making and enabled them to undertake condition management activities that may not have been possible if the self-management support was not available. Each different participant group had their own criteria for judging the relevance of self-management support. Parents of participants required self-management support to assist them to understand their child's symptoms. Teenage participants required self-management support to directly align with their current interests and assist them to reduce the amount of parental reminders. Adult

participants required self-management support to be time efficient and to be adaptable to their current daily routines. Self-management support was required to be non-intrusive, and an activity that aligned to the participants' understandings of self-management. Self-management was concerned with both the verbalised concept of self-management, and the assistance sought to undertake self-management activities for the participants in this research.

The links between symptom planning and health care professional guidance is evident through the participants' requirements of self-management support. This is an important connection, as the verbalised concept of participant self-management appears to agree with the current literature surrounding self-management definitions, as discussed in section 3.4. Self-management, as discussed by the participants, included concepts of planning and strategy for maintaining a balance between treatment and life activities. The differences between current definitions of self-management and the participants understanding of self-management become apparent with the application of self-management support requirements to the participants life situation. Participants desire self-management support to assist them to undertake condition management and treatment activities as prescribed by their specialised CF health care professional. Self-management activities are completed to follow their prescribed treatment and medication regimes. Minimal partnership exists between the specialised CF health care professional and the participants as the treatment and medication activities are determined. The participant understanding of self-management is of treatment planning and exacerbation prevention within pre-determined parameters as given by their specialised CF health care professionals. As illustrated in section 3.4.2, the traditional model of health care is not supportive of self-management practices.

8.2.4   FINDING FOUR

Expectations of online symptom monitoring diary usability do not alter between mobile and computer based platforms.

Participants experienced being both enabled and frustrated by the compatibility with mobile technologies. The myCF pilot implementation could be accessed through a desktop computer or through mobile technologies that supported an Internet browser (see section 3.4.1). The ability to use the myCF pilot implementation with mobile technologies suggested the participants had flexibility of use, potentially becoming a factor in the participant's Collective Action component of Normalisation Process Theory (see sections 3.3.2 and 8.2.6). The mobile friendly nature of the myCF pilot implementation caused participants to have several expectations when using it on a mobile device. The participant expectations included the visual layout and the ease of navigation. The main expectation was that the flexibility of use did not diminish the quality of the visual layout or ease of navigation.

There were mixed experiences when the myCF pilot implementation was used on mobile technology. For some participants, the ability to use the myCF pilot implementation on their preferred platform over-rode the incomplete functionality of the online symptom monitoring diary that was a result of the altered mobile layout. For other participants the

limited navigation and change in the online symptom monitoring diary appearance overrode the flexibility that mobile technology offered. This illustrated the individual nature of the Normalisation Process Theory component of Reflective Monitoring (see section 3.3.2 and 8.2.6) each participant experienced.

> *[I didn't like the little – on the small screen on the iPhone, and a lot of the stuff I would be doing my mobile um I didn't, its not very good on there at all and most most um websites would have a mobile interface just by innately…]* *Wilson*

Previous studies have reflected the convenient nature of mobile technologies used for symptom monitoring (Cummings et al., 2011). According to the Australian Bureau of Statistics, 31.9% of children between the ages of 5 years and 14 years owned a mobile phone in Tasmania (Australian Bureau of Statistics, 2012). For adults over 18 years of age, 83.7% were mobile phone users (Flanagan, 2010). Overall in Tasmania, the subscription of mobile phones is increasing at a greater rate than the majority of other Australian states (Australian Bureau of Statistics, 2011b). Mobile phones have the additional advantage of a higher level of dispersion, compared to other technologies, across the different socio-economic groups (Boland, 2007).

The participant acceptance of a mobile platform for the myCF pilot implementation reflects the growing trends of mobile phone use by both children and adults in Tasmania. The mixed access across the different mobile technologies, with varying levels of participant satisfaction, illustrates the myCF pilot implementation currently requires both a traditional computer access point and a mobile access point. Symptom monitoring via mobile technology requires careful planning to align with the increasing expectations of mobile access and service delivery. This creates difficulties for development processes that do not adequately involve individual in online symptom monitoring diary development (see section 3.3.1).

8.2.5 <u>FINDING FIVE</u>

The myCF pilot implementation is perceived to be helpful even when not used.

It is evident that it was the concept of the myCF pilot implementation that assisted participants when evaluating the helpfulness of the online symptom monitoring diary. The variation in the number of times the online symptom monitoring diary was used did not alter their perception of helpfulness and usefulness. Participant interaction levels with the myCF pilot implementation did not have a direct relationship to positive perception. The evaluation by participants included the ease of use of the online symptom monitoring diary, the relevance to their current symptoms, their emotive connection to the online symptom monitoring diary, and the perceived future use of the online symptom monitoring diary in their own condition management.

> *[We don't need to use it daily anything, it's good to know that it is there.] Iain's Mum*

Parents of participants used the online symptom monitoring diary an average of 15 times, out of the possible 42 times. The lowest number of entries for parents of participants was 4 times and the highest number of entries was 30 times. Teenage participants used the online symptom monitoring diary an average of 38 times, out of the possible 42 times. The lowest number of entries for teenage participants was 15 times and the highest number of entries was 53 times. Adult participants used the online symptom monitoring diary an average of 32 times, out of the possible 42 times. The lowest number of entries for adult participants was 13 times and the highest number of entries was 39 times. All participants perceived the online symptom monitoring diary to be helpful and a tool that was helpful for them in their own condition management, regardless of the level of use.

> *[Um it hasn't been useful to me right now but I reckon it will be in the future.]*
> *Saxon*

For each participant group, participants who interacted with the online symptom monitoring diary at bi-daily or greater rate were in the minority. Out of all the participant groups, the teenage participants were the only group to record a 100% or greater symptom entry rate. For the teenagers who achieved greater than 100%, a daily diary entry was recorded twice during the same 24 hour period. The weblogs illustrate that the majority of participants, across all participant groups, did not use the online symptom monitoring every day, or even every second day. Regardless of the minimal use, participants still perceived the online symptom monitoring diary as a tool that would assist them in the future.

> *[Um, yeah at this point in time because he is well we don't use it as much but if*
> *he was unwell or unstable would definitely use it more, but not at this point of*
> *time.] Dennis' Mum*

The regular use of the online symptom monitoring diary and helpful perception could be easily explained. Participants found the myCF pilot implementation to be helpful and so they continued to use it. Greater exploration reveals that assistance with symptom monitoring was not the only measure of helpfulness used by participants. Participant evaluation included emotive aspects and assistance during formal care interaction.

> *[Now um, yeah basically yeah like what it is doing and is um, it just helps me*
> *and I don't want to see it go because it's just, is my friend at the moment.]*
> *Keir's Mum*

This evaluation draws in the relationship that the specialised CF health care professional and participant have, and how participants carry out their condition management. Do participants find the online symptom monitoring diary helpful for their own condition management, or is it due to the online symptom monitoring diary being introduced by CF health care professionals? The parents of participants additionally have an agency on the teenage participants. For teenage participants using the online symptom monitoring diary regularly, what is the role of the parent influence?

The irregular use of the online symptom monitoring diary offers similar questions to be answered.

- Why did participants like the online symptom monitoring diary if they discontinued or reduced their use?
- What is the role of the specialised CF health care professional when participants are forming their evaluation?
- How do the current relationships participants have with their support network frame their condition management activities?
- What type of value does the online symptom monitoring diary offer to participants during times of irregular or no use?

Until recently, patients had a passive role during their interactions with the health care system (Kyngäs et al., 2000). Health care professionals are perceived as authority figures and patients, if in a satisfactory relationship with their health care professional, will act accordingly with the advice given (Brincks et al., 2010). The perception of helpfulness by the participants may be an extension of the influence of health care professionals in the participants' health care (see section 3.4.2). While there is no direct evidence of the health care practitioner's influence on the participants' perception of the myCF pilot implementation, perceived modes of use for the online symptom monitoring diary included using the symptom data to report back to their specialised CF health care professionals.

8.2.6 FINDING SIX

Online symptom monitoring tool provides symptom support during unstable symptom periods.

Participants found symptom entry during stable symptom periods as repetitive and predictable. The entry of stable symptoms was not helpful for condition management or improving symptom awareness. Stable symptoms reduced the online symptom monitoring diary to an activity that was non-essential and with minimal return for improving symptom awareness and condition management.

> *[Um, yeah at this point in time because he is well we don't use it as much but if he was unwell or unstable would definitely use it more, but not at this point of time.] Iain's Mum*

Participants predicted that interactions during unstable symptom periods would assist in tracking symptoms for reporting to the specialised CF health care professionals, and for the participants own condition management. Participants perceived that forward planning would be possible during times of unstable symptoms, enabling them to start treatment or seek help before the symptoms changed significantly. This finding was consistent for all participant groups in this research.

The priority of CF in relation to everyday life additionally influenced the online symptom monitoring diary interaction during stable symptom periods. The priority of CF was lower than life activities during stable symptom periods, this is reflective to the literature found in section 3.5. It was therefore unsurprising that interaction with the online symptom monitoring diary, requiring participants to focus on CF symptoms, would also be a lower priority. Stable symptoms lead to routine control; medication is taken, treatment is applied

and participants can take part in life activities with minimal thought for the impact of CF. During periods of stable symptom, parents of participants find it difficult to place the perceived appropriate level of focus towards their child's condition.

[I wish I took it more seriously, but it's hard when he is so good.] Keir's Mum

The priority of CF is greater during periods of unstable symptoms. Patterns in symptoms are less predicted and life activities cannot always be carried out. During unstable symptom periods participants require a greater level of control over CF. To achieve this, participants focus on their symptoms and increase treatment activities. Participants perceived that symptom change outside of their ideal symptom state gives cause to use the online symptom monitoring diary. Despite this, there is uncertainty in the participants prediction, as given they will not be feeling well the question must be asked if they will self-monitor during times of unstable symptoms or will they be focusing on treatment that will assist in becoming well once more.

The term 'change' is an indicator that a shift has occurred for participants and they are no longer operating in a known environment in regards to their CF management. Normalisation Process Theory (see section 3.3.2) is concerned with what is required for people to implement the new practice or technology into a routine and has been used to assist with eHealth implementations (Murray, 2012, May and Finch, 2009). Normalisation Process Theory is aimed towards organisations and ICTs requiring some form of interaction with healthcare professionals, rather than a standalone system such as the online symptom monitoring diary (Murray et al., 2011, Mair et al., 2008). Regardless of this, Normalisation Process Theory is founded in sociology and does not appear to be limited in its intended application (May and Finch, 2009). For participants experiencing periods of unstable symptoms, a change has occurred and they will go through several processes to achieve a new known environment.

Normalisation Process Theory provides further illustration of the motivation to use the online symptom monitoring diary during periods of unstable symptoms. The theory is not in a particular sequential order and is considered an action theory, it explains what people do rather than what their attitudes are or what they believe when in action (May et al., 2009). At the surface level, the components of Coherence, Collective Action and Reflective Monitoring best explain why the participants perceive the potential for a higher level of use during periods of unstable symptoms. Normalisation Process Theory does not require the application of all four components in order to understand how participants can use the online symptom monitoring diary to assist them when their known condition activities change (May et al., 2010).

Figure 8.1 summaries the activities of the participants during each component of Normalisation Process Theory and has been adapted from figure 3.2 in section 3.3.2.

Coherence (sense making work)	Cognitive Participation (relational work)
- Participants recognise what is different about current symptoms. - Motivation is given to move from mental reflection of symptoms to physically recording symptoms. - Participants attempt to work out how the change in the CF symptoms will be actioned on and worked into daily management. - Participants work out why the physical recording of symptoms will assist them during their defined periods of online symptom monitoring diary use.	- Participants work out why the use of the online symptom monitoring diary is valid. - Participants work out how the use of the symptom monitoring diary fits in with current activities.
Collective Action (operational work)	**Reflective Monitoring (appraisal work)**
- Participants attempt to work the new practice into everyday settings. For the use of the online symptom monitoring diary this practice was no longer desired when symptom entry was perceived to be repetitive and did not assist with CF symptom management. - Participants developed confidence that the symptom reporting was accurate. - Participants understand how spending time using the online symptom monitoring diary will mix with other conventions of daily life.	- Participants collect information to determine how useful symptom monitoring during defined periods is. - Participants discuss with support networks (parents, spouse, child) if symptom monitoring during defined periods is providing anticipated assistance. - The participant conducting the symptom entry will start to assign a worth to symptom monitoring activities. During the defined periods of new diagnosis and unstable symptoms this research has identified a high worth. Once symptom monitoring becomes repetitive, boring or impairs life activities (identified as occurring during stable symptom periods) the worth of symptom monitoring lowers. - Participants develop their preference of symptom entry for the defined period. Refinement of symptom entry activity would occur until symptom entry is no longer required and the symptom entry is ceased.

Figure 8-8-1 Components of Normalisation Process Theory illustrating participants perception of use during unstable symptoms

During Cognitive Participation participants identify with using the online symptom monitoring diary and attempt to make symptom entry a routine behaviour (May et al.,

2010). Once participants perceive that symptom entry no longer fits with their current activities, symptom entry is no longer a required routine behaviour and ceases to occur. Participants appraise their use of the online symptom monitoring diary and either continue their symptom entry practice or abandon it during Reflexive Monitoring (May et al., 2010). From this research, participants perceive that abandonment occurs once unstable symptoms become stable once more. Wangberg et al. (2008) link this to a positive 'ceiling effect' of an ICT intervention.

During Collective Action, the accuracy of the symptom reports was required to be accepted by participants otherwise the entry of symptoms does not provide assistance. It was evident in this research study that the traffic lights did influence those to change condition management behaviour, regardless of the flawed implementation of the traffic light reporting system. This research also found that participants perceived that the online symptom monitoring diary would be of assistance to those who are newly diagnosed with CF, or parents of a newly diagnosed child. Faircloth et al. (2004) explored a number of physiological, psychological and social changes individuals undergo after the experience of a stroke. This exploration was concluded to be generalizable at a broad level for illness in general. Faircloth et al. (2004) found that illness creates changes in current life activities and ideals. Motivators for symptom entry can be explained through the changes created by their child's diagnosis for the parents of a newly diagnosed child. The parents are attempting to understand their child's diagnosis and understand what they will be faced with (Chiu and Eysenbach, 2011). Normalisation Process Theory again provides a framework to show the processes the parent goes through and how using the online symptom monitoring diary can be viewed as a part of their condition management for that point of time.

8.2.7   FINDING SEVEN

The online symptom monitoring diary supports daily condition management.

It was evident that participants largely complied with prescribed treatments. A significant part of participant condition management was concerned with treatment and medication activities that had either been prescribed or introduced by their specialised CF health care professionals. Participant decision-making for their condition management was focused on the activities suggested by their specialised CF health care professionals. The online symptom monitoring diary was compatible with participants current methods of condition management as it was an introduced concept from their specialised CF health care professionals.

> *[I usually try to participate in anything. That they ask.] Paige*

Decision-making for condition management was not prioritised during periods of stable symptoms illustrating the Normalisation Process Theory component of Coherence (see sections 3.3.2 and 8.2.6) the participants used to indicate if change from their current treatment management activities was required. Due to this, regular symptom monitoring is not considered a part of condition management. Intermittent use of the myCF pilot implementation was evident during the six-week period when participants experienced

stable symptoms. An interesting comparison to this pattern of use was found with an adult participant, with stable symptoms, who provided a daily symptom entry for all but one day of the six-week period.   This entry pattern illustrates the tendency for participant compliance to prescribed condition management activities.

> [Just missed one night in the last six weeks, so that's been good and yeah.] Martin

During the Normalisation Process Theory component of Coherence (see section 3.3.2 and 8.2.6) participants make decisions about, and create priorities for, their condition management to appease themselves or others in their support network. Participants made decisions that either aligned prioritised life activities above condition management activities, or prioritised condition management activities above life activities. Adult participants had the greatest tendency to either make condition management decisions for their own peace of mind, or to reduce concerns of family members. Teenage participants also showed a capacity to make decisions for themselves but had a greater tendency to make decisions to appease their parents. Parents of participants were fulfilling their own need for condition management decision-making.   For all groups of participants there was evidence of condition management decision-making to appease their specialised CF health care professionals.

> [I find it hard when I go to appointments, when they ask me stuff about her symptoms and stuff like that over the last few months, so I don't know —If this is what I think it is, this will help me when I'm at her appointments and things at that.] Tamryn's Mum

The myCF pilot implementation supported participant symptom planning and tracking activities that formed a large portion of their own condition management.   Condition management was found to consist of treatment and medication activities. Both of these activities revolved around reacting to participant current symptom status, forming a part of the participant's Normalisation Process Theory components of Coherence and Reflective Monitoring processes (see sections 3.3.2 and 8.2.6). The online symptom monitoring diary provided an avenue for participants to record symptoms and to view their current symptoms. Participants perceived an increased ability to tailor their condition management through the activity of symptom monitoring. Teenage participants altered bedtime habits and were able to increase treatment activities after using the online symptom monitoring diary and viewing a decline with some of their symptoms. Participants also perceived the online symptom monitoring diary to be helpful during unstable symptoms periods, allowing them to track the fluctuations of symptoms and to compare how their condition management activities were impacting on their symptoms.

> [I like knowing if am going to be sick, it helps me to prepare for that.] Nate

Participants' decision-making, when concerned with their CF condition management, was focused on the specific treatment activities or on the participants preferred life activities. For all participant groups, treatment activity decision-making revolved around how the treatment activity could be included into current routines. Participants adjusted treatment

activities so that the same benefit could be received through a less formal setting, using guidance from their specialised CF health care professional. An example of this includes swapping chest percussion therapy for jogging, dancing or jumping on the trampoline.

> *[He does jumping on the trampoline, he does exercises on the fit ball.] Iain's Mum*

Participants used self-reflection to rationalise the change in treatment activities to suit their current lifestyles. The decision-making that created priorities between life activities and condition management activities suggests that participants are combining self-management and risk taking behaviours. The risk taking behaviours produces positive and negative risks, depending on how the priorities between life activities and condition management activities are managed.

Patient education for chronic disease self-management involves developing the capacity to make decisions that are appropriate (Clark and Gong, 2000). The appropriateness of such decisions may be different, depending on if participants or health care professionals are making the judgement. Compliance is interchangeable with adherence to treatments (Clark and Gong, 2000) and if prescribed condition management is not followed then the person is not compliant (DiMatteo, 2004, Zolnierek and Dimatteo, 2009). Those who first appear non-compliant in condition management are creating their own opportunities for increasing their likelihood to manage their condition. The perceived increased use of the online symptom monitoring diary during times of unstable symptoms forms a part of a participants decision making process that indicate they have the capacity for CF condition management.

8.2.8   <u>FINDING EIGHT</u>

The evaluation of the online symptom monitoring diary is dependent on if the person has CF.

The role of the online symptom monitoring diary was different for the carers of people with CF, and those with CF. Within each group there is additional considerations that will influence how each person will evaluate the online symptom monitoring diary. This research begins to highlight the varying elements that contribute to each of the different participant evaluations of the online symptom monitoring diary. Each participant had their own individual process of evaluation, reflective of each person's CF situation.

> *[Because it isn't – the diary is very personal like if I had cystic fibrosis and if you had cystic fibrosis our diaries would be very different.] Denis' Mum*

Symptom monitoring was a central condition management activity for parents of participants, particularly for parents of younger children. Symptom monitoring is the only way symptom information can be obtained for parents of young children. The evaluation of the online symptom monitoring diary for parents of participants was focused around three dimensions.   The first dimension was concerned with CF condition management and included the relevance of the symptoms in the online symptom monitoring diary to their child, and how effectively the online symptom monitoring diary assisted parents of

participants with reporting symptoms to the specialised CF health care professionals. The second dimension was concerned with the actual platform of the online symptom monitoring diary and included the usability of the online symptom monitoring diary and how the myCF pilot implementation compares with their current Internet access. The third dimension was concerned with the parent's confidence in dealing with their child's CF and included their current level of education of CF, their support network and the relationship they have with their child's specialised CF health care professional. Encompassing the three dimensional nature is that the parents of participants do not have CF, those who are caring for participants with CF are providing the evaluation.

> [Before when I went to clinic they would ask how often do she do a poo and
> what are they like and I just couldn't remember. So I just wasn't really sure.
> But with this, way easier, breaking down each day.] Caitlyn's Mum

Teenage participant evaluation of the online symptom monitoring diary was concerned with the perceived relevance to their current life activities and the nature of their symptoms. Symptom monitoring was not a central condition management activity for teenage participants. The role of their parent is still in organising the teenagers condition management and the teenager moves between initiating their CF treatment and being reminded to undertake their CF treatment. During this time the teenagers are under the care of their parents and their CF health care professional. The teenage participants relationship with their CF health care professional and their parents relationship with the CF health care professional may also have an influence during the teenage participants evaluation of the online symptom monitoring diary. The teenage participants need for independence also has an influence on the relationships with their care givers and how they perceive self monitoring for their CF condition management. It is the teenage participants relationship with their care givers and their perception of CF that forms their initial evaluation of the online symptom monitoring diary. The teenage participants had the greatest tendency to evaluate the online symptom monitoring diary on the perceived relevance to their current interests, compared with the other participant groups.

> [I like that I get to use a computer to use it.] Saxon

The evaluation of the online symptom monitoring diary for adult participants was not restricted to the relevance of the included symptoms, or the usability of the platform. The role of the online symptom monitoring diary was not as central to their condition management as it was for the parents of participants. Adult participants experience the symptoms and can feel how the symptoms impact on their bodies. They have previous experience of what may happen and how their body feels when the symptoms are changing. Regardless, the online symptom monitoring diary is still viewed as helpful and valuable. Adult participant evaluation included the future use of the online symptom monitoring diary and the role the online symptom monitoring diary could have for others living with CF. The adult participants may dismiss the online symptom monitoring diary as being irrelevant for their own personal use, however, they could see it assisting other people living with CF. The adult participants did not automatically dismiss the perceived helpfulness of the online symptom monitoring diary. Benefit for others, particularly younger people, resulted in a

complimentary adult participant evaluation. As with the other participant groups, the relationship with their CF health care professional additionally influences their evaluation of the online symptom monitoring diary.

> *[I think older people like myself, know how to manage yourself. Anyway it and um and have been doing it for a fair while. So yeah um just need to train people to start using it, um basically young people.] Wallace*

Interestingly, it was found in this research that the number of times the online symptom monitoring diary was used did not influence the participants evaluation, regardless of the participant group. Referring to Chiu and Eysenbach (2010) and their Stages of Use framework (see section 3.3.2), the authors note that the perceived usefulness of a system will act as the lead in to the Consideration stage. It is the dissatisfaction with the ease of use with a system that will prevent the individual from moving forward to the Initialisation stage or creating attrition at the Utilisation stage (Chiu and Eysenbach, 2010).

What is perceived as ease of interaction for one participant group, is perceived as a disabler for another. For a diverse range of groups such as those using the myCF pilot implementation the difficult question are, whose desires are the priority. Whose voice should be heard first? The answer appears not to be simple, nor obvious. The fall back option can move to those who directly interact with the online symptom monitoring diary as first priority and to the support base as a secondary priority. The support base often provides the incentive to interact with the online symptom monitoring diary and both the direct user and support base gain symptom and non-symptom benefits. This dilemma frames the participant evaluation of the myCF pilot implementation as the traditional metric of system use does not capture the intangible benefits suggested by this research.

8.3 ANSWERING THE RESEARCH QUESTIONS AND OBJECTIVES

This section provides a re-introduction of the research aims and research questions to provide focus for the discussion provided in this chapter. As presented in chapter 1, section 1.3.1, this research explores the implementation of an online symptom monitoring diary developed to support people living with CF in Tasmania. The online symptom monitoring diary was designed to support individuals in their CF self-management by increasing symptom awareness.

As demonstrated in Finding 6 (see section 8.2.6) and Finding 8 (see section 8.2.8) Normalisation Process Theory (see section 3.3.2) assisted uncovering the influences of symptoms on the use of the online symptom monitoring diary, and the process of evaluation participants apply to the online symptom monitoring diary. Additionally, Finding 3 (see section 8.2.3, Finding 4 (see section 8.2.4), and Finding 7 (see section 8.2.7) can be enriched through the application of Normalisation Process Theory. It is important to highlight that there is a current focus on innovation being strongly linked to technology and the authors of Normalisation Process Theory state that this does not always need to be the case (May et al., 2009). Innovation can be concerned with processes and practices and ensuing that the required processes are understood and normalised. Normalisation Process Theory draws the focus of this research from technology supporting symptom monitoring and self-

management, to the factors that promote or prevent the actions of symptom monitoring and self-management.

The following research questions and associated research objectives were designed to meet the research aims.

RQ1:   How can an online symptom monitoring diary support individuals with self-management of cystic fibrosis?

The participants' understanding of self-management must first be understood to answer this question. What self-management represents to participants is the first indication of how the online symptom monitoring diary can support individuals with their self-management of CF.

The tasks, activities and behaviours that are supported by the online symptom monitoring diary highlights how well the support aligns to providing self-management support. The execution of the information provided by the online symptom monitoring diary illustrates if the task, activities and behaviours are supported to become self-management of CF.

The interactions between the participants' self-management 'understanding' or 'knowledge' and the online symptom monitoring diary indicates the type of support provided by the online symptom monitoring diary. The tangible, or intangible nature of support the online symptom monitoring diary provides is revealed by comprehending how self-management 'understanding' or 'knowledge' influences use.

> ***RQ1 O1:   To identify what individuals understand as cystic fibrosis self-management.***

The definition of self-management has evolved over time, and has been the subject of many reviews (Barlow et al., 2002, Bodenheimer et al., 2002, Clark et al., 1991, Kawi, 2012, Lorig and Holman, 2003, Muir Gray, 2004). Attributes such as collaboration, planning, learning and ownership (see section 3.4) are found in definitions of self-management and so it is important to once again clarify that for this research, self-management is defined as;

> *"Self-management is a dynamic process incorporating an individual's capability and confidence to be self-reliant in undertaking responsibilities and engaging in activities, such as adopting health-related behaviours, in a self-tailoring context to deal with the impact of living with a chronic condition on all aspects of their life: a sense of self and medical, emotional and social domains. In order to retain an acceptable and meaningful quality of life, such management involves the capability to undertake core tasks or responsibilities." (Cameron-Tucker, 2008), p 365.*

Self-management is a changing concept, and does not remain static for any one person. As situations change, the method of self-management would ideally adjust accordingly. The foundations of self-management, as presented in section 3.4, are essential in providing the skills and knowledge to make independent and informed judgments about their management of their condition.   The dynamic processes include partnership and

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collaboration between patients and the health care system, with both parties contributing to the patients' health care actions and decision-making. As a self-tailoring process, self-management is adapted to each person's circumstance, and provides the opportunity to deal with their CF from both a life and health context. People with CF are able to maintain an acceptable and personally meaningful quality of life through planning, learning, collaboration, and prioritising.

Condition management involves similar activities as self-management, but the execution does not consider the longer term, or strategic directions of the activities. Condition management in this research is a set of preventative tasks performed by individuals on a daily basis (Clark et al., 1991). The aim of condition management is completing activities, similar to completing a checklist, and is reflective of complying with prescribed health care professional directives. Actions are based on information provided by the health care professional, and participants are applying the rules of their action plan, as prescribed by their health care professional. Condition management is lacking the dynamics of self-management. Partnership of health care decisions is not evident in condition management as the health care professionals provide the direction for maintaining the person's CF symptoms.

Participants demonstrated they were capable of learning symptoms and managing exacerbations, the foundations of self-management behaviours. Self-management included concepts of planning, adapting and recognising symptom patterns. Participants understood what self-management was as a concept however their condition management behaviours revealed they were undertaking condition management as a part of a compliance model. This is an important distinction as the on the surface, participants could describe self-management behaviours. However it was through the exploration of this research that showed self-management behaviours were not reflected in their actions. This demonstrates that participants are aware of what self-management is but they either do not want to incorporate self-management behaviours into their routines, or they are unsure how to incorporate their understanding of self-management into meaningful behaviours.

The use of self-management support was the key indicator that illustrated the understanding of self-management did not translate into self-management behaviour. Self-management support was used to assist with formal care interactions, to remove parental or family reminders, and to create efficiencies in time management.   At the surface, these all involved the skill sets of self-management of planning, adapting and recognising symptom patterns. The individual and collective participant experience in this research highlighted the underlying role of self-management support linked back to compliance with prescribed health care activities. Participants wished to use the online symptom monitoring diary to provide information for the specialised CF health care professionals, rather than to inform their own CF management activities. To improve compliance to treatments activities, participants followed alternative treatment patterns as suggested by their health care professionals, rather than create their own opportunities for working treatment benefits into their daily activities.   While it is acknowledged that the role of the health care professional is the prescription of medication, antibiotics were prescribed to participants with flexibility on when they could be used. The antibiotics were rarely used in a flexible

manner, when symptoms became unstable, participants contacted their health care professional before commencing the course. These are all demonstrative of directive led activities, rather than the dynamic process of working self-management into a partnership with life priorities and health care priorities. Self-management awareness is evident, however, it is the use of self-management support that demonstrates that self-management 'understanding' translates to effective condition management on a compliance model.

> **RQ1 O2:**   **To identify whether an online symptom monitoring diary can support an individual's self-management of cystic fibrosis.**

The myCF pilot implementation was a part of the larger myCF project that was founded on the one basic assumption that an online symptom monitoring diary could support individuals with CF self-management. This assumption requires that the specialised CF health care professionals and the participants have the appropriate knowledge of self-management. Participants and specialised CF health care professionals also need to have similar ideas to what symptom monitoring entails.

Activities of self-management include daily condition management activities, planning and dialogue with health care professionals. Breaking those activities down into tasks results in symptom monitoring, symptom recall and reflection, treatment management and deciding when their CF takes priority and when preferred activities take priority. If the tasks of self-management are provided with adequate support and combined with appropriate knowledge, they ultimately become self-management behaviours. The online symptom monitoring diary assisted participants with symptom monitoring and symptom recording, during times of interaction. The symptom monitoring tasks were supported by the online symptom monitoring diary.

The online symptom monitoring diary also supported participants by emphasising the processes that underpin symptom monitoring. Symptom identification, symptom reflection, and symptom impact are all processes that underpin symptom monitoring. The initial interaction with the online symptom monitoring diary illustrated these processes to the participants and placed an increased focus onto their symptom monitoring activities. The evaluation of how the online symptom monitoring diary supported symptom monitoring moved from an reflection of the online symptom monitoring diary interaction, to a reflective process that did not always require the online symptom monitoring diary. The support provided by the online symptom monitoring dairy was no longer focused on the outcomes of online symptom monitoring, but from an increased understanding of the processes each participant goes through when monitoring their symptoms.

The move from self-management tasks to symptom monitoring process introduces a new complexity into the evaluation of the online symptom monitoring diary. Typically, as presented in section 3.3.2, traditional evaluation methods of ICT projects have included hard metrics, such as use, improvement in efficiencies, task completion time and number of reported errors (Turner et al., 2010). eHealth projects used for patient support include similar metrics that are tangible and quantitative in nature (Ammenwerth et al., 2003, Gomez and Pather, 2012, Zayas-Cabán and Marquard, 2009). The rate of use as an intervention metric is a key indicator to the success of the project (Kaufman et al., 2006),

with an emergence for an increased qualitative evaluation of eHealth tools (Gustafson and Wyatt, 2004, Gomez and Pather, 2012) for both traditional and eHealth projects. The interaction rates of the online symptom monitoring diary represents a failed project by traditional evaluation. However, the participant evaluation of an online symptom monitoring diary developed for self-management of CF has moved beyond the tangible evaluation of use metrics. The online symptom monitoring diary represented a safety net, as increased levels of support was perceived to be provided during times of unstable symptoms. Participants did not explicitly link the use of the online symptom monitoring diary to perceived support, the existence of the online symptom monitoring diary was appreciated even when not in use.

The evaluation introduced intangible concepts of participant perception of helpfulness without use, support as a transition object (safety net) and something that is 'nice to have.' The difficulty lies in the capture of this evaluation and why these concepts were important to participants. The relationship with their support network, health care professionals and CF as a disease all have the potential to influence the emotive aspects of the evaluation of the online symptom monitoring diary.

The support provided to participants was multi-layered and involved self-management task support, symptom monitoring process support and emotional support. Despite these rich offerings, the online symptom monitoring diary provided an effective mechanism for condition management. It does not support an individual's self-management of CF.

> ***RQ1 O3:*** ***To explore the interaction between self-management knowledge and use of the online symptom monitoring diary.***

Expanding on sections 3.2.2 and 3.4, knowledge is a complex concept and is a combination of data, information and experience, although the relationship between the three is not as straightforward. There are a variety of ways to define and express knowledge and so it is important that for this research, knowledge is defined as;

> *"Knowledge is a fluid mix of framed experience, values, contextual information, and expert insight that provides a framework for evaluating and incorporating new experiences and information. It originates and is applied in the mind of knowers." (Davenport and Pruzak, 2000), p5.*

Understanding must be able to be converted to action in order to have knowledge (Davenport and Pruzak, 2000). Without action, the information and experience leads to 'understanding' but not 'knowledge'. The online symptom monitoring diary provides symptom data that informs the current symptom pattern which, in turn, can be used to develop experience for when the symptom pattern reappears. Condition management of CF provides both first hand symptom experience, and second hand symptom experience.

During childhood management of CF, symptoms are experienced by the child first hand, and by the parent through second hand experience. The parental experience is gained through observation, information provided by their child and symptom monitoring activities. Parents learn symptom patterns and symptom impact by gathering symptom data that informs them

for managing their child's condition. Symptom data is provided by first hand experience as the child moves away from parental condition management and takes ownership. Reactions to symptoms are through observing how their parent's managed their condition, starting as second hand experience and moving to their own experiences of monitoring symptom patterns and understanding symptom impact.

The state of symptoms ultimately dictates the focus of CF management. Stable symptoms provide patterns that are recognisable and predictable, creating a routine for condition management that remains as a background activity. During these periods, the information and experience that participants have about their symptoms is sufficient for condition management and does not offer an opportunity to provide additional information that adds to stable symptom condition management knowledge.

Knowledge of symptom patterns and impact is not sufficient for condition management during times of unstable symptoms. The online symptom monitoring diary provided a mechanism to improve the understanding of participants symptom state, impact and presentation pattern. The use of the online symptom monitoring diary during times of unstable symptoms could be questioned as when in crisis, an individual will attempt to interact with something they believe can provide relief from crisis, if they feel well enough to do so. Despite this, the recording and tracking of symptoms is perceived to enable the experience of symptoms to be transferred into tangible symptom data. The symptom data is then be used to inform participants of symptom status and assists in the planning the response to the different symptom fluctuation. The interaction of the online symptom monitoring diary during times of symptom crisis reveals that current participant understanding of self-management does not support condition management during times of unstable symptoms. The online symptom monitoring diary provided tangible data support that enables participants to create meaningful information about the new symptom patterns.

> In summary, self-management 'knowledge' is required for the online symptom monitoring diary to support an individual's self-management on CF. The online symptom monitoring diary clearly supports condition management however the tools was designed to support self-management. Participants posses self-management information, self-management 'understanding', and the ability to reproduce their self-management 'understanding', however they are unable to convert their self-management 'understanding' to action and therefore 'knowledge'. The use of self-management support in this research revealed that the support was used to execute action plans.

> The online symptom monitoring diary provided support by emphasising the processes that underpin symptom monitoring, rather than through the outcomes of symptom entry. The support provided by the online symptom monitoring diary was not governed by times of use, emotional support was provided during times of no use. The perception of helpfulness was linked to the existence of the online symptom monitoring diary, rather than the use of the online symptom monitoring

diary. Despite this, the online symptom monitoring diary provided a mechanism for condition management, not self-management.

Stable symptoms revealed little opportunity for participants to gain additional symptom information that would assist in condition management. During times of unstable symptoms, the online symptom monitoring diary enabled new information to be generated by participants to understand new symptom patterns.

RQ2: How do people with cystic fibrosis incorporate symptom monitoring into their daily life?

To answer this question the priority of CF and life activities must be understood. It strives to understand if the basis for the participant's decision is condition or lifestyle.

The nature of decisions that participants make about their lifestyle, and how they consider their condition as they make those decisions, provides a comprehensive explanation of how symptom monitoring can be incorporated into their daily life. The different ways participants incorporate symptom monitoring into their life routines provides a guide to how successful symptom monitoring can be incorporated into daily life.

> ***RQ2 O1:***   ***To understand the nature of the choices that people living with cystic fibrosis make about their lifestyle.***

Living with a chronic disease does not define the person. They are a person first and a patient second. Lifestyle choices still align with current interests and there can be a number of considerations people take into account when making lifestyle choices (see section 3.5). Whilst lifestyles choices can be made independently of CF, this research has identified a different order of priorities between lifestyle choices and CF for each of the different participant groups.

During early childhood, parents of children with CF prioritise the CF condition. Condition, treatment and symptom information are a premium need and parents are constantly seeking new information from other parents and health care professionals on how to manage their child's CF. Parents first consider the condition and then make their lifestyle choices in the early period of diagnosis. The emphasis of the condition could be attributed to parents not actually experiencing symptoms as they have only second hand experience of what their child is currently experiencing.

Teenagers are going through a specific developmental stage of gaining independence and finding their own place in the world. They strive to move away from complete parental control, just as the parent struggles to decrease the decision-making they perform for their child. Parental condition management is not as focused at this age, as the teenager has taken ownership of some treatment and medication tasks. A conflict can arise as the teenager wishes to prioritise life choices over their condition whilst the parent would prefer greater reflection on how their condition would be impacted by their life choices. The emphasis on life choices could be a result from the developmental period they are moving through, or a result of their increasing experience with their CF symptoms. Life choices may

have a greater reflection on symptoms than is first apparent as they continuously feel their symptoms.

Adults living with CF move between prioritising their condition and prioritising lifestyle choices. The adult support network may cause them to reflect on how life choices impact their CF. Adult decision-making emphasises the need to prevent further exacerbations during times of unstable symptoms. The experience the adult has gained by living with CF and managing their condition enables them to make decisions that take into account their condition status, without placing emphasis on their current symptom status. Adults maintain their CF so they can make lifestyle choices that suit their interests, rather than their condition.

Lifestyle choices are made with minimal deference to their CF during stable symptom periods for all participant groups. The balance shifts during unstable symptom periods and lifestyle choices are made with direct consideration to how their CF symptoms will be impacted.

RQ2 O2: *To understand the interaction between the lifestyle of people living with cystic fibrosis and symptom monitoring.*

Symptom monitoring is a recurring measurement that guides condition management activities with studies indicating that it is preferred to be preformed as an at need basis (Glasziou et al., 2005, Yoos et al., 2002). It is an activity that can be performed by individuals and health care professionals, with the symptom monitoring data used by individuals alone, shared with their health care professional, or shared to the individual by the health care professional. As highlighted in section 3.3 the method of monitoring needs to fit in with their lifestyle when participants undertake symptom monitoring.

Mobile devices provide an opportunity to access web based information away from the traditional desktop computer. Smart phones are increasingly used to access the Internet and are becoming a major method of Internet access (Australian Bureau of Statistics, 2013). The online symptom monitoring diary was accessible from a smartphone or mobile technology web browser and this draws in expectations of symptom monitoring convenience.

Participants who regularly used mobile technologies preferred to interact with the online symptom monitoring diary on mobile technologies, this aligns with the nature of health seeking behaviour as reviewed in section 3.4.1. The convenience of using the online symptom monitoring diary with mobile technology was overridden when participant expectations of the visual layout were not met. Symptom monitoring was no longer convenient as they were required to either work on a visual layout that was not ideal, or they had to use a laptop or desktop computer to complete the online symptom monitoring diary entry.

Symptom monitoring is expected to merge with current condition management activities, reflecting the background focus condition management has for participants with stable symptoms. Extra focus was placed on symptom monitoring tasks and contradicts how

participants prioritised symptom monitoring during periods of stable symptoms due to the changed visual format of the online symptom monitoring diary on mobile technologies. The recording of symptom monitoring was accepted into condition management tasks with greater success during periods of unstable symptoms.

> In summary, there is a different order of priorities between lifestyle choices and CF for each of the participant groups. Emphasis is placed on learning the condition by the parents of young children, teenagers place greater emphasis on lifestyle choices over their CF, and adults strive to maintain a balance between lifestyle and CF management. During unstable symptom periods CF condition management choices are prioritised, regardless of the participant group.

> Symptom monitoring is required to fit in with their lifestyle. Mobile technologies appear to provide a convenience for routine based activities however difficulties arise when the mobile technologies require a greater focus on symptom monitoring than first anticipated.

> Periods of unstable symptoms created a greater acceptance of symptom monitoring priorities, as symptom monitoring during stable symptoms was not a deliberate activity.

8.4 RESEARCH KEY FINDINGS

This section presents the key findings from this research that were developed from the interpretation and discussion of the research findings from section 8.2 and addressing the research questions and research objectives in section 8.3.

8.4.1 KEY FINDING ONE

Without a transition from self-management 'understanding' to self-management 'knowledge' it is not possible for an online symptom monitoring diary to provide self-management support.

This research has found that the online symptom monitoring diary did not support participants with their self-management of CF. Participants must possess the appropriate knowledge of self-management to be able to use the online symptom monitoring diary for CF self-management and it is evident that participant understanding of self-management has not evolved to 'knowledge' of self-management. Participants have self-management information, they understand self-management information, and can reproduce self-management information. Self-management 'knowledge' is action upon data, information and experience. The lack of self-management behaviours, and therefore self-management 'knowledge', is a significant finding as the online symptom monitoring diary cannot support an individuals self-management of CF if participants do not possess self-management 'knowledge'. Participants are undertaking condition management on a compliance model and the online symptom monitoring diary provides effective support for this.

Participants demonstrated they have the potential for self-management behaviours however currently participant knowledge of self-management does not exist. The decision-making processes participants go through when prioritising CF or lifestyle choices illustrate that participants are aware of balancing condition management with life activities, through informed consideration of their current life and condition situation. The application of Normalisation Process theory has provided a framework in which this process can be explained at both the individual participant and group level. Changes in condition management activities occur due to an outside catalyst and can be summarised as clinician driven or symptom driven. The decision-making processes all reflect the different components of Normalisation Process Theory without the application of technology. Greater emphasis on self-management concepts during the components of Coherence (see section 8.2.6) and Cognitive Participation (see section 8.2.6) has the potential to establish the links to self-management concepts that will translate into an embedded behaviour.

Condition management activities all link to self-management concepts. Learning symptoms, managing exacerbations and learning the patterns of symptoms are foundation activities of self-management (Brown et al., 2010). Previously, terms such as self-care, self-monitoring and self-management have been used interchangeably (Novak et al., 2013) and this is reflected by the participant experiences in this research. Participants used the term self-management to describe a number of condition management activities that included problem solving, decision-making, reaching out to health care professionals and taking pre-determined actions. At a glance all these activities are skills of self-management (Novak et al., 2013) however the dynamic processes of partnership and independent action are not demonstrated.

The participants' main source of condition management support was obtained from their specialised CF health care professionals, or their regular GP. Collaboration with health care professionals is not evident. The online symptom monitoring diary clearly supported participants condition management by providing reports for the perceived future use of health care professional interaction. Discussions with their health care professionals involved the health care professional prescribing actions for participants to take during different types of symptom events. Support for participant condition management assisted participants to manage their condition and comply with prescribed actions given by their health care professionals. Expanding on the definition in section 3.4, collaboration with health care professionals is a key skill that would illustrate the participant moving from condition management activities to self-management activities (Novak et al., 2013, Kawi, 2012, Vassilev et al., 2011). Self-management 'understanding' is present when participants have not yet achieved self-management behaviours. It is how the participant mixed their understanding of self-management with self-management support tools, such as the online symptom monitoring diary, that identifies these behaviours as compliance with prescribed activities for condition management rather than self-management.

This key finding demonstrates that participant knowledge of self-management varied widely and it has emerged as an important factor in influencing whether the tool could be adopted and used successfully.

8.4.2   KEY FINDING TWO

Symptom monitoring is a background activity for those with CF, and a focused activity for those who care for people with CF.

The activity of symptom monitoring does not result in the knowledge of CF symptoms. However, the combination of symptom monitoring activity, and the processes that the person goes through to monitoring symptoms will give rise to symptom knowledge (Hafetz, 2010). As knowledge of the CF symptoms improves, participants perceive a change from the deliberate activity of recording symptoms to incorporating the symptom monitoring processes into daily routines. The processes become deliberate monitoring when a change in symptoms is experienced. As the experience of CF symptoms increases, adherence to symptom monitoring begins to be impacted by time management and severity of symptoms (Modi and Quittner, 2006).

The teenagers and adults who participated in this research demonstrated no evidence of established written or formal symptom monitoring. Their experience of their own symptoms resulted in a different kind of symptom monitoring that is not easily quantified when sharing with other people, in particular their specialised CF health care professionals. Future unstable symptom periods may prompt for symptom monitoring, however, this was not actually demonstrated during the myCF pilot implementation period.

There is a greater dependence on the teenager to disclose symptoms to their parent during the adolescent development period; otherwise the parental symptom monitoring is incomplete. This research reflects other studies exploring teenage symptom disclosure, that teenagers will report symptoms only when they are unsure, or have not experienced them previously (Hafetz, 2010). Aligning with section 3.5.3, teenagers may also be reluctant to undertake symptom monitoring, as a part of the adolescent developmental desires of wanting to be normal (Modi et al., 2008, Modi and Quittner, 2006).

Symptom monitoring is prioritised differently for those who are living with CF. Particularly during the early childhood years, the parents of participants view symptom monitoring as a central role in gathering information and making decisions when undertaking CF condition management. Symptom monitoring occurs to assist with formal care interaction or during times of symptom uncertainty for teenage and adult participants. Information gathering not only gives the parents the ability to gain experience about their child's CF symptoms but also provides the specialised CF health care professional with the required symptom data during health care interactions. The parent can then make decisions based on the child's symptom information and the guidance given by the specialised CF health care professional.

The role of symptom monitoring information undergoes change as confidence grows in managing their current CF symptoms (Brown et al., 2010). Parents and participants use symptom monitoring information in a different manner. Parents rely on symptom monitoring information to inform them of their child's symptoms, to plan for exacerbations and to establish patterns with current symptoms. Participants use symptom monitoring information to re-establish patterns in symptoms when experiencing a change in symptoms. The parent's need for symptom monitoring is on-going, whilst those with CF use focused

symptom monitoring during defined periods. Absence of symptom monitoring records does not result in a lack of symptom awareness. Normalisation Process Theory (see section 3.3.2) illustrates the processes those caring for people with CF go through during the time of diagnosis and new symptoms. As long as the online symptom monitoring diary continues to provide the care-giver with helpful information and aligns with their current condition management activities, it will remain a part of their symptom monitoring activities to some degree. Symptom entry is maintained as a routine behaviour as the people who care for those with CF strive to understand as much as they can about the symptoms they are observing.

This key finding demonstrates that symptom monitoring is a focused activity for those caring for people with CF, and a background activity for those who have CF. The subtle differences between symptom monitoring requirements for care-givers and those with CF are required to be better understood to develop relevant symptom monitoring methods that will assist with eventual self-management.

8.4.3 KEY FINDING THREE

Evaluation methods that focus on use of electronic tools for self-management support are not able to holistically capture all aspects of perception of helpfulness.

ICT project evaluations have previously been based on the interaction with the ICT tool (see section 3.3.2). System usability, system performance, tool effectiveness, cost-benefit, and user satisfaction are just some of the methods by how a project is evaluated (Ammenwerth et al., 2003, Rahimi and Vimarlund, 2007). These methods all require interaction with the ICT, and for some evaluations, low or no interaction with the ICT tool is an indicator that the project may have failed (Eng, 2002). The use of the randomised controlled trials (RCT) as the 'gold standard' of medical interventions is criticised as they miss the more nuanced qualitative aspects of the evaluation (Cummings, 2009). Catwell and Sheikh (2009) also observed the lack of contextual considerations in eHealth evaluations through the use of RCT.

In their exploration of participant drop out of a ICT based asthma education program, Krishna et al. (2003) identified a link between the severity of illness and the inclination to use the ICT intervention. In a similar study that focused on cystic fibrosis self-management and self monitoring, Cummings et al. (2011) identified a usage drop over time, however this was not further explored. A review of participant drop out in chronic disease ICT based interventions has highlighted studies that agree with the link between desire to use and illness status (Dunn et al., 2012). The history of ICT intervention drop out suggests that there is a perceived ideal use period of ICT and this could be attributed to a number of factors, including the status of CF symptoms. Krishna et al. (2003) attributed both a low severity of illness and a high severity of illness as influences towards the continued interaction with their ICT intervention. This differs from the findings of this research, as participants may have clinically severe symptoms, however as the symptoms are stable there is no perceived need to use the online symptom monitoring diary.

The evaluation of the online symptom monitoring diary requires a wider criteria that is balanced between tangible support of providing a focus to symptom awareness, to the intangible support of a safety net and emotional support. Significantly, the use of the online symptom monitoring diary did not provide an effective evaluation in this research. The online symptom monitoring diary is used to assist participant to adapt and understand symptoms during times of change and times of crisis. It was found that applying Normalisation Process Theory (see section 3.3.2) to the changing use of the online symptom monitoring diary explained the fluctuation between periods of use and no use, and highlighted the processes of sense making, information gathering, appraisal and self-awareness participants moves through during changing symptoms. Additionally, the application of Normalisation Process Theory assists in demonstrating that technology is currently not applicable to support the participants' symptom monitoring activities. Periods of no use did not result in lower levels of support, instead the type of support that the online symptom monitoring diary provided moved to the intangible support of a safety net and emotional support. It is difficult as the intangible support provided during times of no use is not easily captured, and may be attributed to the influence of parents or health care professionals. What is clear is that the evaluation of the online symptom is complex due to the lack of self-management 'knowledge' held by participants, the inclusion of different participant groups in the care and management of CF, the changing role the online symptom monitoring diary has during stable and unstable symptom periods, and the different roles participant have in relation to managing CF.

Participants perceived that the existence of the online symptom monitoring diary was reassuring, illustrating an evaluation beyond the physical platform. Research exploring the material and emotional relations between objects and people is well established in traditional social sciences (Beer, 2012, Bretherton, 1992, Kleine and Stacey Menzel, 2004, Bowlby, 1982), and this research draws upon more recent literature concerning attachment to technology (Agosto et al., 2012, Beer, 2012). It was evident that participants perceived the online symptom monitoring diary as a transition object, an artefact that provides reassurance during times of change. The online symptom monitoring diary was not required to be used to be helpful or valuable. Transition objects are generally linked to childhood, but can be present for all stages of a persons life (Myers, 1985). The helpfulness of the online symptom monitoring diary was found to be as a support mechanism – present in the background and available whenever participants determined they had a need to use it. The emotional connection to the online symptom monitoring diary adds to the potential benefits from developing symptom awareness to more intangible benefits that are individual for each different participant.

This research is not alone in identifying a need for ICT evaluation to capture the intangible impacts of ICT implementation (Gomez and Pather, 2012), and the introduction of transition objects in ICT evaluation expands on the literature presented in section 3.3.2. The difficulty lies in creating a framework that captures both the tangible and intangible benefits of ICTs that support chronic disease self-management. The individual perceptions of emotional support and object attachment is subject to an undefined number of social, family, economical and cultural factors.

Symptom status had a significant influence on the perception of the helpfulness of the online symptom monitoring diary. It is important to reinforce that according to this research participants may be experiencing a high severity of symptoms, however, if those symptoms are stable they are less likely to increase their interaction frequency with the online symptom monitoring diary. Normalisation Process Theory emphasises the processes of sense making, information gathering, appraisal and self-awareness the participants goes through when making the decision to use or not to use the online symptom monitoring diary.

The participant's experience in this research calls for the evaluation of ICT tools that support CF self-management to move beyond measuring use as an indicator for success. It was evident that the online symptom monitoring diary introduced benefits that were already detailed in the current literature. As shown in section 3.3.2, the ability to increase condition ownership and recognise patterns in symptoms (Winkelman et al., 2005) and inform formal care interactions (King et al., 2012) were identified as perceived benefits. However, it is clear that the participant evaluation was not restricted to the tangible, or easily defined aspects of monitoring CF symptoms and managing the condition. The online symptom monitoring diary holds a different role for each of the different participant groups in this research, making the evaluation different for each participant group. The evaluation of the online symptom monitoring diary becomes complex, as illustrated by the conflict between the parents of the participants, and the teenage participants regarding the ease of interaction with the click through interface. The development of a meaningful evaluation where the use of the online symptom monitoring diary is not linked to perceived helpfulness is challenging. If the traditional ways of evaluation do not capture the participants perception of the online symptom monitoring diary, alternatives must be considered that do consider the emotive aspects to participant evaluation.

This key finding demonstrates that current evaluation techniques do not capture the intangible criteria that indicate whether the online symptom monitoring diary was a success or a failure.

8.4.4   KEY FINDING FOUR

Lack of consistency in user-interface design directly impacted on perceptions of satisfaction during interaction and overall evaluations of the entire online symptom monitoring diary.

The online symptom monitoring diary was developed to be accessed via a desktop computer however it could also be accessed through mobile technologies with Internet browsers (see section 2.4.1). Participants accessed the myCF pilot implementation initially through their desktop computer and then moved to their preferred mode of use, which was desktop computer or mobile technology. The myCF pilot implementation could only be accessed via mobile technologies that had a compatible web browser. Despite this, participants had an inherent assumption that their experience would be the same regardless of the mode of use.

Participants identified with previous experiences of mobile user-interfaces and compare those experiences with the myCF pilot implementation. In addition to the use of familiar technology (see section 3.3) as a motivator of symptom monitoring, there is also an expectation of a seamless transfer between different user-interfaces. Previous experience with desktop based user-interfaces that have been rendered for mobile technologies, or further developed into a mobile application, sets up false expectations for the interaction of the myCF pilot implementation. The myCF pilot implementation user-interface was not rendered to mobile technologies.

A consistency with the interface can be considered as doing similar things in similar ways (Reisner, 1993). The user-interfaces is a highly visible component of the myCF pilot implementation and therefore play an important part in the initial adoption of the technology (Büyüközkan, 2009), and this is aligns with the literature present in sections 3.3 and 3.3.2. The participant experience with the multiple user-interfaces was dependant on what mobile technology was used to access the myCF pilot implementation and how much attention they paid to the visual layout on their mobile technology, reflecting the mixed experiences of mobile technology use in this research.

Participants indicated that a mobile entry point would enable greater flexibility when using the site. Participants with a preference for mobile technologies accessed the online symptom monitoring diary through the web browser on their mobile phones or tablets. Teenage and adult participant groups accessed the online symptom monitoring diary through a desktop computer and mobile technologies. Parent participants only accessed the online symptom monitoring diary with a desktop computer. Mobile Internet browsers resulted in mixed evaluation, some participants placed priority on the mobility of access over the layout of the online symptom monitoring diary. Other participants placed priority on the layout of the online symptom monitoring diary, moving away from the mobility of access when the navigation proved to be difficult. The relationship with mobile technology is reflective of the literature presented in section 3.3. Jarvenpaa and Lang (2005) identified the 'love hate' relationship individuals experience with mobile technology in service delivery and communication flexibility. Participants embraced mobile technology when the user-interface met their expectations. The use of mobile technology became more of an inconvenience when the consistency between the desktop and mobile user-interface was not maintained.

The uptake of ICTs for health monitoring unsurprisingly depends on aligning the persons interest with the health monitoring and the technology (Rhode, 2011). In addition to the alignment of technology use and health monitoring in section 3.3, the expectations of the myCF pilot implementation's user-interface on mobile platforms can initiate a premature evaluation. Incompatibility with participant expectations increases the likelihood of lower levels of future interaction and is reflective of research carried out by van Gemert-Pijnen and colleagues (see section 3.3). This is problematic for future symptom monitoring ICT tool developments as the evaluation by participants may contain bias for considerations of mobile platforms when the development process has not considered consistency of user-interface between desktop based and mobile technologies.

This key finding demonstrates that despite the nature of the platform that hosts the online symptom monitoring diary, participants expect consistency of the user-interface. Expectations of unchanged user-interface lead to dissatisfied interaction and impacts on the overall evaluation of the entire online symptom monitoring diary. Most importantly, dissatisfaction with the consistency of the user-interface results in declining use of the online symptom monitoring diary. Developments that are specifically catered to desktop environments should clearly articulate this to participants to mitigate the risk of failure associated with false expectations.

8.5 CHAPTER SUMMARY

This chapter has presented the discussion of the data from the analysis and interpretation provided in Chapters 5, 6 and 7. By answering the research questions, this chapter has presented four key findings:

- o **KF1: Without a transition from self-management 'understanding' to self-management 'knowledge' it is not possible for an online symptom monitoring diary to provide self-management support.**

- o **KF2: Symptom monitoring is a background activity for those with CF, and a focused activity for those who care for people with CF.**

- o **KF3: Evaluation methods that focus on use of electronic tools for self-management support are not able to holistically capture all aspects of perception of helpfulness.**

- o **KF4: Lack of consistency in user-interface design directly impacted on perceptions of satisfaction during interaction and overall evaluations of the entire online symptom monitoring diary.**

The final chapter of this thesis outlines the conclusions of this research.

CHAPTER 9   CONCLUSION

9.1 INTRODUCTION

The final chapter provides a summary of the research findings and discusses the contributions to knowledge this research has made. Additionally it discusses the limitations of this research and suggests future research directions in this area.   The chapter is structured into the following sections:

- Section 9.2 provides a summary of the answers to the research questions.   It concludes that CF self-management was not supported by the online symptom monitoring diary and describes how individuals attempt to incorporate symptom monitoring into their daily life.

- Section 9.3 summarises the contributions to Information Systems knowledge of this research at a substantive, methodological and theoretical level.

- Section 9.4 indicates the implications for practice for this research.

- Section 9.5 discusses the limitations of the research which includes the scope of the research, the researchers bias and the lack of generalisability.

- Section 9.6 indicates areas for future research directions.

- Section 9.7 provides a summary of this research.

9.2 SUMMARY OF RESEARCH FINDINGS

This section provides a summary of the findings that were presented in Chapter 8.

The key findings for the research are as follows:

- **KF1:** **Without a transition from self-management 'understanding' to self-management 'knowledge' it is not possible for an online symptom monitoring diary to provide self-management support.**

- **KF2:** **Symptom monitoring is a background activity for those with CF, and a focused activity for those who care for people with CF.**

- **KF3:** **Evaluation methods that focus on use of electronic tools for self-management support are not able to holistically capture all aspects of perception of helpfulness.**

- **KF4:** **Lack of consistency in user-interface design directly impacted on perceptions of satisfaction during interaction and overall evaluations of the entire online symptom monitoring diary.**

The aim of this research was to explore the implementation of an online symptom monitoring diary developed to support people living with CF in Tasmania. The online symptom monitoring diary was designed to support individuals in their CF self-management. The research has addressed the following research questions:

Research Question One: How can an online symptom monitoring diary support an individual's self-management of cystic fibrosis?

Research Question Two: How do people with cystic fibrosis incorporate symptom monitoring into their daily life?

9.2.1 RQ1: SUPPORTING SELF-MANAGEMENT

This research has found that support for a person's self-management of CF with an online symptom monitoring diary is only possible if the person demonstrates they have transitioned from self-management 'understanding' to self-management 'knowledge'. Condition management of CF includes self-management information and an understanding of self-management and it was illustrated that the translation of that information and understanding to knowledge was not evident (see section 8.4.1). Participants are undertaking condition management with a compliance model of care. Self-management can only be supported by an online symptom monitoring diary when the users demonstrate self-management 'knowledge' through self-management behaviour.

It is evident that the use of an online symptom monitoring diary provides additional support that is not directly related to CF self-management. An online symptom monitoring diary has the potential to act as a transition object, or a safety net, particularly during times of unstable symptoms. An agency exists between those who interact with the online symptom monitoring dairy and the online symptom diary itself and the benefits of that agency are not always tangible. Tangible support included a physical record of symptoms, and the entry of symptoms prompted symptom reflection during times of online symptom monitoring diary use. Intangible support included the online symptom monitoring diary acting as a safety net, and providing emotional support that is difficult to quantify. Participants found comfort in the online symptom monitoring diary however the potential impact of health care practitioner, parental and support network influence cannot be ruled out.

Symptom recall, symptom reflection and symptom planning are processes of symptom monitoring and do not need to be deliberately planned or performed. The processes of symptom monitoring were also emphasised during times of online symptom monitoring diary use. For those who have CF, the experience gained by living with their symptoms enabled them to reflect on symptoms without the need to record symptoms. The online symptom monitoring dairy placed focus on symptom monitoring processes thereby providing benefit regardless of use.

9.2.2   RQ2: INCORPORATING SYMPTOM MONITORING

Insights were found into the role of symptom monitoring for people who have CF and for people who are providing care for those with CF. Symptoms are learned through experience for those who have CF. For the parents and carers of individuals with CF, symptoms are learned through gathering symptom information. Unsurprisingly, symptom monitoring is an intrinsic activity for those who have CF and an extrinsic activity for those who care for people with CF. The multiple roles of symptom monitoring for the multiple people affected by CF creates different priorities for symptom monitoring. Those with CF prefer symptom monitoring to be complimentary to daily life, their condition management should occur as a part of their routine. Symptom monitoring, therefore, is in the background. The commitment to symptom monitoring does fluctuate and during unstable symptom periods it moves from a task level process to an activity that requires strategic planning. Symptom monitoring is a method for gaining symptom information and creating symptom awareness on behalf of another person for the parents and carers of children with CF. The development of symptom monitoring records therefore provides guidance to those who are caring for people with CF. Symptom monitoring is not solely performed by people who have CF, parents and carers also monitor symptoms. The activity of symptom monitoring does not have to be observed in order for symptom awareness to be present.

There is no evidence of the influence of parental and health care professional on the evaluation of the online symptom monitoring diary. However, the online symptom monitoring diary was perceived to be helpful for the participants, regardless of use. Balanced criteria can assist with a meaningful evaluation that includes both symptom awareness and emotional benefits. Such criteria should take into consideration usage profiles, symptom outcomes compared to symptom data entry and the intangible worth of

emotional support the online symptom monitoring diary has for participants. The tangible benefits derived from the online symptom monitoring diary are linked directly to symptom control and as a learning tool during times of unstable symptoms. This research has shown through the application of Normalisation Process Theory that lower levels of use did not result in lower levels of support.   Normalisation Process Theory demonstrates that low or no use of the online symptom monitoring diary is a part of the individuals processes for condition management. Crisis management processes indicate that the online symptom monitoring diary becomes active in CF condition management as periods of unstable symptoms create change in symptom patterns.

9.3 RESEARCH CONTRIBUTIONS

This section reflects on the contributions this research has made to information systems knowledge by exploring the implementation of an online symptom monitoring diary developed to support people living with CF in Tasmania. The contribution to knowledge is presented at three levels: the substantive level, the methodological level and the theoretical level.

9.3.1 <u>SUBSTANTIVE LEVEL</u>

At a substantive level this research has provided a rich case study of how an ICT symptom monitoring tool in the form of an online symptom monitoring diary was incorporated into the lives of participants. Gaining access to research involving individuals living with CF is difficult due to privacy and burden of care concerns, and the research has enabled insight to participants living with CF, their understanding and knowledge of self-management and the role of symptom monitoring in their daily lives.

The research commenced with an aim to explore the pilot implementation of an online symptom monitoring diary that was developed to support people living with CF through symptom monitoring. The initial focus was explored through technology however as the research progressed it became evident that technology currently did not support participants in the self-management of CF. This research has demonstrated that the use of an online symptom monitoring diary was not directly linked to perceived support. Self-management was not supported by the online symptom monitoring diary. However, for participants the online symptom monitoring diary provided support during times of unstable symptoms. Times of crisis was linked to benefits of symptom pattern identification and gaining control of symptom information. The case study provided insight to both the individual use of the online symptom monitoring diary, and the collective use of the different participants groups.

It is evident that despite the nature of the platform that hosts the online symptom monitoring diary, participants expect a comparable user-interface. Interaction with the myCF pilot implementation with mobile technology was perceived to enable greater flexibility for when and where they could enter symptoms. Dissatisfaction with the consistency of the user-interface results in declining use of the online symptom monitoring

diary. The expectation of user-interface consistency resulted in a participant evaluation that was formed from false expectations.

The case study focused on the myCF pilot and provided access to the background of the online symptom monitoring diary, and the larger myCF project. Additionally, the research provided the opportunity to combine the background information of the myCF project with the real-time account of participant experience during the 6-week implementation.

9.3.2 <u>METHODOLOGICAL LEVEL</u>

At a methodological level the design of this research has demonstrated the value of linking the analysis of the research stages through comprehensive inductive thematic analysis. The thematic analysis moved the segmented data to abstracted themes that facilitated individual case development of the participants' experiences during the research. The interpretation of the analysis through the use of a concept map developed the basic initial findings into comprehensive research findings that reflected both the individual and group perspectives present in this research.

The research design was arranged into three research stages and ensured a holistic approach to the research questions to be answered by this thesis. The dual focus of the myCF pilot implementation experience and the participants' life context allowed each stage of the research to design to link together and this further enhanced the rich case study design. The data gathered in research stage one informed research stages two and three, the data gathered from research stage two – informed research stage three.

The thematic approach used in this case study is a widely used qualitative method of analysis yet guidance in the literature is minimal (Attride-Stirling, 2001). This research has provided a detailed demonstration of thematic analysis, providing guidance on the thematic analysis method. The thematic analysis was preformed at a latent level, revealing meaning beyond the mere content of the data. The process of thematic analysis raised the level of the data to themes, where the point of required abstraction was achieved. The theme abstraction enabled the capturing of insights offered by stakeholders, both as a collective group and the individual points of view. This method of thematic analysis enabled the building of an understanding of the research area that covers a range of multiple perspectives. The iterative process addressed the lack of constant comparison in thematic coding as identified by Boyatzis (1998).

Finally, the interpretation of the research completes the methodological contribution of this thesis. The three phases of interpretation moved the data from data to comprehensive findings that related to each research stage, and the research as a whole. After the development of the initial findings from the themes, the interpretation was assisted with the use of concept mapping. The concept map related the initial research findings to other initial findings from different research stages. The comparison abstracted the initial findings to form research findings. The three phases of interpretation developed the basic initial findings into key findings that reflected both the individual and group perspectives present in this research. The use of a concept map to assist the interpretation in this thesis expands on the inductive philosophy that guided the research.

9.3.3   <u>THEORETICAL LEVEL</u>

At a theoretical level the research has highlighted that participants have not yet demonstrated self-management 'knowledge' however have demonstrated an understanding of the foundation of self-management. The research has additionally demonstrated that current evaluation techniques do not capture the all benefits that would indicate whether the online symptom monitoring diary was a success or a failure.

Self-management 'knowledge' is the combination of self-management information, understanding and self-management action. This thesis has shown that the online symptom monitoring diary clearly supports condition managements however people need to demonstrate self-management 'knowledge' before self-management support is possible. Without aligning self-management 'understanding' to self-management action, demonstrating self-management 'knowledge' is not possible.

This research has highlighted that an online symptom monitoring dairy developed for self-management support needs to consider participant understanding of self-management, as the health care professional understanding of self-management may not match the self-management 'understanding' held by the participants. The current tendency of performing condition management under a compliance model of care creates further difficulties in enabling the development of self-management 'knowledge'.

The application of a sociology theory to an information systems case study has discovered unstable symptom patterns as the main driver for interaction. During times of unstable symptoms, symptom priorities are placed over life activities in order to adjust to the changing symptoms. Normalisation Process Theory enhances this explanation through the illustration of participants undergoing the four components of Coherence, Cognitive Participation, Collective Action, and Reflective Monitoring. Unlike (MacFarlane and O'Reilly-de Brún, 2012) this research did not map the inductive themes to Normalisation Process Theory, instead the framework was introduced as an additional lens for the discussion of the findings. This application uncovered that the participants understanding and knowledge of self-management needs to be first considered and addressed before technology can be re-introduced as a supportive tool. The actions and reasoning participants undertake during unstable symptom periods are driven by symptoms but are also framed by how the online symptom monitoring diary was perceived to meet participant needs, their current interactions with technology and the helpfulness of the feedback received from the online symptom monitoring diary. Once symptoms are stable participants move through the components of Cognitive Participation, Collective Action and Reflective Monitoring to reach temporary attrition of the online symptom monitoring diary. Normalisation Process Theory was used to inform the findings of this research and to assist in the explanation of the differences between CF condition management and self-management, and the current intermediate role of technology in symptom monitoring.

Theoretical models of eHealth evaluation have been built upon in this research and continues on from the identification by Cummings (2009) that ICT symptom monitoring tools developed for chronic disease self-management have moved away from mandatory use and that there are a variety of factors influencing the interaction with ICT symptom monitoring

tools. Evaluation of ICT symptom monitoring tools can no longer be assessed by pure interaction rates. The perceived usefulness of a system for self-management support goes through a cycle of requiring interaction during unstable symptom periods and requiring access during stable symptom periods. A greater emphasis on the intangible benefits is required when evaluating participant controlled ICT symptom monitoring tools that take life, family and symptom priorities into consideration. The intangible benefits identified in this research consist of emotional support and acting as a transition object.

9.4 IMPLICATIONS FOR PRACTICE

From an information systems perspective, an improved appreciation of how an individual utilises symptom, condition and self-management information is needed, in order to develop an appropriate online symptom monitoring diary for CF self-management support. The improved understanding of information manipulation by individuals has the potential to better integrate an online symptom monitoring diary into their lifestyle and chronic disease condition management, and enable ICT symptom monitoring tools to fulfil the initial development aims.

The evaluation of online symptom monitoring tools that captures the tangible and intangible benefits will enhance the understanding of online symptom monitoring diary attrition. The acknowledgement of value through the existence of the online symptom monitoring diary, in addition to the use of the online symptom monitoring diary, creates a need for the emotional benefits to be captured during the evaluation of ICT symptom monitoring tools. This research has built on previous research that called for a greater use of qualitative evaluation techniques to include greater consideration of the emotional benefits that could potentially be provided.

From an eHealth perspective, this research has identified that participant self-management 'knowledge' requires addressing before the implementation of an online symptom monitoring diary to support self-management. ICT symptom monitoring tools that are individually controlled, outside of the health care system, are required to be more than just a technical intervention that solves a health care professionals perceived need. Without the clear understanding of how individuals understand and demonstrate self-management, the introduction of ICT symptom monitoring tools is solving a dilemma that is not appropriate with the ICT symptom monitoring tool self-management aim.

9.5 RESEARCH LIMITATIONS

This section presents the limitations of this research and how it was addressed. Every research method can be characterised by a set of strengths and weakness therefore it is important to acknowledge and demonstrate how the weaknesses have been addressed. The limitations of this research are the scope of the research, the researcher bias and the lack of generalisability.

9.5.1 <u>SCOPE OF RESEARCH</u>

The research was conducted in the myCF project with its own aims and objectives, as presented in Chapter 2. This meant the research was limited by the online symptom monitoring diary that was designed and the project teams' preconceived notions. The alignment of this information systems research to the chronic disease health care pilot meant there was little room for the researcher to control design, implementation and recruitment. An illustration of the restraint of ICT design is reflected in this research by the flawed implementation of the traffic light feedback system. However, the interviews were developed with the control of the researcher and therefore complimented the quantifiable online symptom monitoring diary interaction data used from the myCF pilot implementation, enabling the research aims to be achieved.

9.5.2 <u>RESEARCHER BIAS</u>

As presented in Chapter 4, section 4.2.3 qualitative research draws on individual perceptions and experiences (Liamputtong and Ezzy, 2005). It is important to highlight when discussing researcher bias, objectiveness and validity are not the overall intent of interpretative qualitative researcher. In order to address the issue of researcher bias in this case study research, Lincoln and Guba's four trustworthiness criteria of creditability, transferability, dependability, and conformability (Lincoln and Guba, 1985) have been applied.

The credibility of this research is provided in the research design. Lincoln and Guba (1985) refer to the researcher having a significant time involvement with the phenomena under study, with continual observations to ensure credibility. The design of this research (see section 4.4) was based on the researchers involvement with the myCF project for a period of one year. During this time, observations were undertaken by the researcher and are supported through the documentation of field notes.

In order to achieve transferability researchers are required to gather sufficient data for the readers of the research to draw comparisons to other contexts, if so desired (Bradley, 1993). The transferability of this research has been provided through the transparent provision of data that was used in the research. In addition, the discussion of cases in chapter 7 and the background of the myCF project evolution further adds to the transferability of this study.

The methodology outlined in Chapter 4 illustrates how the dependability of this research was achieved. The use of multiple collection techniques and sources throughout the three research stages adds to the dependability of this research. The data analysis, outlined in section 4.6 was applied separately to each of the three stages before observing the inter-relationships and moving to the development of the cases.

The conformability of this research is achieved through the insights gathered by the data collection and analysis that occurred over the research period. The myCF pilot study concept and design is presented in this thesis (see chapter 2) and the characteristics of the data and research results are clearly detailed.

9.5.3 <u>LACK OF GENERALISABILITY</u>

Case study research is often linked with a lack of generalisability. This case study research is bounded by the myCF pilot implementation and further complimented by the individual case studies. It is not easily generalisable to other chronic diseases and is specific to those with CF in Tasmania. However this research may provide some guidance with the findings presented on how an online symptom monitoring diary can support self-management. Additionally it may also provide insight in how symptom monitoring is incorporated into daily life. The research has taken the opportunity to improve the individualisation of the research through the development of multiple cases.

9.6 FUTURE RESEARCH

The current body of literature concerned with ICT supported symptom monitoring for chronic disease self-management appears to be largely focused towards electronic capturing and linking between individuals and health care practitioners. Literature that focuses on stand-alone, individually controlled online symptom monitoring appears to be scarce. In relation to the specific findings of this research, the small body of knowledge can be contributed to by the following future endeavours:

The application of the Normalisation Process theory as proposed by May et al. (2009) to the interaction with the online symptom monitoring diary has built on previous research (Cummings, 2009, Dunn et al., 2012, Krishna et al., 2003) on symptom motivation for ICT symptom monitoring use. The severity and stage of illness as motivators for increased ICT symptom monitoring has been expanded to the overall influences of unstable symptom periods. Periods of unstable symptoms can include a new diagnosis or a change in the known experience of current symptoms. Further work exploring the degree of fluctuation required for symptom monitoring behaviours would assist in determining qualitative measures for system usefulness that would enhance the current tendencies to quantitatively evaluate ICT system usefulness.

The development of a modern evaluation framework that represents the different tangible and intangible benefits present in systems evaluation would not only clarify definitions of system success and failure, but would additionally assist in developing an increased understanding of the role of ICT symptom monitoring tools in moving from a compliance model of chronic disease care to one that creates greater partnership between the health care systems and individuals. The creation of such an evaluation framework may also address the issues of creating dependence on ICT symptom monitoring tools.

The timeline for this study was bounded by the myCF pilot implementation recruitment and implementation period. The adoption of a longitudinal study on the influence of long term context development for future ICT symptom monitoring tools to support CF condition care in Tasmania could effectively build on the findings from this research.

Greater exploration of the assumptions made when developing ICT symptom monitoring tools to support chronic disease self-management may reveal strategies that ensure that problem resolution occurs to benefit the individuals using the system, rather than resolving

health care system problems that are not reflected by the patients. A step towards this would be the inclusion of participants during the development of ICT symptom monitoring tools and the inclusion of exploring the possibilities of smart phone symptom monitoring technology. The perception of increased use during periods of unstable symptoms requires greater exploration, as previous research has shown that when ill, symptom monitoring is a low priority and treatment of symptoms is a high priority. Additionally, this research has identified that participant self-management 'knowledge' is not yet evident. Future research is required to discover if the appropriate self-management 'knowledge' is generic or individualised in order for self-management behaviours to be executed.

Finally, this research highlighted a non-traditional use of the traffic light feedback system when reporting symptom status to the participants interacting with the online symptom monitoring diary. Greater exploration of the impact on this use of traffic light feedback would assist in understanding the response to symptom feedback and how useful the traffic light system is in providing meaningful feedback for individually controlled symptom monitoring.

9.7 SUMMARY

This thesis commenced with an exploration of the pilot implementation of an online symptom monitoring diary developed to support people living with CF through symptom monitoring. The online symptom monitoring diary was designed to support people living with CF in their self-management by increasing symptom awareness. It was developed in response to the increasing burden of care due to chronic disease in Tasmania, and the intensive nature of CF condition management. Specialised CF health care professionals anticipated that ICT enabled symptom monitoring would assist participants by supporting their self-management of CF. The research design presented in this thesis enabled the development of a rich case study that captured the individual and group experiences of participants using an online symptom monitoring diary. The use of Normalisation Process Theory during the discussion of the research findings has demonstrated the need to focus on the participants understanding of self-management. The role of technology for symptom monitoring activities cannot be clearly understood until this has been achieved.

Significantly, this research found that an online symptom monitoring diary does not support an individual with their self-management of CF if they do not possess the appropriate self-management 'knowledge'. This research has shown that participants are currently undertaking condition management with a compliance model of care. It was found that symptom monitoring is focused for those caring for people with CF, and background for those who have CF. Evaluation of an online symptom monitoring diary is complex due to the lack of self-management 'knowledge' held by participants, the inclusion of different participants groups in the care and management of CF, the changing role of the online symptom monitoring diary has during stable and unstable symptom periods, and the different role participants have in relation to managing CF. Finally it is evident that despite the nature of the platform that hosts the online symptom monitoring diary, participants expect consistency of the user-interface.

Significant contributions have been made at a substantive, a methodological and a theoretical level. At a substantive level it has provided a case study of how the online symptom monitoring diary was used by participants, and that self-management support was not provided to participants. Access to patients can be problematic and this research has provided contributions by following the implementation of an online symptom monitoring diary, at the implementation occurred. At a methodological level the design of this research has demonstrated the value of linking the analysis of the research stages through inductive thematic analysis. The thematic analysis moved the segmented data to abstracted themes that facilitated individual case development of the participants' experiences during the research. The interpretation of the analysis through the use of a concept map developed the basic initial findings into comprehensive research findings that reflected both the individual and group perspectives present in this research. At a theoretical level the research has highlighted that self-management 'knowledge' is not yet demonstrated by participants however they do understand self-management. The research has additionally demonstrated that current evaluation techniques do not capture the intangible benefits that indicate whether the online symptom monitoring diary was a success or a failure.

This research has laid the foundations for future research to occur in understanding the interactions with ICT supported, individually based symptom monitoring and the development of a holistic evaluation framework when developing online symptom monitoring tools for chronic disease self-management on behalf of the individuals concerned.

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APPENDIX A PRE-IMPLEMENTATION QUESTIONS

Expectations

1. From your understanding of the project, tell me what your expectations, if any, are of the myCF website?

2. What current services do you receive from Tas CF Clinics?

Knowledge of computers/internet

1. Do you have easy access to the internet? (If not, why is this?)

2. What changes, if any, could you make in order to access myCF?

Knowledge of self-management

1. What does self-management mean to you?

2. Tell me how myCF will affect your self-management of your CF.

3. Do you keep a diary of your symptoms?

Meeting needs

1. What are your needs in regards to a site like myCF? What goals would you like to achieve through the use of myCF?

Their point of view on the process

1. Have you had enough information about the project? (Where from? Do you think it was accurate?)

2. Would you have liked to have been involved in the design and development of myCF? Tell me how you would see your involvement in the design and development of myCF.

APPENDIX B DIARY USER GUIDE

Start your internet browser. Depending on your system, this could be any of the following programs:

Internet Explorer, which will be represented by the following image:

Safari, which will be represented by the following image:

Firefox, which will be represented by the following image:

Once you have started your internet browser of choice, click on the address bar (shown below) and type in http://www.cystic-fibrosis-self-management.org.au
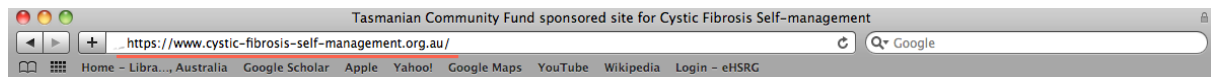
This is the address bar as shown in Safari, but it will be in the same position no matter which browser you are using.

The site you reach should look like this:

From here, click the LOGIN link, underlined below.
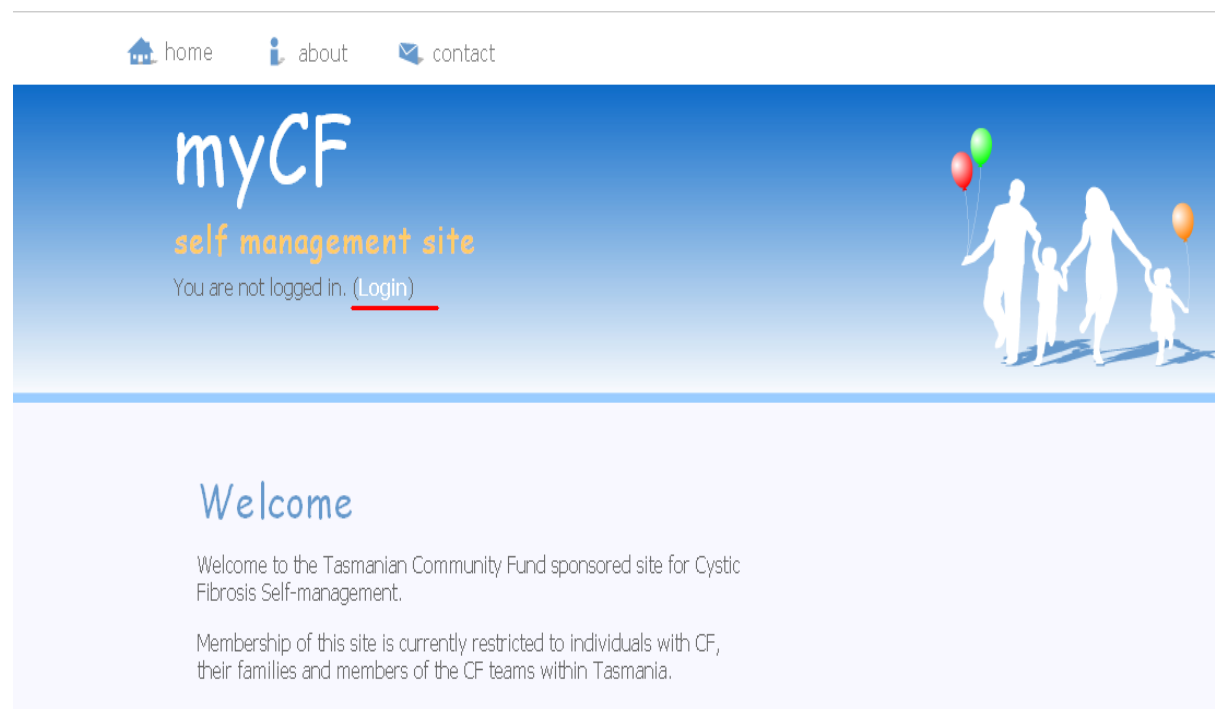
This should take you to this page:

You should have been provided with a username and a password by a member of the project team. Use them here, as shown below.

If you do not remember your password, click the button marked "Yes, help me log in", marked below.

This will take you to the following page:

Enter EITHER your username (if you have forgotten your password) OR your email address (if you have forgotten your username) in the appropriate field, then click the OK button (marked above). If you do not have an email address, or do not remember it, please contact the member of the project team who issued you with your username and password.

After entering your username and password, click the button marked "Login", marked below.

This will take you to the following page:

This page resembles the page from before you logged in, but you will notice several new sections up the top are available. For now, click on the DIARY section, underlined below.
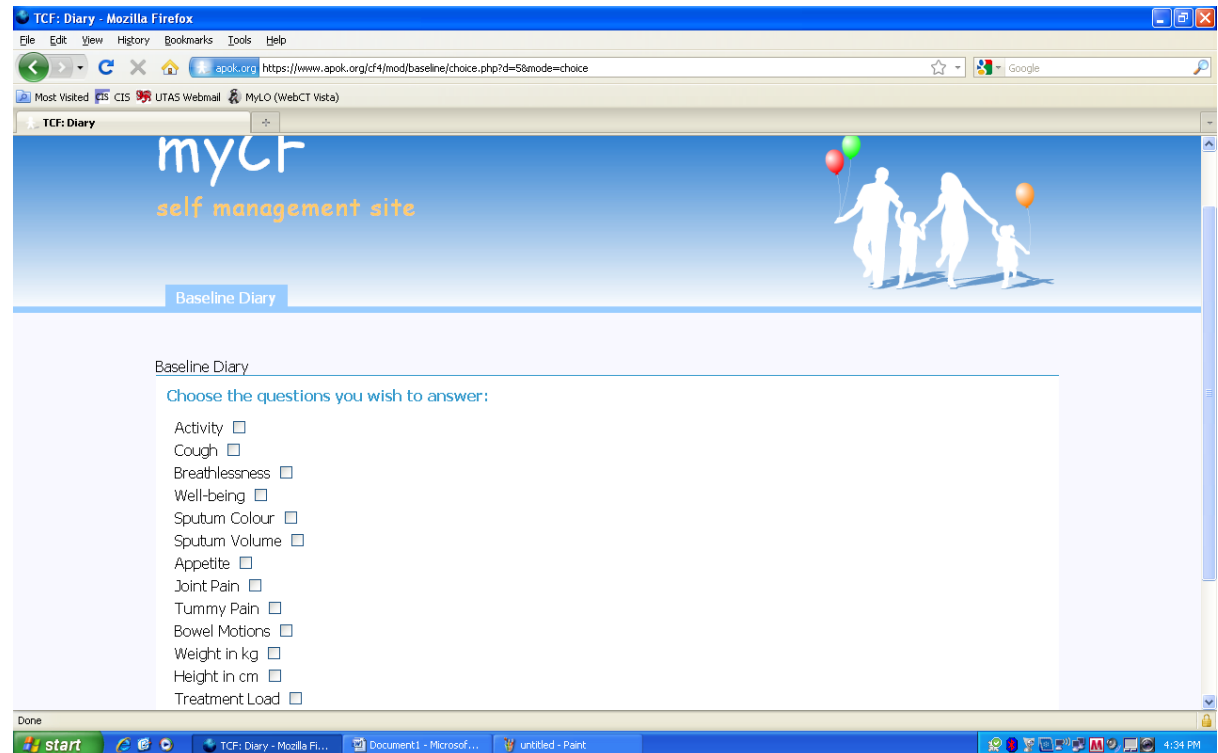
If this is your first time using the diary, it will take you to the BASELINE DIARY. The BASELINE diary is a summary of your condition at the peak of your health, setting a baseline on which all the DAILY diaries will build. The BASELINE diary begins with the following page:

You will notice this page has a list of questions. These are the questions that you will answer whenever you use the diary. Here, you can select which questions you would like to answer, by clicking on the box next to the question. Do this, and a tick will appear in the box. This means you WILL be answering that question.

Here, I have clicked all the boxes, and will therefore be answering all the questions. After selecting which questions to answer, click the "Save settings" button, marked below:

You will now be taken to a page with a list of questions for you to answer.

You will notice that the questions have a series of images following them. These are the answers. If you select an image by clicking on it, text will appear which shows you what that image means. Here, I have selected the far left image, highlighted, which has given me the text shown:

If the image you have selected is not accurate, and you want to change your answer, you can simply click on a different image, and your answer will be changed.

Moving down the page, using arrows on the bar on the side of the screen, you will notice that there are many different questions. Almost all are answered in exactly the same way as the first question, but several are different. The following questions have the same format, but different images:

Here, you should select the image which most accurately represents the volume of sputum coughed up on your best day.

Sputum Colour

when you have been at your best health, what colour was your sputum?

Here, you should select the image which most accurately represents the colour of the sputum coughed up on your best day, if any.

The last two questions are different again. They are text fields, requiring you to type in your weight in kilograms and height in centimetres using your keyboard. To do this, click on the text field next to each question and then simply type in the appropriate number, as shown below:

Weight in kg

Enter your weight today?

98

Height in cm

Enter your height today?

172

Once you have finished, and are happy with your answers, click the "Save and view" button, marked below:

This will take you to a summary of your answers, if you wish to change any of your answers, click the "Edit" button, shown below:

When you are happy with your answers, you are free to leave the page or to start your DAILY diary.

The DAILY diary is a record of your health throughout that day. It is accessed in the same way as the BASELINE diary, by clicking the DIARY section after you have logged in (covered at the beginning of this guide).
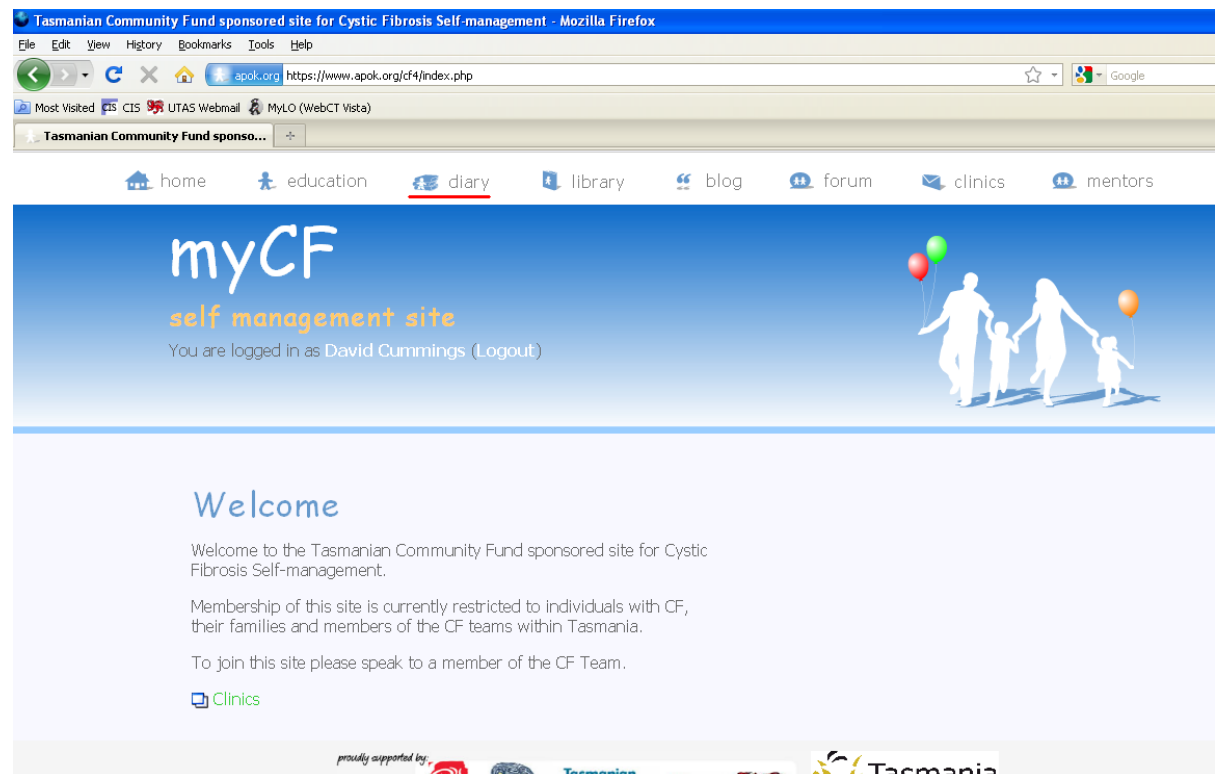
This shows where the DIARY section can be found. After clicking this, you will be taken to the following page:

There is a simple guide on how to use the DAILY diary on the top of the page, as you can see, with the questions to be answered below it. Like the baseline diary, you can choose what questions to include in your diary, just follow the steps in the baseline dairy section.

You can now go through the daliy diary, the questions will be presented in the same way as the baseline dairy. The baseline diary is your answers at your BEST health. The daliy diary is your answes on how your are currently feeling. Once you have now completed a daily diary entry you will be taken to a page showing a set of graphs of your progress so far, which looks like this:
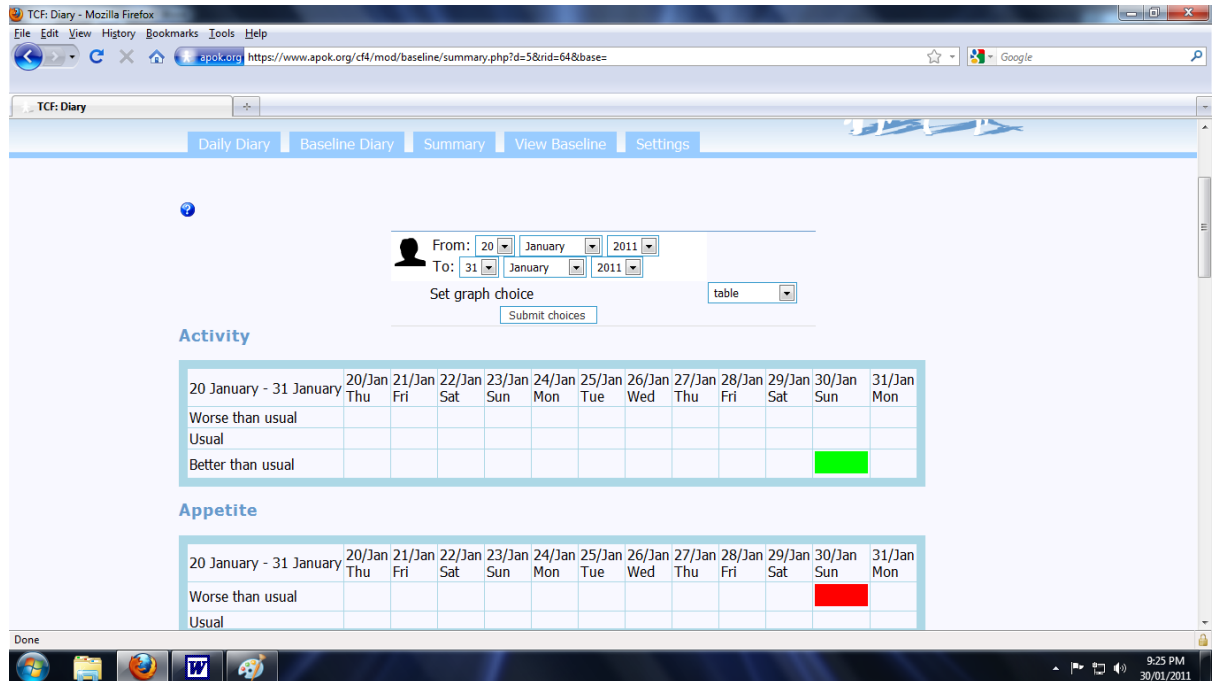
You can also view these graphs as ring graphs:

or see a graph of your body-mass index:
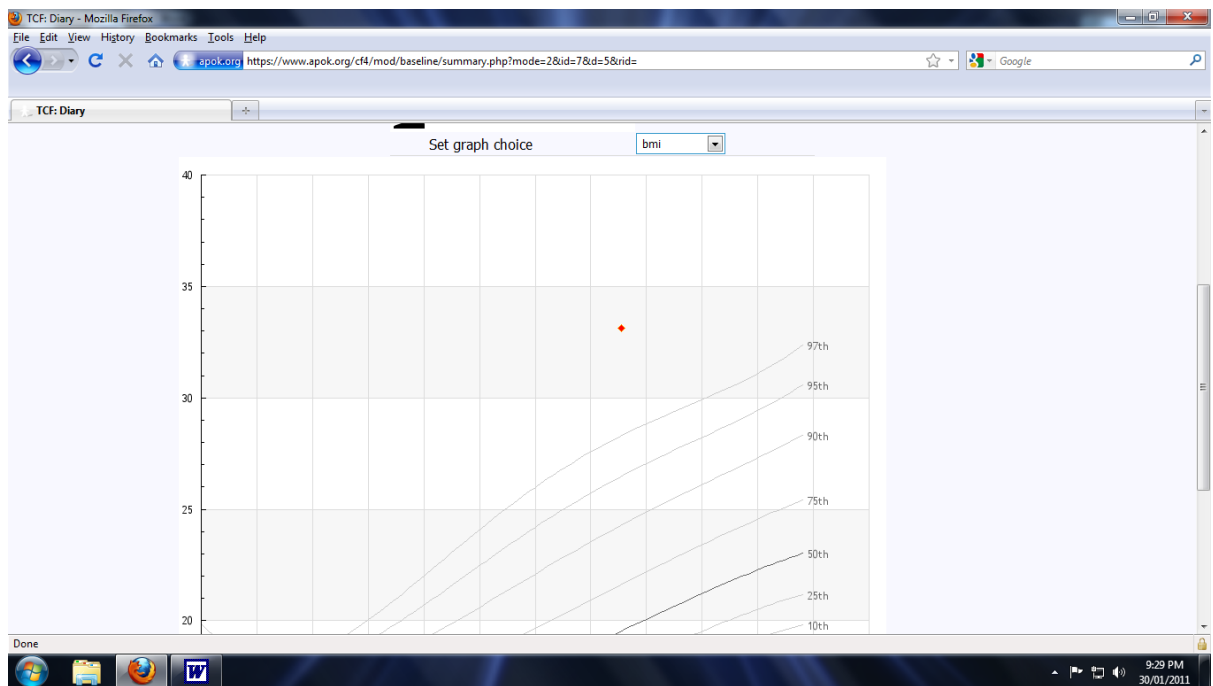
By clicking the small box highlighted below:
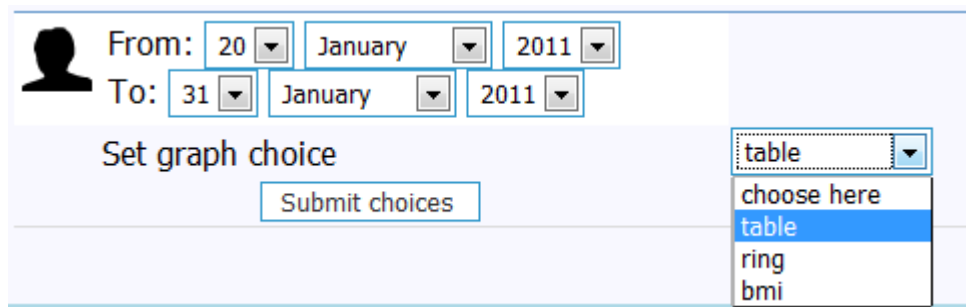
On clicking it, you will be given the three options Table, Ring, or BMI, which show the graphs as tables, as rings, or your Body-Mass Index respectively.
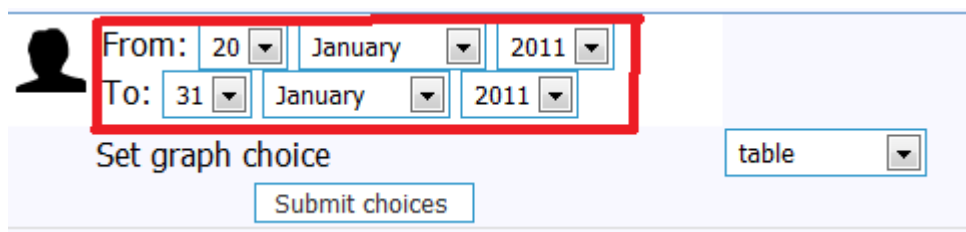
Simply click on an option to select it and be shown the respective graph.

You can also change the dates shown on the graphs in a similar manner by clicking the options shown here:

APPENDIX C POST-IMPLEMENTATION QUESTIONS

Expectations

1. Going by the experiences you've had over the last six weeks, what is myCF?

2. What were your expectations of the myCF website before you began the pilot?

3. How does the site compare to your expectations at the start of the trial, from the information you were given, either verbally or through the information sheet?

Experience of myCF/usability

4. Tell me about the navigation of the site? (i.e. – were you able to find the diary?)

5. Tell me how you are using the myCF website? How often or how regularly?

6. Has it changed anything you do in relation to your CF?

7. Tell me about your diary use. Has it been useful? Does it fit your needs?

8. Do you see the myCF website being a part of your everyday life? In what way?

9. What do you like about myCF?

10. What don't you like about myCF?

11. What would you change and why?

Knowledge of self-management

12. Did you notice any change in your symptoms during the pilot? Was this obvious from the diary? Did this change the way you managed your CF? How?

13. How does this differ from your current management of symptoms?

Meeting needs

14. Are there any features you would really like to see included in myCF that aren't currently there?

15. Do you see for this site? (for you? For other people??

16. Do you have any ideas for changes?

17. Do you think that anyone else in your family or your friends would like to use myCF? How could this change the way you live with CF?

Their point of view on the process

18. Have you had enough information about the project? (Where from? Do you think it was accurate?)

19. Would you have liked to have been involved in the design and development of myCF? Tell me how you would see your involvement in the design and development of myCF.

Other comments

20. Is there anything else you would like to tell me?
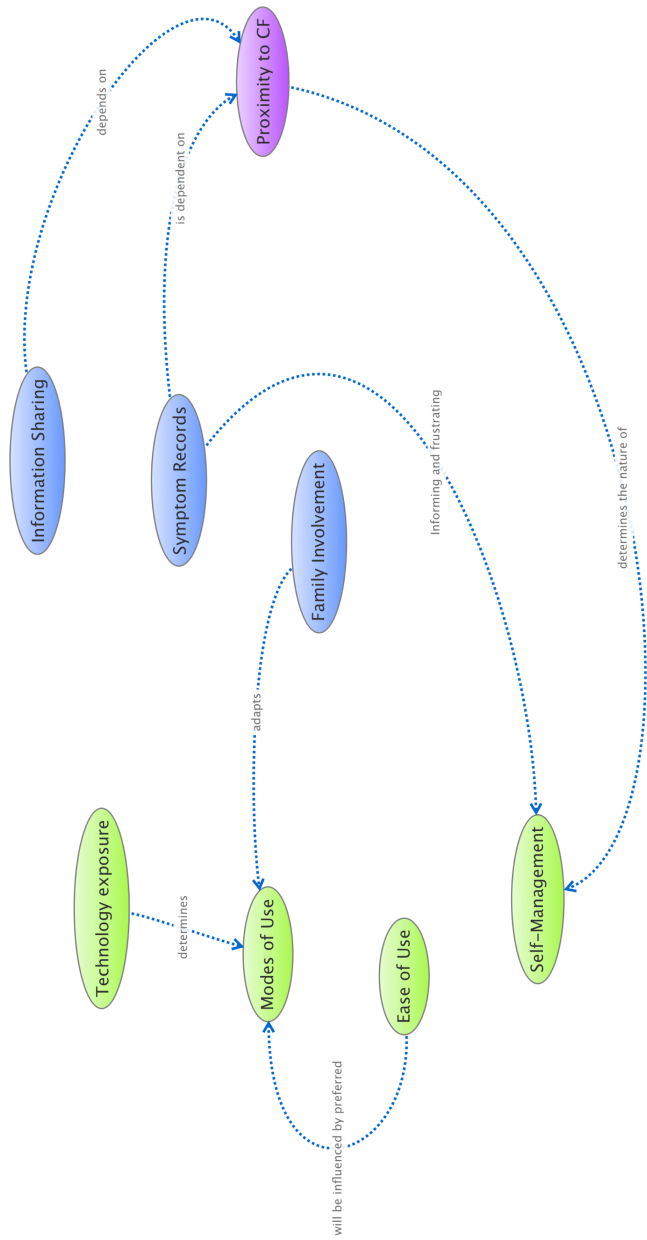
APPENDIX D FIELD NOTE EXAMPLE

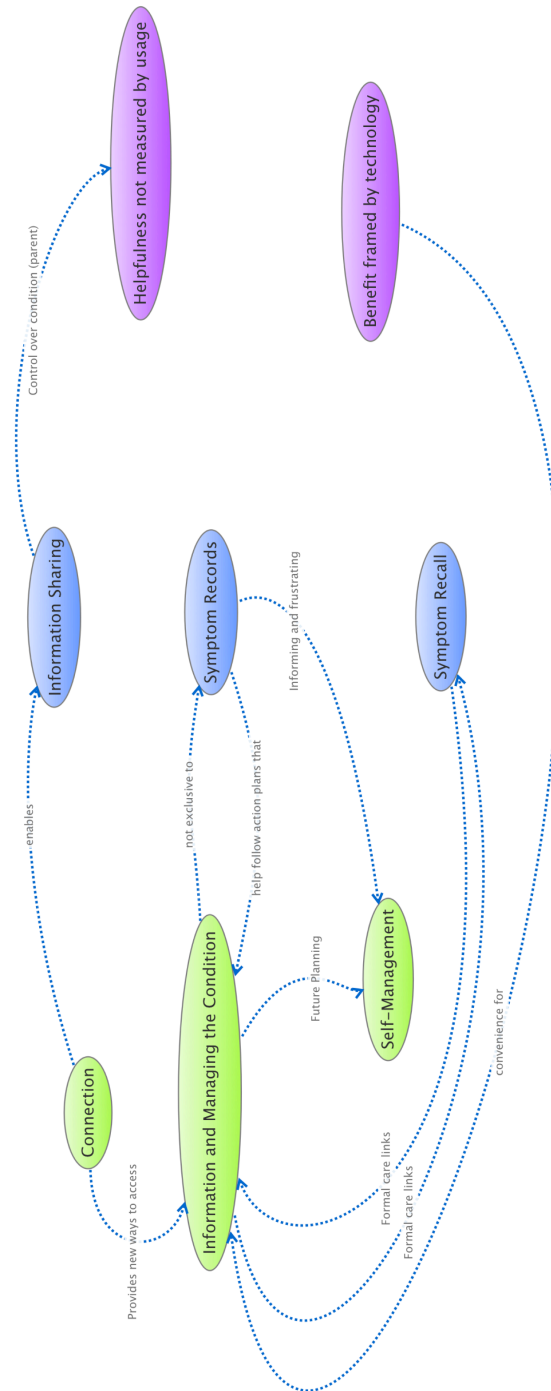| Date	14th June 2011
Place	Participant P002's residence
Time	13:00
Topic	Introduction to myCF
Participants	Erin Roehrer, Participant P002, Participant P002's mother
Content	The introduction session took place in the participant's living room. The participant's mother used a laptop when being introduced the website. There is no fixed PC in this residence, the family uses the laptop due to its portable nature. The participant's mother filled out the survey's with little comment. There were only 2 questions that the participants mother asked for clarification on. When filling out the dairy the participants mother asked participant P002 his perception of the symptoms. The participants mother offered detailed answers to the questions. She indicated that they were participating to help out and to hopefully provide a future benefit to her son.
Personal Notes/Observations	The participants mother illustrated that while she knew the benefits of CF treatment and management, it was sometimes difficult as her son did not seem to exhibit any major CF symptoms. She did, however, make comment that it was important for her son to understand his condition from his own age level, and what it meant when he didn't follow through on his treatments. Whilst the participants mother did not place emphasis on the clinical treatment and management of his CF, she did maintain that his daily activities maintained treatments. The participants mother was more interested in the site for what it could do for her son. While a community development focus was briefly touched upon, it was not the main element for their participation.

APPENDIX E INTERPRETATION CONCEPT MAP
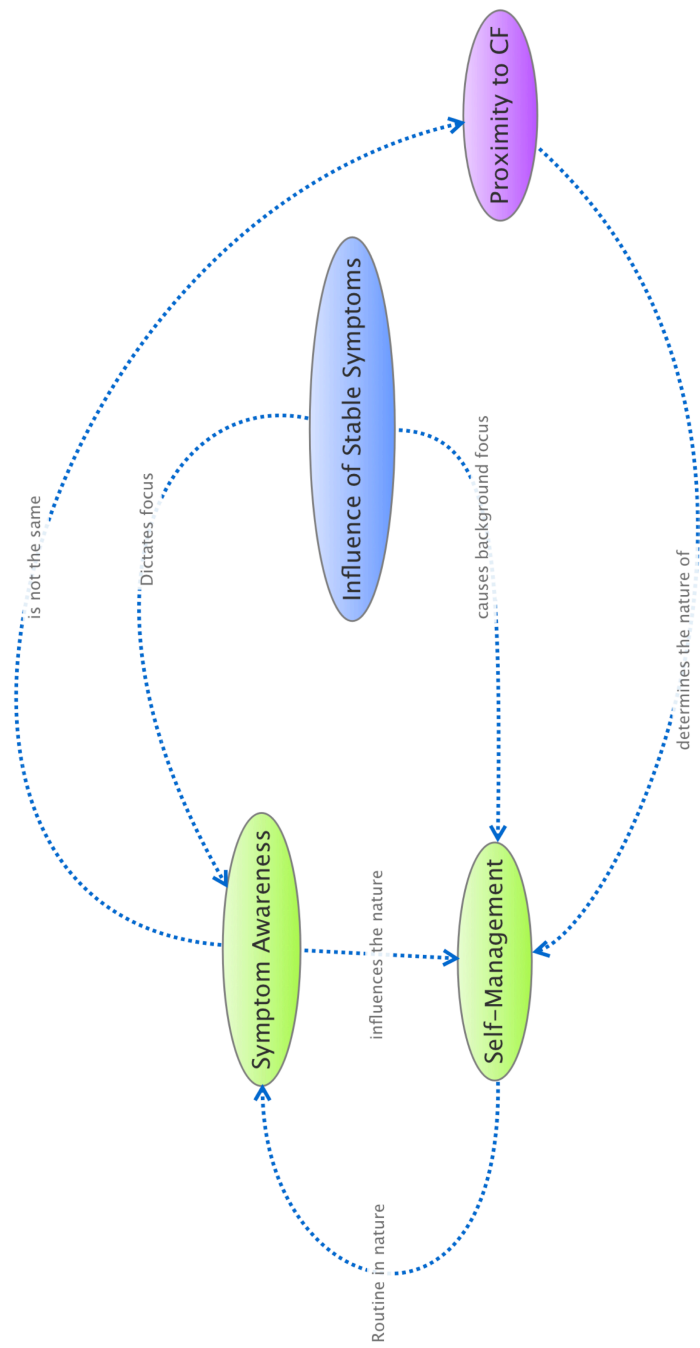
APPENDIX G FINDING TWO CONCEPT MAP
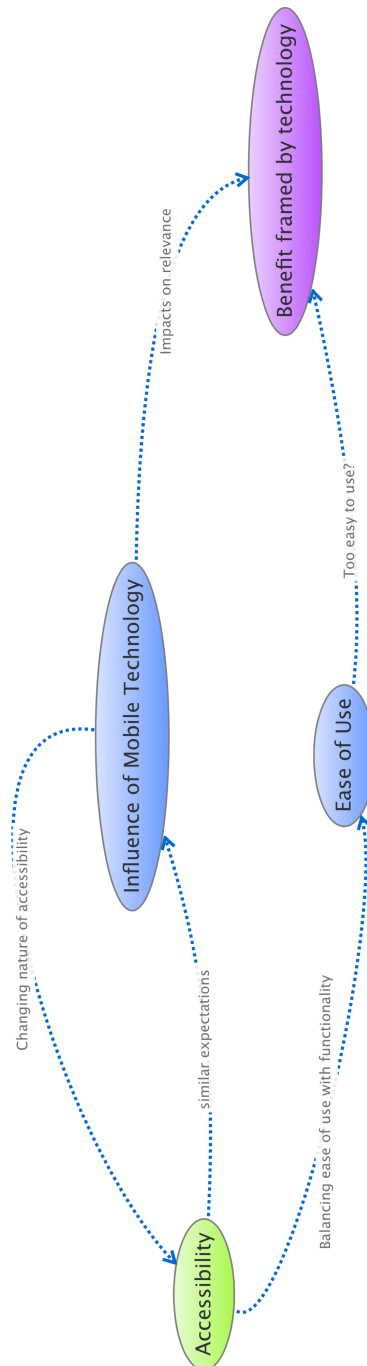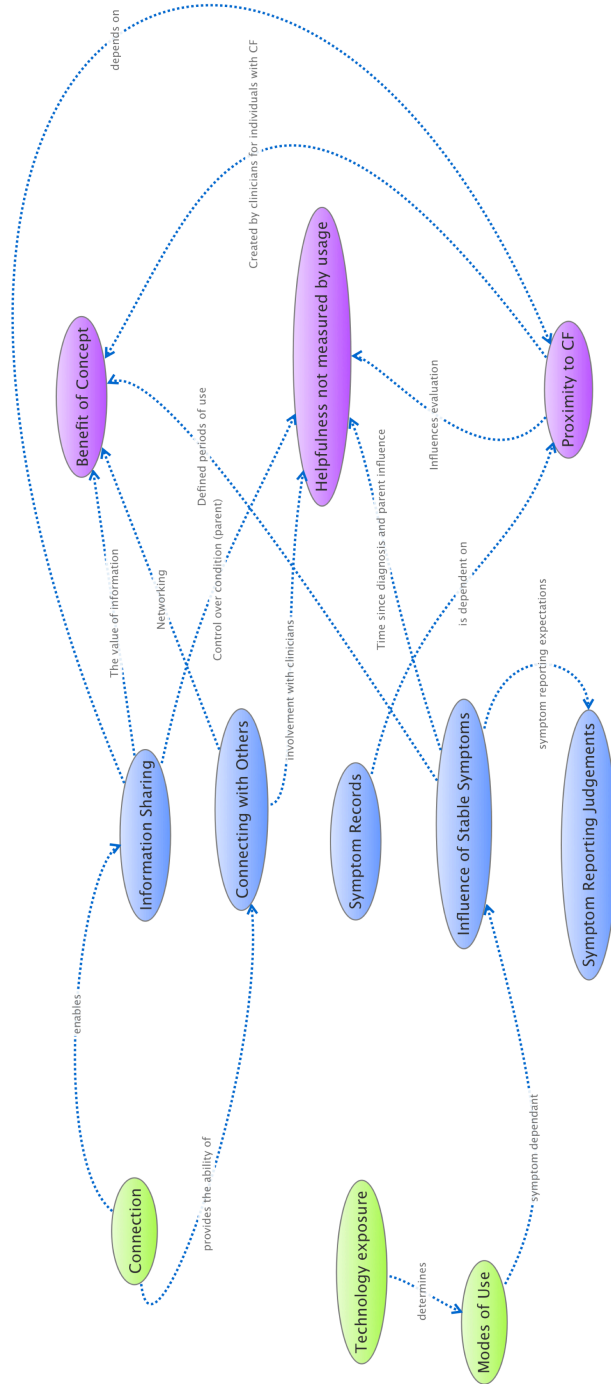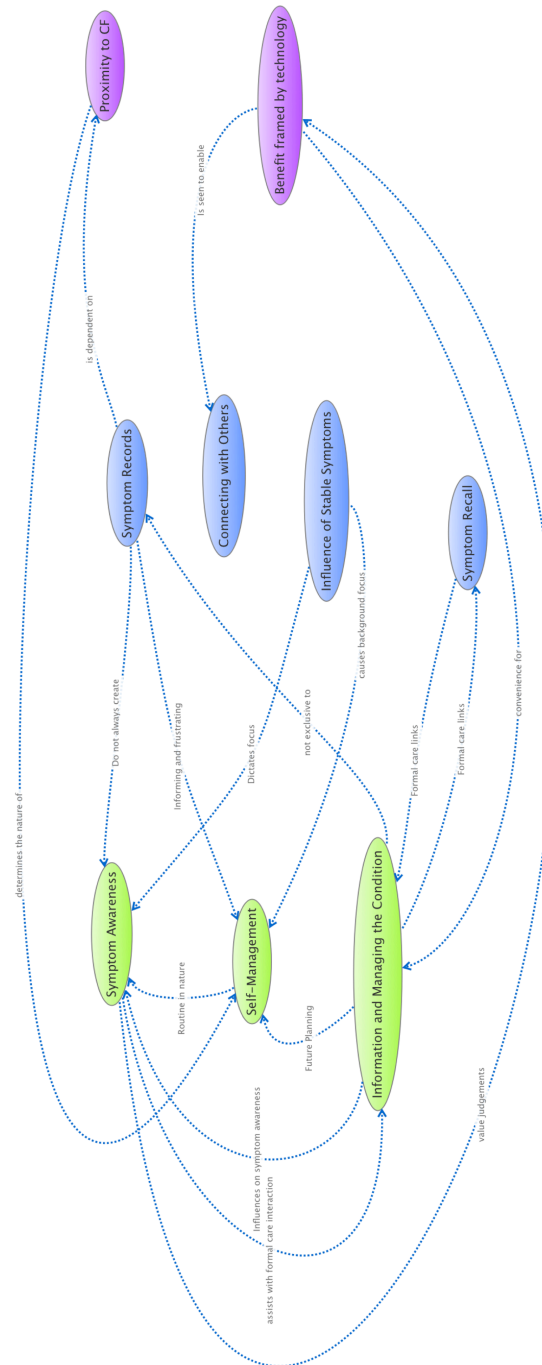
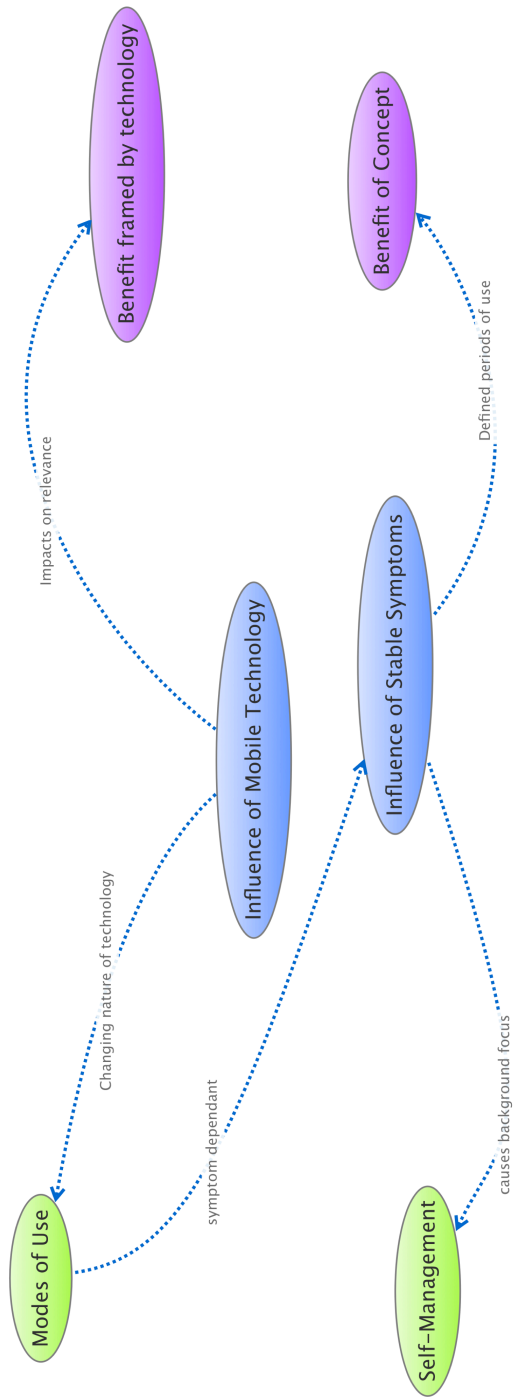# APPENDIX H FINDING THREE CONCEPT MAP

APPENDIX I FINDING FOUR CONCEPT MAP

Benefit framed by technology

Influence of Mobile Technology

Ease of Use

Impacts on relevance

Too easy to use?

Changing nature of accessibility

similar expectations

Balancing ease of use with functionality

Accessibility

APPENDIX K FINDING SIX CONCEPT MAP

APPENDIX L FINDING SEVEN CONCEPT MAP

APPENDIX M FINDING EIGHT CONCEPT MAP