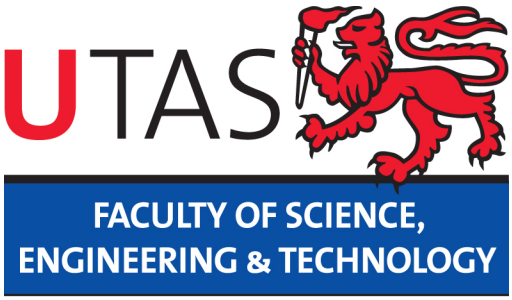

School of Computing
& Information Systems

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

BCom, BIS (Hons).

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This dissertation contains no material which has been accepted for the award of any degree of diploma by the University of Tasmania or any other institution, except by way of background information and duly acknowledged in the thesis, and to the best of the candidate's knowledge and belief no material previously published or written by another person except where due acknowledgment is made in the test of the thesis.

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.

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- International Journal of Healthcare Technology and Management (2013)

Finally, I would like to dedicate this research to my sons. William and Luke – you have had patience when I had none, laughter when I had tears, and the power to make it all better with just one hug. ♥

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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