

UNIVERSITY OF CALGARY

Can Home Telehealth Technology Support Disease Management in Teens with Asthma?

by

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "Can Home Telehealth Technology Support Disease Management in Teens with Asthma? " submitted by Pin Cai in partial fulfilment of the requirements of the degree of Master of Science in Health Research.

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Abstract

The purpose of this multiple case study was to explore the role of home telehealth technology in teens' asthma management. Six female teens were recruited from the Asthma Clinic at Alberta Children's Hospital. Semi-structured interviews were conducted with the teens, their parents, and their health care providers before and after they used the CareCompanion®, the technology used for 3 months in the study. Interviews were recorded and transcribed verbatim and Social Cognitive Theory was used as a conceptual framework to guide data analysis. Results suggested the role of technology was influenced by teens' self-management behaviour and asthma status without the technology. Usability of technology also influenced the effect and use of the technology. The study highlighted aspects of the CareCompanion® for improvement and discussed implications of using the technology in clinical practice.

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CHAPTER ONE: INTRODUCTION

1.1 Statement of the Problem

Asthma is the most common chronic disorder of children and adolescents. Children with asthma account for significant physician visits and hospitalizations each year (Health Canada, 2001). Direct and indirect costs associated with caring for children with asthma are substantial (Lozano, Fishman, Vonkorff, & Hecht, 1997).

Self-management plans (or action plans) integrate changes in symptoms or Peak Expiratory Flow (PEF) measurements with written directions to introduce or increase therapy. Recommendations to monitor symptoms and/or PEF in the home management of asthma have been made in many pediatric asthma clinical guidelines ("The British Guideline," 1997; American Academy of Allergy Asthma & Immunology [AAAAI], 1999; Boulet, Becker, Berube, Beveridge, & Ernst, 1999; Streck, 2001). However, there is a huge gap between current concepts of best practice and the reality of persistently poor asthma self-management behaviour and outcomes (Forero, Bauman, Young, Booth, & Nutbeam, 1996). This is particularly true in adolescent asthma patients (Forero et al., 1996; Randol & Fraser, 1999).

Availability of the technology has opened up an unprecedented range of strategies for disease education and prevention programs and research. Some attributes of new communication technologies are relevant to health related behaviour models and theoretically may support chronic disease self-management including asthma.

There is a need to study the role of the technology in asthma self-management. In particular, research regarding asthma in adolescence, an important transition period that might influence patient's health behaviour in adulthood, is warranted.

1.2 Study Purpose

The purpose of the study was to explore the role of home telehealth technology in teens' asthma self-management.

1.3 Research Questions

The central research question guiding the study was:

What was the role of home telehealth technology in teens' asthma management?

More specific subquestions included:

1. How did teens manage asthma without using home telehealth technology?
2. What happened in the 3-month period? (How did the home telehealth technology work? How did the technology influence teens' asthma self-management? How did the technology influence their daily life?)
3. How did home telehealth technology influence teens' perceptions of asthma management?

1.4 Significance of the Study

The findings of the study helped to understand the role of home telehealth technology in teens' asthma self-management. It identified areas for further investigation in evaluating telehealth technology in chronic disease management. Knowledge generated can be applied to improve development of self-management programs incorporating telehealth technology, particularly in adolescents. It was also the first study where the CareCompanion® was used in teenagers with asthma. The results of the study can be used to improve the technology prior to its use in clinical practice.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter reviews the current literature addressing relevant topics including burden of asthma, asthma self-management, health behaviour models, and telehealth in chronic disease management. The review focuses on the paediatric asthma population.

Asthma is a major public health problem for both adults and children. The complexity of managing asthma at home and at work or school can be overwhelming for many patients and their families. Numerous studies have been conducted to assess asthma self-management educational programs but few are available targeting the adolescent population. Some attributes of home telehealth technology used in chronic disease management are relevant to the health behaviour models, and may play an important role in asthma self-management. However, little is known about whether and how the technology could influence health behaviour or health outcomes in asthma management. The literature review highlights the gaps in our current knowledge in these areas.

2.2 Burden of Asthma

Asthma is a chronic health disorder affecting a substantial proportion of children and adults worldwide. The burden of asthma to governments, health care systems, families, and patients is increasing worldwide (Masoli, Fabian, Holt, & Beasley, 2004). It is even larger for children than for the rest of the population (Grant et al., 1999; Mannino et al., 2002). Many studies suggest that asthma has become more common in both children and adults around the world in recent decades (Downs et al., 2001; Kay, 2001; Kuehni, Davis, Brooke, & Silverman, 2001; Maziak et al., 2003; Upton et al., 2000), although factors behind the increasing asthma burden remain unclear (Akinbami & Schoendorf, 2002).

The 2000/2001 Canadian Community Health Survey found that the prevalence of physician diagnosed asthma in Canada is 8.4% among people aged 12 and over, and 12.6% among teens and young adults aged 12 to 19 (Statistics Canada, 2005). Prevalence of asthma in the 5-19 age group was 13% in Student Lung Health Survey (SLHS) in Canada (Mo, Robinson, Choi, & Li, 2003). In 2000/2001, 8.2% (66,112) of the population aged 12 and older in the Calgary Regional Health Authority were diagnosed by a health professional as having asthma (Statistics Canada, 2005).

The burden asthma places on those with asthma, their families and the health care system, as seen in potentially preventable hospitalizations, urgent care visits and lost days of work and school is high (Lozano, Sullivan, Smith, & Weiss, 1999). The 1996/97 Canadian National Population Health Survey (NPHS) Asthma Supplement found that 43% of individuals with current asthma visited their doctors one to three times in the previous year and 18% of individuals with active asthma had visited the emergency department at least once in the past year (Health Canada, 2001). According to the NPHS Asthma Supplement, 5.3% of those diagnosed with asthma in Canada require hospitalization each year.

Paediatric asthma not only affects children's lives in terms of symptoms and restrictions of daily activities, but also has negative impacts on parents' lives (AAAAI, 1999). A few studies showed that caregivers' loss of workdays owing to their children's asthma is substantial and is highly correlated with the level of asthma control (Diette et al., 2000; Laforest et al., 2004).

Contrary to public beliefs, studies revealed that children do not outgrow asthma ("Worldwide variations," 1998; Essen-Zandvliet, Hughes, Waalkens, Duiverman, &

Kerrebijn, 1994). The severity of asthma exacerbations among adolescents is significant. Near-fatal episodes are reported to be highest in the 12-15 year age range (Randolph & Fraser, 1999). A study in California found that adverse asthma episodes resulting in intubations, cardiopulmonary arrest, and death were more likely to occur in the adolescents (12 to 17 year old) compared with younger children (Calmes, Leake, & Carlisle, 1998). Asthma remains one of the most frequent causes of preventable hospital admissions among children aged 3-15 years (Gurkan, Ece, Haspolat, Derman, & Bosnak, 2000).

2.3 Asthma Self-management

Although our understanding of the management of asthma has increased significantly in the recent past, surveys in Canada and other countries have shown that asthma management goals are not being achieved in a high proportion of patients including children and adolescents (Sawyer & Fardy, 2003). There is still a huge gap between current concepts of best practice and the reality of persistently poor asthma outcomes. Successful clinical management in children with asthma may reduce the economic burden of asthma by lowering the morbidity associated with it (Mellon & Parasuraman , 2004).

The concept of asthma self-management arose as clinicians realized that delays in recognizing asthma exacerbations and initiating appropriate therapy were important factors contributing to asthma morbidity and mortality (Jalaludin et al., 1999; Jorgensen et al., 2003). Most exacerbations occur when patients are at home and they have to handle the situation without immediate help from physicians. Many deaths are preventable,

being due to suboptimal long-term medical care and delay in obtaining help during the final attack (Beasley, 2004).

Self-management comprises “activities initiated or performed by an individual patient, family, or community in the hope of achieving, maintaining or promoting maximum potential for good health” (Hanson, 1999, p.184). Asthma self-management is defined as “effective behaviour regarding asthma, based on sufficient knowledge about asthma and its provoking factors, adequate coping behaviour, compliance with inhaled medication, attention to changes in disease severity, adequate inhalation technique, and the correct use of a peak flow meter” (Van Der, Klein, Zielhuis, Van Herwaarden, & Seydel, 2001, p. 161). Within the context of health care for paediatric asthma patients, self-management includes activities that the child or parent/caregiver performs to prevent and treat asthma episodes (Hanson, 1999).

A large number of studies have been done to examine the impact of asthma intervention programs for self-management of asthma in children (Christiansen et al., 1997; Cowie et al., 2002; Krishna et al., 2003; Shah et al. 2001). The results were inconsistent partly because the educational programs incorporated a variety of self-management strategies with various lengths of intervention and were targeted to different patient groups. A recently published meta-analysis supported the conclusion that self-management educational interventions for children and adolescents with asthma (2-18 years old) compared to usual care resulted in improved physiological function, decreased asthma morbidity, improved self-perception, and reduced health care utilization (Wolf, Guevara, Grum, Clark, & Cates, 2003).

Self-management plans (or action plans) can be symptom based or Peak Expiratory Flow (PEF) based. They allow patients to monitor daily changes of asthma, to adjust the level of therapy accordingly, and to seek a health care professional's help when necessary.

2.3.1 PEF monitoring

Guided asthma self-management is usually based on symptoms. The rationale for a peak flow based asthma self-management plan is based on the assumptions that 1) changes in PEF over time reliably reflect changes in asthma severity; 2) PEF is blown reliably at home and recorded truthfully in a diary; 3) peak flow based self-management plans reduce asthma morbidity (Kamps, Roorda, & Brand, 2001). All these assumptions are currently being challenged.

Despite lack of consistent evidence on the role of PEF monitoring in asthma self-management, PEF monitoring is included in many of the asthma guidelines because it has few risks and low costs, and it may improve communication between the patient and physician (Mintz, 2004). However, most studies have shown no difference in outcomes (Wensley & Silverman, 2001). One randomized controlled trial conducted in Calgary, Alberta found there was a significantly greater reduction in emergency department visits for asthma in the peak flow-based action plan group compared to symptom-based action plan group (Cowie, Revitt, Underwood, & Field, 1997). A more recent review found no overall evidence of a difference in outcome for self-management based on PEF monitoring and self-management plans based on symptom monitoring in adult asthma patients (Powell & Gibson, 2003). Limited data are available for children, showing no statistically significant difference in asthma control between children who monitored PEF

and those who did not (Wensley & Silverman, 2004; Yoos, Kitzman, McMullen, Henderson, & Sidora, 2002).

2.3.2 Adherence to Asthma Self-management Plans

Non-adherence to asthma self-management is a common phenomenon and may account for a significant proportion of the continued morbidity and mortality associated with asthmatic patients even after appropriate management strategies have been determined. Patients may not follow their self-management plans even when they have them. As well, they develop their own interpretations of symptoms and treatment strategies. Generally, adherence to long-term treatment regimens has always been a challenge. Low adherence to prescribed treatments is very common, with typical adherence rates for prescribed medications about 50% ranging from 0% to over 100% (Sackett, 1979). Estimates of adherence to therapeutic regimens range from 20% to 80% in asthma patients (Cochrane, 1992; Rand & Wise, 1994). Physicians and researchers are aware of poor patient adherence to asthma management plans even in clinical trials where compliance is usually much better (Burkhart, Dunbar-Jacob, & Rohay, 2001; Cote, Cartier, Malo, Rouleau, & Boulet, 1998; Hyland & Crocker, 1995; Kamps, Roorda, & Brand, 2001b; Malo, L'Archeveque, & Trudeau, 1993; Verschelden, Cartier, L'Archeveque, & Trudeau, 1996; Wensley et al., 2001).

The unreliability of PEF diaries is probably one of the main reasons why PEF monitoring does not contribute as much to the success of asthma self-management as might be expected (Sly & Flack, 2001). Peak flow monitoring is often perceived as time-consuming and insensitive, and is characterized by a lack of compliance, particularly in children (Mannino et al., 2002; Redline, Wright, Kattan, Kerckmar, & Weiss, 1996). The

reliability of PEF values recorded in a diary have been questioned because both asthma adults and children missed, incorrectly entered, or self-invented peak flow values (Downs et al., 2001; Kuehni et al., 2001; Malo et al., 1993). Compliance is particularly low in adolescents (Roorda, 1996). Wensley's (2001) study showed that children were capable of maintaining the technical quality of their peak flow measurement over 4 months but, like adults, their compliance decreased after 4 weeks. Even apparently well motivated children with asthma and their families did not provide a reliable PEF diary (Kamps et al., 2001; Kamps, Roorda, & Brand, 2002). Therefore, home peak flow monitoring is not widely used in clinical practice. For example, in Alberta Children's Hospital Asthma Clinic, less than 5% of the patients are asked to use their peak flow meters on a daily basis (S. Spier, personal communication, September 2004).

2.3.3 Adolescents' Asthma Self-management

Increases in morbidity and mortality as children grow into adolescence may partly be explained by the fact that their caregivers have reduced roles in controlling the youth's asthma (Bruzzeze et al., 2004). From a developmental perspective, adolescence can be a tumultuous transitional period because of the desire for autonomy, a sense of invincibility, denial of disease, and susceptibility to peer pressure. For these reasons, fostering effective self-management strategies with asthmatic adolescents can be particularly challenging (Cohen, Franco, Motlow, Reznik, & Ozuah, 2003). Adolescence is an important transition period that may even influence asthma self-management behaviour in adulthood. Although there are many theoretical models available, factors that may be related to low compliance amongst adolescents remains largely unknown.

2.4 Telehealth in Asthma Management

Telehealth is defined as “the use of advanced telecommunications technologies to exchange health information and provide health care services across geographic, time, social, and cultural barriers” (Reid, 1996, p. 10). The availability of the technology has opened up an unprecedented range of strategies for health behaviour change programs and research. Some attributes of new communication technologies are relevant to health behaviour models (Owen, Fotheringham, & Marcus, 1998) and theoretically may help patients change disease management behaviour.

The results of evaluations of telehealth to date demonstrate that home telehealth technology is feasible in support of chronic disease self-management including diabetes and asthma monitoring (Bruderman & Abboud, 1997; Finkelstein, Hripcsak, & Cabrera, 1998b; Finkelstein & Cabrera, 2000; Finkelstein, O'Connor, & Friedmann, 2001; Mantzouranis, 2002; Steel, Lock, Johnson, Martinez, & Marquilles, 2002). Technology can facilitate both the monitoring itself and incorporation of the data into customized asthma self-management plans.

The validity of electronic spirometers to measure and store lung functions at home, as part of the asthma self-management plan, has been assessed (Bastian-Lee, Chavasse, Richter, & Seddon, 2002). Use of electronic devices resulted in higher adherence and accuracy compared with paper based monitoring in a 8-week study (Chowienczyk, Parkin, Lawson, & Cochrane, 1994). Another study demonstrated that patients preferred electronic diaries to paper based monitoring (Godschalk, Brackel, Peters, & Bogaard, 1996). Their potential to document longitudinal changes in lung function in children with respiratory disease at home merits further study.

Feasibility studies have demonstrated that use of technology to support interactive health communications is effective in terms of validity of PEF data, successful data transmission via the system, and patients' acceptance assessed by questionnaires (Bruderman et al., 1997; Finkelstein, Hripcsak, & Cabrera, 1998a; Finkelstein et al., 1998b; Finkelstein et al., 2000; Finkelstein et al., 2001; Steel et al., 2002). More recently, a randomized clinical trial evaluated the efficacy of a new interactive device, the Health Buddy®, programmed for the care of inner-city children (8-16 years) with asthma (Guendelman, Meade, Benson, Chen, & Samuels, 2002). The study showed that compared with children assigned to an asthma diary, children randomized to the Health Buddy® were more likely to improve self-care behaviours and to reduce asthma symptoms, while making fewer urgent calls to the hospital. It is possible that symptoms and PEF telemonitoring can provide much more reliable PEF values by eliminating retrospective data entry and fabrication of results. Improved communication between patients and clinicians based on daily transmitted clinical and PEF data may also have an effect on asthma self-management.

Despite the technology's potential and the increase of the number and range of technology applications in asthma self-management, there is a shortage of high quality data to support its use. Generally quality of the published research in this area is poor and very few studies target adolescent asthma patients. The limitations of telehealth research in asthma patients are similar to those found in a systematic review of telemedicine research, e.g. inadequate details of the design and conduct of the study, and the statements in discussion and conclusions not supported by data and analysis given earlier (Hailey, Roine, & Ohinmaa, 2002).

2.4.1 CareCompanion®

The CareCompanion® (Figure 1) is a self-contained home unit developed for a patient requiring assessment and reminders. It was approved by the U.S. Food and Drug Administration and Health Canada and complies with HIPAA (The Health Insurance Portability and Accountability Act) and HL7 (Health Level 7) (AMD Telemedicine, Inc., 2005).

Figure 1. CareCompanion® with Peak Flow Meter



It prompts the patient to take medications and answer programmed questions related to their specific health needs. Peripheral devices used with the CareCompanion® also allow patients to take important measurements such as blood pressure, PEF, and SpO₂. Data collected by the CareCompanion® are sent to a CareCompanion® server via the patient's home telephone line. The physicians and/or nurses can access the data by connecting to the server. The CareCompanion® Web Software is an internet enabled data management software application that can be used by healthcare professionals to view the data of patients enrolled in the program. There is no published research on use of the CareCompanion®. Little is known about the usability of this particular technology or its effectiveness at the clinical level.

2.5 Health Behaviour Models

Current goals of asthma therapy include normal lifestyle with less activity restriction, eliminating and preventing symptoms, normalizing or optimizing lung function, and less rescue medications (Canadian Lung Association, 2003). The most frequent and important steps to achieve these goals are taken by the patient. The Canadian Asthma Consensus Report recommended that asthma intervention programs should assist people to achieve their control of asthma via improved knowledge and change in behaviour (Boulet et al., 1999). Health professionals should therefore focus their efforts on understanding patients' behaviours to make sure that individual asthma patients follow their advice in asthma self-management. Applying the most relevant health behaviour theory and research methods in this new context is important to build a sound base of evidence to support the development of innovative and effective asthma intervention programs. Interest in examining the theoretical foundations of disease self-management is increasing with the recognition that theory-based research is an important step in the development of effective interventions (Walker et al., 2003). A variety of theories and models available provide insights into the different factors affecting health-promoting behaviours, with no single model being all-encompassing (Clark & Becker, 1998). The traditional theoretical model used to predict adherence to treatment is Health Belief Model. This model has been used both to explain change and maintenance of health-related behaviours and as a guiding framework for health behaviour interventions. It predicts that people will take health actions if the perceived susceptibility and severity is high and if benefits of the behaviour are perceived to outweigh the barriers. However,

this model does not include important factors other than health beliefs, such as previous experiences and external influences.

One of the most widely and successfully used models is Social Cognitive Theory (Bandura, 1995). According to Social Cognitive Theory, an individual's own behaviour and perceptions influence and are influenced by the external environment. Behaviour is depicted as dynamic, depending on aspects of the environment and the person, which influence each other simultaneously (Baranowski, 2002). This continuing interaction among personal, environmental, and behavioural factors is called *triad reciprocal determinism*. Change strategies therefore must consider all three determinants of behaviour, i.e. environmental factors, personal factors, and behavioural factors.

The theory suggests that motivation to change arises primarily from (1) outcome expectations, i.e. person's expectations that a favourable outcome will follow a particular behaviour, and (2) self-efficacy, i.e. "beliefs in one's capabilities to organize and execute the courses of action required to manage prospective situations" (Bandura, 1995, p. 2).

Several factors have been identified to affect one's judgement of self-efficacy: lack of access to information, difficulty in obtaining health resources, ambiguous management goals and insufficient support from professionals in the process of change (Po, 2000).

Self-efficacy may be increased in several ways, among them by providing clear instructions, providing the opportunity for skill development or training, and giving reassuring messages about the patient's ability to control the disease (Bandura, 1995; Clark, Gong, & Kaciroti, 2001).

This theory is particularly amenable to clinical aspects of asthma as patients must learn a range of control measures, such as monitoring symptoms or peak flow and taking actions

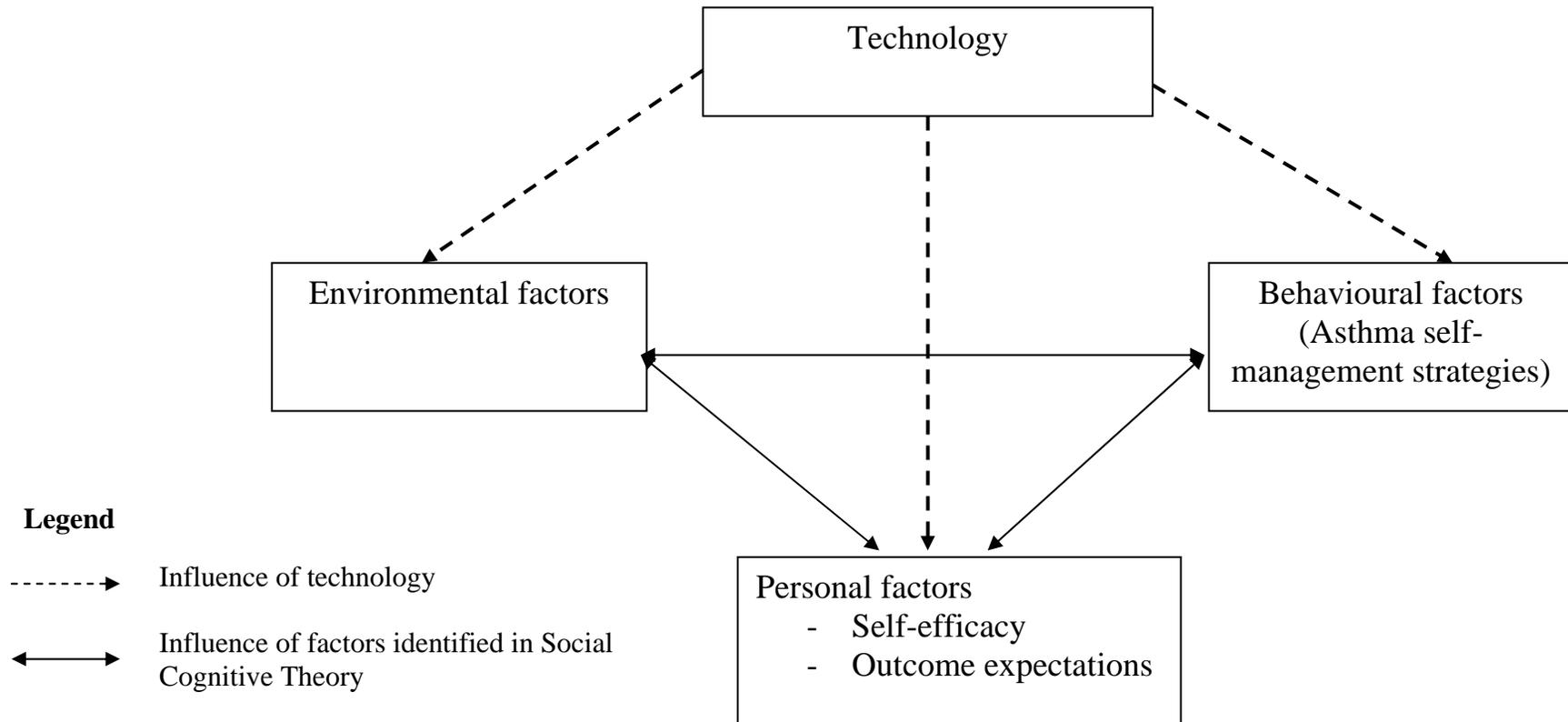
that require being observant and making informed judgments. The Social Cognitive Theory is well recognized as a useful framework for the design of asthma self-management programs (Clark & Valerio, 2003).

2.6 Conceptual Framework

A conceptual framework consists of a selection of factors, concepts and presumed relations among them (Miles & Huberman, 1994, chap. 2). It explains the main things to be studied. Even exploratory case study research can make use of a conceptual framework to define the priorities to be explored (Yin, 1999).

Social Cognitive Theory, the basis for the conceptual framework proposed for this study (Figure 2), suggested that the research should focus on environmental, personal, and behavioural changes related to asthma self-management when technology is used. The conceptual framework provides a way to study the role of home telehealth technology, by directly or indirectly influencing the environmental, personal, and behavioural factors related to asthma self-management, which may lead teens to undertake asthma self-management behaviours differently.

Figure 2. Conceptual Framework



Although early identification of possible constructs (e.g. self-efficacy) and relationships (e.g. influence of technology on personal factors) allowed them to be explored in qualitative interviews, it was recognized that a conceptual framework evolves and is “simply the current version of the researcher’s map of the territory being investigated” (Miles & Huberman, 1994, p.20). Therefore, the conceptual framework and its constructs were used solely as a starting point of the study. The researcher tried not to be constrained by prior theory and instead kept open to the emerging themes.

2.7 Summary

The literature review shows that the disease burden of asthma is high in both adults and children including adolescents. Despite the extensive research related to asthma self-management and considerable examples of home telehealth applications in asthma patients available in the literature, there is a lack of well-designed and conducted studies on whether and how the home telehealth technology might influence patients’ disease management behaviour and therefore health outcomes. Given the developmental challenges unique to adolescents and widely available home telehealth technologies, an increase in the knowledge of the use of available home telehealth technology in asthma self-management, particularly for adolescents, is required. There is a strong need to study the role of telehealth technology in asthma self-management for adolescent patients. Based on our research questions and the literature review, a conceptual framework was developed based on the Social Cognitive Theory.

CHAPTER THREE: METHODS

3.1 Study Design

This study was designed as a multiple case study within a qualitative paradigm. The purpose of the study was to explore the role of home telehealth technology in teens' asthma management. Qualitative research design is preferred when the research project purpose is to explore a complex phenomenon where variables cannot be easily defined (Creswell, 1998). Qualitative research allows subjects to raise issues and topics which the researcher might not have included in a structured research design, which adds to the quality of data collected (Carr, 1994). Therefore, a qualitative approach was appropriate for the exploratory and complex nature of the research project.

Case studies are research situations where the number of variables of interest far outstrips the number of data points (Yin, 1999). The greatest advantage of case studies is the depth that is possible when a limited number of individuals, institutions, or groups is being investigated (Polit & Hungler, 1999). In the context of this study, case study design provided an opportunity to explore various aspects of the role of home telehealth technology in teens' asthma management.

Studying multiple cases supports inquiry into a particular phenomenon, population, or general condition (Stake, 1998). The aim is to "see processes and outcomes across many cases, to understand how they are qualified by local conditions, and thus to develop more sophisticated descriptions and more powerful explanations" (Miles & Huberman, p. 172). Extension of the study to multiple cases facilitated understanding and interpretation of the role of the CareCompanion® in teens' asthma management through not only within-case but also cross-case analysis.

In this study, a “case” was defined as an adolescent female with asthma who used the CareCompanion® for 3 months. The time boundary was the time just prior to and following the use of the technology. The data sources for the case study not only included the teens, but also other persons such as the teens’ parents as well as the asthma specialists connected to their care.

3.2 Perspective of the Researcher

Qualitative research acknowledges the presence of the researcher conducting the research. “The researcher’s own background practical knowledge is considered as part of the perceptual lens, enabling skills and limits for conducting the study”, therefore it is necessary that the researcher’s personal values, assumptions, and biases are identified at the outset of the study (Benner, 1994, p. 103).

The researcher has a medical background and was involved in several randomized clinical trials of asthma drugs when she worked for a pharmaceutical company. As a graduate student in Health Telematics Unit at University of Calgary, she is very interested in telehealth research projects, particularly those related to clinical applications. With her prior knowledge in asthma management and telehealth technology, she wondered if technology would help patients with asthma manage their disease better. Based on her experience with pharmaceutical drugs, she expected the technology had been tested and proven to be effective before regulatory approval was granted.

3.3 Purposeful Sampling

Qualitative research, as opposed to quantitative research, involves many variables but a few information-rich cases (Creswell, 1998). The sample size in a qualitative study is often between five to twenty units of analysis (Kuzel, 1999). A sample of six was chosen

based on inclusion/exclusion criteria in a homogeneous group of teens. Theoretically interviews could be conducted until no new information is found. However, given time and funding constraints, the sample was limited to 6.

Participants in this qualitative study were selected purposively. Purposive sampling selects information rich-cases for in-depth analysis related to the central issues being studied (Miles & Huberman, 1994).

Two sampling strategies were used: criterion sampling and homogenous sampling. The inclusion criteria were: (a) Girls 14-16 years; (b) Physician diagnosed asthma for more than one year; (c) Prescribed inhaled corticosteroids for daily maintenance; (d) Having a self-management plan (Appendix A) for at least 3 months prior to enrolment; (e) Suitable home environment to use CareCompanion® (e.g. availability of analogue phone and electricity); (f) Living in one residence (so that the CareCompanion® could be installed in one place). Exclusion criteria included: Children living outside Calgary Health Region were excluded for easier study management.

Homogenous sampling allowed the study to focus on a particular sub-group with similar important characteristics that would influence asthma management, such as age and gender, to increase the potential to reach saturation given the small sample size.

Gender has been identified as an important factor in management and outcomes of asthma during adolescence (Wijnhoven, Kriegsman, Snoek, Hesselink, & de Haan, 2003; Williams, 2000; Woods, Sorscher, King, & Hasselfeld, 2003). A sample of 6 teens may be too small to adequately address gender as a factor in the teen's experience using the CareCompanion® to manage his/her asthma. Therefore, only female teens were studied at this time to minimize the effects of gender.

The age range was selected to include only participants in their middle adolescence (14-16 years of age). Physical, social, emotional, and cognitive changes occur during different stages of adolescent development. Middle adolescence is a time of engaging in activities which prepare them for adulthood. At this stage teens are quickly acquiring a range of skills needed for adulthood (Paget & Kritter, 1985). In the context of asthma management, they are less dependent on their parents and more likely to take charge of their asthma self-management.

Alberta Children's Hospital is located in Calgary and serves patients from southern Alberta, south-eastern B.C. and south-western Saskatchewan. A respiratory therapist working at the Asthma Clinic in Alberta Children's Hospital was hired as a research assistant for the study. She identified potential subjects from current patient charts and made phone calls to the potentially eligible teens with approval of their physicians at the Asthma Clinic. The respiratory therapist provided the teens and their parents with further information about the study and scheduled visits to their residences if they were interested in the study.

3.4 Data Collection Methods

For case studies, data collection may involve a broad variety of data collection methods. The more data collection methods are used in the same study, the stronger the case study evidence may be (Patton, 1999). A variety of data collection methods were used in the study, including: interviews before and after using the CareCompanion® to explore change over time, review of the electronic records stored in the laptop, and review of the telephone contacts between the respiratory therapist and adolescents or parents. As

Creswell (1998) suggested, a data collection matrix was used to present detailed information about the data sources and timing of data collection (Table 1).

Table 1: Data Collection Matrix- Type of Information by Source

	Interview #1	Documents	Interview #2
CareCompanion®	N/A	Clinical data, PEF/FEV1 values)	N/A
Anna	October 6, 2004 (Face-to-face)	Action plan	February 9, 2005 (Telephone)
Anna's father	October 6, 2004 (Face-to-face)	N/A	February 24, 2005 (Telephone)
Anna's asthma specialist	October 8, 2004 (Telephone)	N/A	N/A
Betty	October 29, 2004 (Face-to-face)	Action plan	February 19, 2005 (Telephone)
Betty's mother	October 29, 2004 (Face-to-face)	N/A	February 19, 2005 (Telephone)
Betty's asthma specialist	November 24, 2004	N/A	N/A
Christina	November 7, 2004 (Face-to-face)	Action plan	February 14, 2005 (Telephone)
Christina's parents*	November 7, 2004 (Face-to-face)	N/A	February 14, 2005 (Telephone)
Christina's asthma specialist	December 9, 2004	N/A	N/A
Liz	November 2, 2005 (Face-to-face)	Action plan	February 12, 2005 (Telephone)
Liz's mother	November 2, 2005 (Face-to-face)	N/A	February 12, 2005 (Telephone)
Liz's asthma specialist	February 15, 2005	N/A	N/A
Jane	November 6, 2004 (Face-to-face)	Action plan	February 15, 2005 (Telephone)
Jane's mother	November 6, 2004 (Face-to-face)	N/A	March 1, 2005 (Telephone)
Jane's asthma specialist	December 9, 2004	N/A	N/A
Rebecca	November 7, 2004 (Face-to-face)	Action plan	February 17, 2005 (Face-to-face)
Rebecca's mother	November 7, 2004 (Face-to-face)	N/A	February 21, 2005 (Telephone)
Rebecca's asthma specialist	November 24, 2004	N/A	N/A
Respiratory therapist	February 26, 2005 (Telephone)	Phone contacts	N/A

* Initially Christina's mother was interviewed. At the time of the second interview, she had to take care of Christina's grandfather in the hospital, so Christina's father was interviewed on the telephone after 3 months.

Plans for who would be interviewed, timing, topics, and level of detail were outlined at the proposal stage. These were evaluated and modified as data were examined and analyzed. For example, contacts were made during the 3-month monitoring period so that the role of the CareCompanion® in asthma disease management could be best understood “from a position of more familiarity and closer rapport with the informant” (Morse, 1991, p.190). This was not originally planned. However, during the monitoring period, some teens sent emails to the researcher or called the respiratory therapist to discuss issues with the equipment. These emails and telephone contacts were reviewed and analyzed together with the other data.

The data collection plan included interviewing teens’ asthma specialists before and after 3-month monitoring. The first few interviews showed that we would not be able to obtain more information from a second interview with the teen’ asthma specialist. The teens in the study visited the Asthma Clinic every 6-12 months. Most of them did not see their specialists when they were using the CareCompanion®. The after-monitoring interviews with the asthma specialists were cancelled. Instead, the respiratory therapist was closely involved in data monitoring during the 3 months and was an unexpected rich information source for understanding teen’s experience using the CareCompanion® in asthma management. She was interviewed at the end of the study.

3.4.1 Data Collected via the CareCompanion®

Due to the small number of patients, the CareCompanion® monitoring system was set up as a stand-alone-unit. In other words, data were only accessible via the server, which was a laptop connected to a separate telephone line at the respiratory therapist’s house. Data were not accessible through external internet connections. The patient name showed on

the web page but the name itself was not transmitted when the unit communicated with the laptop over the phone line.

The CareCompanion® could be programmed with a set of activities for a monitoring session. For this study, a monitoring session included: peak flow measurement, asthma control check with 5 questions (Appendix B), reminder notices to take medication and follow action plan. When it was time for the monitoring session to occur, the CareCompanion® unit activated by flashing the display and sounding the beeper. Once a user touched the display screen, the flashing and beeper would stop. If nobody responded to the unit's signal, it would continue to flash and beep for 30 minutes. After 30 minutes it would stop flashing and beeping and would skip the monitoring session.

A peak flow meter (Piko-1; Pulmonary Data Services, Inc; Louisville, USA) was added to the CareCompanion® unit as the peripheral device. Although diurnal variability of PEF (morning and evening) has been proved to be related to asthma symptoms and airway hyperresponsiveness, and is an important parameter of day-to-day management (Cross & Nelson, 1991), none of the participants wanted to work with the CareCompanion® more than once a day. As a compromise, they were asked to choose a convenient time to complete all the activities once daily.

The unit gave step-by-step instructions on the display to guide the teens through each of the activities scheduled. Once all of the activities for the session had been completed, a message was displayed signalling the end of the monitoring session. The CareCompanion® went into the power-saving mode after a few seconds.

The information collected was saved by the unit and sent automatically to the laptop at the respiratory therapist's house through a telephone line. The information transfer period

lasted one or two minutes, during which time the telephone line was busy. When the information transfer was completed, the telephone line would be available for normal use again.

The participants were expected to take adequate actions based on symptom changes according to their asthma self-management plans. Software installed on the laptop allowed the respiratory therapist to track symptoms, PEF values and medications taken for an individual patient. She monitored the results daily, but follow up was only initiated under emergency situations. An emergency situation was defined in the research proposal as PEF less than 60% of the baseline value.

The participants were aware at the beginning of the study that the CareCompanion® schedule could only be changed at the respiratory therapist's laptop. They were asked to contact the respiratory therapist if they wanted to change their schedules during the study. If a new schedule was set up by the respiratory therapist at her laptop, it would be retrieved by the CareCompanion® during the next data transfer session. For example, if a participant called the respiratory therapist to change her schedule from 7 AM to 7 PM for the next day, even if the respiratory therapist changed the schedule right away, the CareCompanion® would only retrieve the new schedule after data transfer for the 7 AM monitoring session.

Medication use, clinical data about asthma control, and PEF/FEV₁ reports generated by the software were reviewed by the researcher after 3 months. They provided information about use of the technologies, as well as data related to each participant's asthma management.

3.4.2 Qualitative Interviews

Two qualitative interviews using an interview guide were conducted separately with each teen and her parents. The first interview was conducted when the CareCompanion® was installed and took place in a quiet room in their house. The researcher explained the study purpose and procedures to the participant and her parents before each interview. Both the participant and her parents provided written informed consent. They were asked to share their experience about asthma knowledge, asthma self-management, and asthma control, prior to using the CareCompanion®. The second interviews were scheduled and conducted after the teens had used the CareCompanion® for about 3 months. Most of the second interviews were conducted over the telephone, as preferred by the teens and their parents. The researcher asked the teens about their experience using the CareCompanion®, their asthma self-management and asthma control with the use of the CareCompanion®. The interviews lasted about 20-30 minutes.

The teens' asthma specialists and the respiratory therapist were interviewed on the telephone. Due to their busy schedules, interviews with some of the asthma specialists were conducted at the end of the study. The interviews lasted about 30 minutes. Consent was obtained on the phone before the interview with the asthma specialists and the respiratory therapist.

Interviews were initially guided by interview protocols with broad and open-ended questions (Appendix C), which allowed interviewees to express their opinions. New questions arose as a result of the topics identified in the first few interviews.

3.4.3 Other Documents

Telephone contact records and emails sent to the researcher were also reviewed at the end of the study. They provided additional information about what had occurred with the teens' asthma management during the 3 months.

3.5 Data Management

A case study database was created to “markedly increase the reliability of the entire case study” (Yin, 1994, p. 95). The database included the audiotapes of interviews, interview transcripts, email print-outs, phone contact records, and monitoring reports generated by the software. QSR NVivo®, a computer based qualitative data management program, was used to help store, organize, and analyze the data.

3.6 Data Analysis

According to Yin (1994), it is important to have a general analytic strategy prior to data collection. One of the strategies suggested by Yin is to rely on theoretical propositions.

This case study analysis followed the conceptual framework (Figure 2) that home telehealth technology might influence some key factors involved in teens' disease self-management behaviour, leading them to undertake certain disease management strategies to achieve a desired outcome.

Interviews were audiotape recorded and transcribed verbatim. The researcher (interviewer) listened to the tapes and reviewed the transcripts to ensure they were complete and accurate. Interview transcripts and other documents were imported into QSR NVivo®. Data analysis occurred continuously throughout the project, which helped to re-formulate interview questions as new topics were identified from the data.

A provisional starting list of codes arising from the research questions and conceptual framework were created prior to conducting the interviews (Miles & Huberman, 1994). These codes were entered into QSR NVivo® and stored as nodes. They were hierarchically structured as categories and subcategories (Figure 4). A description was given to each node to clarify use of the node (Figure 5). This ensured that coding was done consistently throughout the text, in the same way every time. Updated lists of nodes with descriptions at different stages of the study allowed the researcher to organize the coding process and to document the process of data analysis.

Figure 3. Provisional Starting List of Codes

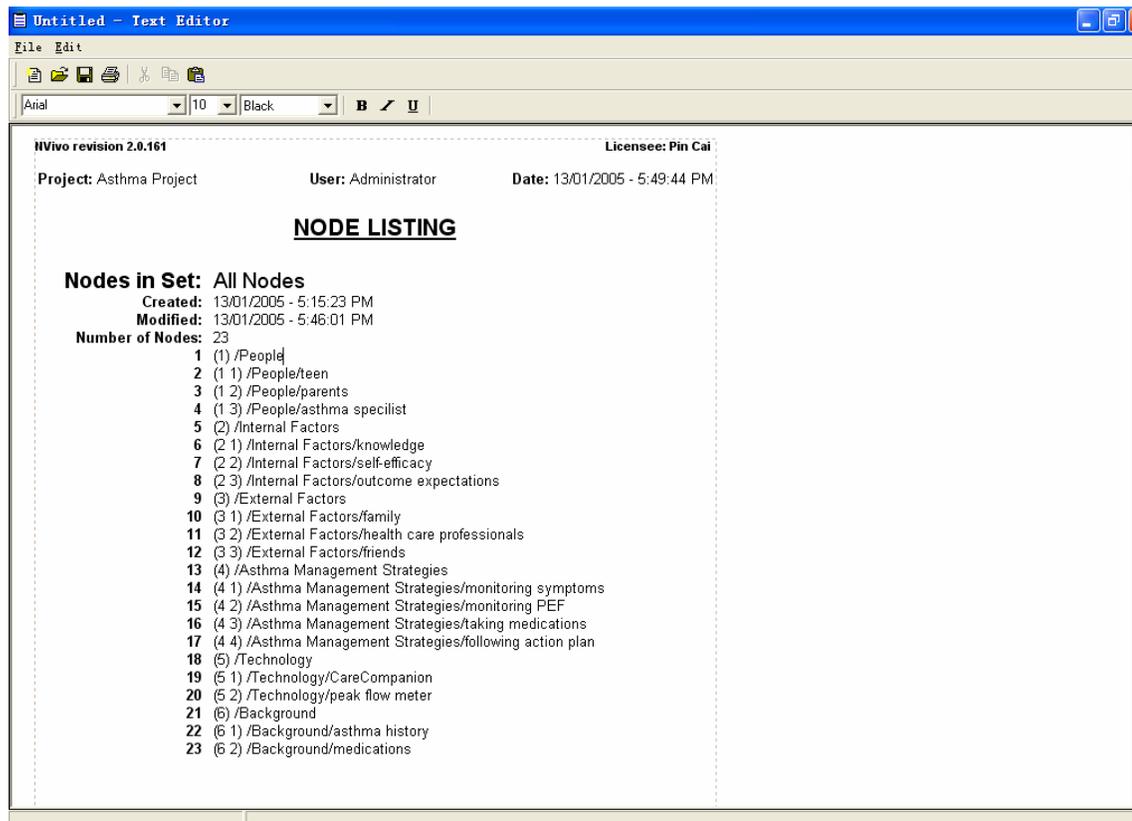
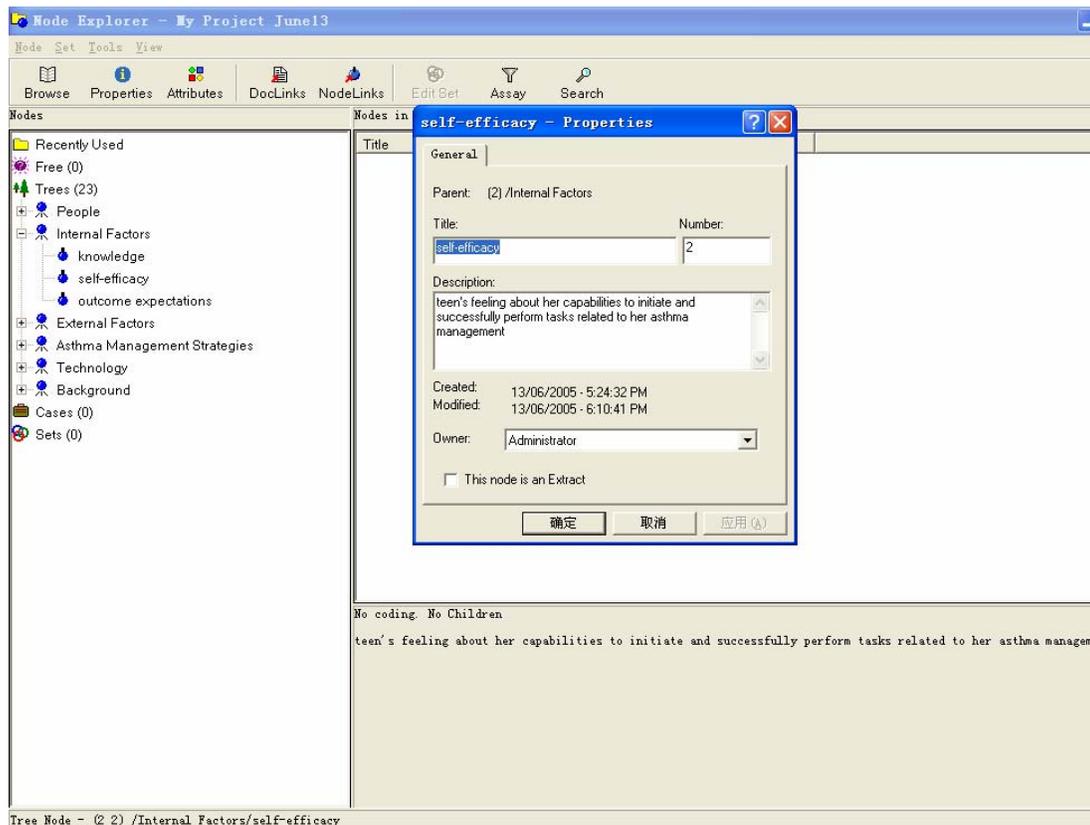


Figure 4. Definition of Codes (Example)

As suggested by Agar (1996, p. 153), researchers should “immerse themselves in the details, trying to get a sense of the interview as a whole before breaking it into parts”.

The researcher read all interview transcripts in their entirety, emails, telephone contact records, and reports generated from the data sent from the CareCompanion®. With the provisional coding template, the researcher returned to data related to each case in order to code at the existing nodes. At the same time, new nodes that did not fit into the coding template were added as they emerged. Nodes, their definitions, and their structures developed as the research continued, e.g. some nodes in the starting list did not work, while new nodes were created from the data. The “tree diagrams” were regularly revisited, and the descriptions and structures were revised as understanding grew.

After all the transcripts were coded in NVivo and the local dynamics of each case were better understood, pattern coding was conducted to take the coded data into more general, meaningful, and higher-level categories (Miles & Huberman, 1994). Pattern coding helped the researcher to capture the commonalities of experience across cases. The patterns were tested on the next set of transcribed interviews to see whether they fit. Ideas about the pattern codes and their relationships were recorded in memos by the researcher. This helped the researcher to reflect on the coded transcripts and add meaning to them throughout the data analysis process.

Reduced, focused, organized information for each case was displayed on a single page to aid interpretation. An adaptation of Miles and Huberman’s (1994) template of effect matrix was used to display the role of the CareCompanion® in asthma management for each case. After each case was well understood, cross-case meta-matrixes were developed to compare the commonalities and differences across cases.

3.7 Methods for Verification

Multiple perspectives exist regarding the importance of verification in qualitative research including its definition and the procedures for establishing it (Creswell, 1998).

Some verification procedures suggested by Creswell were undertaken to ensure trustworthiness in this study.

Acknowledging researcher biases (or bracketing)-Bracketing requires putting the researcher's personal knowledge and the knowledge gained from the literature aside or making it overt so that fresh insights might emerge in the study (Morse & Richards , 2002). The researcher's past experiences, biases, and prejudices that may have influenced the interpretation and approach to the study were recorded in the research proposal, acknowledged through data management and analysis, and reported in the thesis.

A journal was kept to record interview notes and personal reflections of the researcher's assumptions and possible biases. Through this process the researcher was more self-aware and was able to learn from the data with an open mind and work inductively. This was an important means of bracketing researcher's presuppositions, and was used to guide researcher's interpretations as well as provide context to the interviews.

Literature review done in the early stage of the study was set aside but not put away. Instead, the researcher constantly reviewed and re-reviewed the reported studies to compare and contrast what she saw in the data with the previous knowledge. These strategies also assisted with bracketing.

Peer review or debriefing- The researcher met regularly with her supervisor to discuss gaps in the data and alternative interpretations of the findings.

Triangulation- Triangulation refers to a data collection approach in which evidence is deliberately sought from a wide range of different, independent sources and often by different means (Mays & Pope , 1995). Triangulation was not used as a means of confirming existing data, but as a means of offering a deeper and more comprehensive picture (Tobin & Begley, 2004). Triangulation in this study involved comparing information derived at different times and by different means (Patton, 1999). For example, we compared interview data from teens, parents, and asthma specialists, electronic data transmitted to the central station, and interviews with the respiratory therapist. Different sources of data provided different information about what the teens were supposed to do, what they reported they did, and what they actually did. The researcher attempted to understand when and why there were differences.

Rich, thick description- Transferability is the range and limitations for application of the study findings to other groups (Maltreud, 2001). As stressed by Lincoln and Guba (1985), it is not the qualitative researcher's responsibility to provide an *index* of transferability; it *is* his or her responsibility to provide the *data base* that makes transferability judgments possible for the reader. Therefore, details are provided regarding participants and settings for future researchers to determine whether or not the conclusions of this study are transferable to their asthma patients.

3.8 Ethical Considerations

The research proposal was approved by Conjoint Health Research Ethics Board at University of Calgary (Appendix D). Written informed consent was sought from the teenagers' parents as well as the teenagers themselves (Appendix E). Telephone consent was obtained from the asthma specialists and the respiratory therapist before each

interview. The participants were informed both of any anticipated acquisition of personal data and of the extent to which privacy and confidentiality would be protected. Study related materials were kept in a cabinet that was only accessible to the researcher and all interview tapes will be destroyed at the end of the project. To ensure anonymity, each participant was given a pseudo name and other identifying information was not included in the final report.

CHAPTER FOUR: RESULTS

4.1 Description of the Sample

The multiple case study included six high school female teens aged 14-16, purposefully selected from current patients of the Asthma Clinic at Alberta Children's Hospital. At the time they participated in the study, all the teens lived with one or both of their parents in a residence with an analogue telephone line enabling them to use the CareCompanion®. Five teens lived in the city of Calgary and one lived in Okotoks, a small town located 20 kilometres south of Calgary.

All study participants had been diagnosed with asthma in their early childhood and had been prescribed regular inhaled corticosteroids (ICS) for daily maintenance for many years. Five of them had their asthma well controlled at the time of their first interviews and two had a family history of asthma.

Each participant had a customized, symptom-based asthma action plan (Appendix A) on the computer system at the Asthma Clinic at the time of their recruitment. The action plan included information about the importance of avoiding asthma triggers, when and how to use medications, and when to call the Asthma Clinic or seek emergency medical care. Some of them were provided with a printed copy of the action plan; others were taught how to vary their dose of asthma medication and when to seek help, but did not have a copy of the written action plan. None of the action plans was based on daily monitoring of peak flow.

4.2 CareCompanion® with Peak Flow Meter

The researcher and the respiratory therapist tested the CareCompanion® at the beginning of the study. The phone at the respiratory therapist's house would ring with the same ring

tone as normal phone calls when data transfer occurred. If somebody in her house picked up the phone, data transfer would not be completed and the CareCompanion® would repeatedly dial her phone number. This could be very inconvenient for her family if six patients were monitored everyday. We decided to use Smart Ring® service provided by TELUS, which gave her 2 phone numbers for a single line, each with a distinctive ring. Therefore they could distinguish which number was ringing to determine whether the call was from the CareCompanion®. Data transfer went well with the Smart Ring®.

The researcher and the respiratory therapist went to each participant's house and installed the CareCompanion® on a scheduled day. The respiratory therapist spent 15-30 minutes demonstrating and teaching the participants how to measure peak flow. Although the 6 participants had used a peak flow meter at some point of their asthma management, they all seemed to have some difficulties blowing the study peak flow meter with a good technique. When the peak flow meter detected a wrong technique, such as a cough, a short blow effort, or a slow start, an exclamation mark was shown on the screen, indicating to repeat the test. The CareCompanion® would not transfer the PEF data if there was an exclamation mark on the peak flow meter. The teen's use of the peak flow meter was checked and corrected when necessary. At the end of the education session, they all managed to get one or two correct peak flow readings. They were asked to try a few more blows later that day. The respiratory therapist also demonstrated how to download the data to the CareCompanion® unit. A CareCompanion® Patient Station User Guide provided by the manufacturer (Neptec) was provided to each teen for her reference.

4.3 Introduction to Themes

The coding template guided by the research questions and conceptual framework was used to identify themes including Using Technology, Technology and Personal Factors, Technology and Environmental Factors, and Technology and Behavioural Factors. Usability of Technology was a theme which emerged from the data. Categories were identified within each of the themes (Table 2).

Table 2. Themes and Their Corresponding Categories.

Themes	Categories
Using Technology	<ul style="list-style-type: none"> - Actual Use of Technology - Intention to Continue Using Technology
Technology and Personal Factors	<ul style="list-style-type: none"> - Self-efficacy - Outcome Expectations
Technology and Environmental Factors	<ul style="list-style-type: none"> - Medical Support - Shared Responsibility
Technology and Behavioural Factors	<ul style="list-style-type: none"> - Monitoring Symptoms - Measuring Peak Flow - Taking Medication - Following Action Plan
*Usability of Technology	<ul style="list-style-type: none"> - Technical Problems - Time Taken - Flexibility - Personalized Interaction - Added Responsibility - Aesthetics

* Emergent theme, defined by the International Standards Organization as “the effectiveness, efficiency, and satisfaction with which specific users can achieve specific sets of tasks in a particular environment” (Dix, Finlay, Abowd, & Beale, 1998, p. 192).

4.4 Within-Case Findings

Data from each case gathered through qualitative interviews with the participant, her parents, and her health care providers, as well as review of the phone contacts, emails, and electronic data sent by the CareCompanion® over the 3 months, were analyzed. The

findings for each of the six cases are presented in the order that the participants began using the CareCompanion®.

Each case begins with a description of a teen's asthma management without technology including a brief background on the unique case, and leads into a report of her asthma management with technology, which is organized around the five initial and emergent themes. Relevant findings in each of the themes are presented: Usability of Technology, Using Technology, Technology and Personal Factors, Technology and Environmental Factors, Technology and Behavioural Factors. This sequence illustrates the relationships of the themes from one to the other, which are further discussed in 4.4. Cross-case Findings. Quotations from the verbatim transcriptions of the interviews are used to illustrate issues that are relevant to the results presented in this chapter. A technology effect matrix summarizes each case following the description.

4.4.1 Case 1-Anna

Asthma Management Without Technology

Anna was a sixteen-year-old high school student living with her parents and one sister.

Anna's parents considered her "more obedient compared to most girls at her age." At the time of the second interview, Anna was in Montreal as an exchange student.

Anna was first diagnosed with asthma when she was about 2 years old and her father also has asthma. Anna expressed frustration about living with asthma, in particular how it affected her lifestyle choices:

It's very frustrating sometimes, especially in the fall and spring when I have cold...I am allergic to lot of things in environment. Really frustrating... It's really frustrating.
(Anna)

[What bothers me most about asthma is] the way it restricts my lifestyle... Most likely physical activity. Not being able to do things like playing soccer. Travel is harder.

(Anna)

Anna had a good understanding of asthma self-management and was confident in her ability to manage asthma. The Asthma Clinic provided her with a written action plan about two years ago, but Anna felt she had known how to manage asthma long before she had the action plan.

Anna's asthma was generally well controlled except for seasonal fluctuations in the spring and fall. Anna strongly believed that following her action plan was very important in her asthma management, and it worked really well for her.

... I think I have it fairly well controlled... So I think I'm pretty independent with that [asthma management] now.

(Anna)

... I don't think it [asthma management] is too hard. Pretty straightforward... It's hard to remember to take your medicine sometimes...

(Anna)

Anna's asthma management strategy was "following the action plan," which included avoiding triggers, monitoring symptoms, and taking preventer (or controller) medication.

At the time of her first interview, Anna took Symbicort® (Combination of Inhaled

Corticosteroids and Long-acting β_2 agonist) 200 mcg twice daily, Singulair®

(Leukotriene Receptor Antagonist, LTRA) 10 mg once daily, and Bricanyl® (Short-

acting β_2 agonist) as needed. She was considered one of the most "compliant" patients by

her physician.

I guess in a way I do [monitor my symptoms] but I don't write it down or anything like that... I know that to prevent an asthma attack you should take medicine regularly... I know that controlling asthma is probably the best thing you can do. Follow your action plan... I follow my action plan

... I keep my medication with me everywhere I go just in case.
(Anna)

Anna had support from the Asthma Clinic and her parents. Each time she went to the Asthma Clinic for her annual check-up, the asthma specialist would review her asthma status and medications. They would discuss and revise her action plan if necessary.

Anna's parents had handed over the responsibility for managing her asthma to Anna:

I think, you know, we have given her a lot of responsibility once she showed the maturity to be able to monitor herself and adjust her daily dose. (Anna's father)

...my parents are always there to support me. They are really, really supportive. If I am getting sick, I have a cold, they'll ask me to take medicine or change whatever. (Anna)

Asthma Management With Technology

Usability of Technology

Anna was the first participant of the study. The first interview was conducted on October 6, 2004 and Anna was ready to use the CareCompanion® right after the interview.

However, the respiratory therapist had to disconnect the laptop for a few weeks because the SmartRing® service did not work well if she left the laptop connected. Her incoming telephone calls would be connected to the laptop if no one picked up the telephone after one or two rings. It took about 3 weeks to install another telephone line in her house.

Anna also had trouble with the Piko-1 electronic peak flow meter when she first started. She sent a few emails to the researcher and talked to the respiratory therapist about the problems she had. The researcher contacted Neptec, the manufacturer of the CareCompanion®, and forwarded their advice on how to use the peak flow meter and transfer data appropriately to Anna. Anna thought the information was useful and she was

able to measure her peak flow and transfer the data through the CareCompanion®, although at times data transfer still did not work properly:

Well, it was really frustrating at first, definitely for the first couple of weeks even, it was ...didn't work properly and took me a while to get used to it. (Anna)

Anna's father witnessed her frustration and as a family member, agreed:

I think initially there were definitely some technical problems that made it an annoyance, and so I think, I think not just for her, but we were all kind of frustrated that it was not working properly. (Anna's father)

During the first interview, Anna chose to work with the CareCompanion® at 7:30 in the morning. However, this was not convenient for her or her family during weekends and holidays. Anna explained that she was not able to send in data during some of the weekends and when she was not around at the time the CareCompanion® started beeping:

...and there were a couple of times when it went off at seven thirty on a Saturday morning....which is not very convenient...I didn't change my schedule but there were definitely lots of times when I just wasn't there....I was at the pool or something, in the morning. (Anna)

Anna thought the CareCompanion® was very easy and quick to use. It only took one minute for her to finish the whole process. She felt the beep was "a little bit annoying," although it was "something you can deal with." She suggested the CareCompanion® would need some changes with respect to its size and appearance to make it more appealing to teenage girls:

... it was pretty ugly so ...not many teenage girls like ugly things. Smaller...'cause if a teenage girl actually need to use [the CareCompanion®], it would probably have to be in their room and it's really awkward and big and clunky

and you don't even need most of that space you just need the screen and a peak flow meter, right? (Anna)

The same questions were asked everyday via the CareCompanion®. Because her asthma was stable and well controlled, Anna ended up answering the same questions with the same answers over and over again. Anna's father felt the same. He thought the questions presented on the screen should be personalized:

Well even just [change] the phrasing of them 'cause it's SO repetitive and you just get in to such a regular habit of pressing the same buttons over and over. (Anna)

...the idea of potentially asking some alternating sets of questions. Personalizing it, 'cause it is a computer, there's no reason why it couldn't say "Hi [Anna's name]".
(Anna's father)

Using Technology

Anna was not able to use the CareCompanion® until the technical problem with the telephone line was resolved. She used the CareCompanion® from November 1, 2004 to January 31, 2005.

According to the report generated by the software, Anna's overall response rates were 41.3% and 18.8% for clinical questions and peak flow measurement, respectively (Table3). Peak flow data were sent less often, because sometimes Anna still had problems transferring the data. Apart from relatively low response rate during weekends and in the days around Christmas and New Year's Eve, Anna's response rate was relatively steady with no apparent signs of declining usage over time.

Table 3. Anna's CareCompanion® Usage Data

	Total days	Days clinical data sent (*%)	Days lung function data sent (*%)
Month 1	30	14 (46.7%)	7 (23.3%)
Month 2	31	11 (35.5%)	5 (16.1%)
Month 3	31	13 (41.9%)	3 (15.8%)
Total	92	38 (41.3%)	15 (18.8%)

***Response Rate %=Days data sent/Total days**

During the second interview, Anna said she would not continue to use the CareCompanion® because she did not think it could benefit her asthma management. Her father was not sure whether Anna should continue to use the CareCompanion®, but he believed it would eventually be Anna's decision and he would support her as long as she managed her asthma properly:

It just didn't do that much for me. It didn't really ... it just didn't. I didn't mind using it but it wouldn't be something I would personally want to use. (Anna)

I think it would really come down to...first of all to her willingness to do it. From a parental perspective, possible...not really sure how to answer that definitively. If she, you know, had internalized some of that behaviour and does it without being prompted by a machine, then okay the, you know, goal accomplished. (Anna's father)

Technology and Personal Factors

Asthma management was not difficult for Anna even without the CareCompanion®. She was able to manage her asthma on her own, so being monitored by the respiratory therapist did not make her more confident in her asthma management. Anna's beliefs concerning the effects of engaging in certain actions related to asthma management did not change when she was using the CareCompanion®.

Technology and Environmental Factors

Anna's family shared some responsibility for using the technology during the 3 months.

Her sister and parents would wake her up in the morning if Anna did not hear the beep

first. All family members were involved in and affected by the process:

... if I wasn't up by seven thirty then my sister would come up to wake me up and... (Anna)

So I think that my observation about the process is that because it was in a sort of family area, and had, you know, sounds or noises that demanded attention, that it got other people in the family involved in the process. So if she [Anna] was upstairs in her room sleeping or listening to music with her head phones on or something like that, other people had to attend and go and get her to pay attention to it. So it definitely became a shared responsibility kind of thing... (Anna's father)

Winter (November to January) was not a bad asthma season for Anna. Both Anna and her father thought her asthma had been stable and well controlled during the 3 months. This was supported by the electronic data sent via CareCompanion®. According to the research protocol, the teens would only be contacted under an emergency situation. Therefore, Anna was not contacted by the respiratory therapist for her asthma management during the monitoring period. Nor did Anna and Anna's father expect to hear from the respiratory therapist about her asthma management. They did not think getting feedback from a health care professional was necessary for Anna:

...the peak flow information is first and foremost for [Anna's real name], not that she is looking to get someone calling her and saying "Oh it looks like your pattern is low" so.....no we weren't looking at it from an external feedback perspective. (Anna's father)

Technology and Behavioural Factors

Daily peak flow measurement helped Anna and her parents “gauge it (lung function) better,” but answering the CareCompanion® questions did not really make her more aware of her asthma:

I think the peak flow meter probably helped me gauge it a little bit better since I don't normally do a peak flow meter every day... I think I'm pretty aware of things and I don't really...pressing buttons and reading things don't really make me more aware of them(symptoms)... Peak flow would probably be the only difference. (Anna)

Taking medication was Anna's routine, and being reminded by the CareCompanion® everyday did not change anything for her:

Yeah, it [taking medication] is the first thing I do in the morning when I wake up and the last thing I do before I go to sleep. And it has always been like that. (Anna)

Case Summary for Anna

The case summary for Anna (Table 4) suggests that Anna was able to manage her asthma well, with or without the CareCompanion®. Anna believed that following her action plan was the best she could do to keep her asthma under control. She was confident and independent in her asthma self-management. Her asthma was generally stable and well controlled.

Although Anna experienced technical problems at the beginning, she found the CareCompanion® easy and quick to use later. However, other than knowing her lung functions better, Anna did not change her asthma management when using the CareCompanion®. The overall response rate to the CareCompanion was 41.3 % and even lower for the peak flow measurement (18.8%) due to the technical problems. Anna would

not continue to use the CareCompanion® because she did not think it was beneficial to her asthma management.

Table 4. Technology Effect Matrix (Anna)

Themes and Categories	Without the CareCompanion®	With the CareCompanion®	Researcher's Notes
*Technical Problems	N/A	"it was really frustrating at first...[peak flow meter] didn't work properly..."	
*Time Taken	N/A	One minute	
* Flexibility	N/A	"...there were definitely lots of time when I just wasn't there..." "...a couple of times it went off at 7:30 on a Saturday morning, which is not very convenient."	This was first labelled as "scheduling problem" but was grouped under "flexibility" later.
*Personalized Interaction	N/A	Questions should be personalized	
*Added Responsibility	N/A	--	
*Technology Aesthetics	N/A	"[should be] smaller...it's really awkward and big and clunky"	
Using Technology	N/A	Response rates: 41.3%/18.8% Would not continue to use the CareCompanion® because "It's not really necessary for me"	
Personal Factors 1. Self-Efficacy 2. Outcome Expectations	1. "I don't think it's too hard. Pretty straightforward" "I am pretty independent with that now" " It's hard to remember to take your medicine sometimes. Bring my ...with me all the time. Sometimes I forget it." 2. "[my action plan] is working really well for me" [my asthma] is really well controlled"	Beliefs about her asthma management capability and outcomes of certain actions did not change	The CareCompanion® did not change how Anna felt about asthma management. She was already confident in her asthma management without the CareCompanion®.
Environmental Factors 1. Medical Support 2. *Shared Responsibility	1. Once-a-year regular check at the asthma clinic 2. Family very supporting and encouraging	1. Anna did not perceive sending data to the RT as additional medical support, nor did she need that. 2. "...it definitely became a shared responsibility kind of thing..." (Anna's father)	.
Behavioural factors 1. Symptom Monitoring 2. Measuring PEF/FEV1 3. Taking Medication 4. Following Action Plan	1. "pretty aware of things" 2. Did not measure PEF/FEV1 regularly 3. "the 1 st thing I do in the morning when I wake up and the last thing I do before I go to sleep" 4. "I follow my action plan"	1. "pressing buttons and reading things don't really make me more aware of them" 2. "helped me gauge it better"/ "more aware of my breathing capacity" 3. Did not change 4. Did not change	Anna managed her asthma well without the CareCompanion®. Other than measuring peak flow every day, Anna did not see any changes in her asthma management.

*=emergent categories from data, i.e. not included in the template codes

N/A=Not Applicable

--= Not mentioned by interviewees

4.4.2 Case 2-Betty

Asthma Management Without Technology

Betty was a sixteen-year-old girl living with her mother and stepfather in Oktokos. Betty thought she had a busier schedule than most high school students. She worked part-time at McDonald's on some of the weekday evenings and visited her father every other weekend.

Betty had been diagnosed with asthma for more than 10 years. She felt not being able to breathe was "really not a great feeling":

...I hate it [asthma attack] – I mean, I have to go to the hospital and stuff, miss school – well I don't mind that (laughter). Yeah, well I always have like a lot of trouble and not being able to breathe and it's really not a great feeling to have ...it's difficult. (Betty)

Betty explained what bothered her most:

I think it's kind of limiting sometimes... I can't do a lot of the same activities as my friends or run as fast or as far as them. (Betty)

Betty received her written action plan more than six years ago. According to Betty's specialist, Betty took a high dose of Symbicort® (400mcg twice daily) regularly and did not have much room to increase it. She would have to take prednisone (oral corticosteroid) if her symptoms worsened. Although her action plan was based on symptoms, her asthma specialist recommended that she should monitor her peak flow when her asthma was not stable. She used to measure her peak flow for quite a while but then she thought she "did not need to do that and stopped."

Betty was aware of her action plan. However, she did not believe following her action plan would actually help her control her asthma in the way she would like to. She thought she knew what to do to manage her asthma. She monitored her symptoms, although less frequently than she should have done. She would take her reliever (or rescue) medication when she was not feeling good.

I almost feel like I'm not progressing, like I'm not going anywhere, like with just keep taking my medicine, 'cause I don't see any change happening... (Betty)

I'm usually pretty good [at monitoring my symptoms] ... almost, now they've become kind of regular so not as much as maybe I should be ... but I know when I'm not feeling good to take more medicine. We have an asthma plan so I know when I start to feel... well if I'm in situation and I'm having trouble I know to take my rescue medication. I know when I'm not feeling up to par to increase the doses and ...if that's not working then I know what I should do ...and maybe going into the emerge [emergency]. (Betty)

When was asked about the difficult part of her asthma management, Betty said that remembering to take her medication every day was difficult, especially the preventer medication, i.e. Symbicort®:

I guess always remembering to take my medicine [was difficult] 'cause I know sometimes I forget. ...rescue [medication] and I'd get that like a lot. So that's like something I never forget to take, 'cause I always have that, but sometimes...my regular inhaler [Symbicort®] I forget to take. (Betty)

Betty's specialist thought she was a "mystery in terms of the severity of her asthma". He thought her asthma was not well controlled and Betty felt the same. She thought her asthma was worse than before. She used to play soccer in elementary school, but now she found it more difficult doing that. On the other hand, waking up during the night or taking rescue medicine was "a norm" for Betty:

I notice ...the questions they can ask to see if your asthma is controlled and like, some of them are if you wake up at night...or if you need to take your inhaler more...so if you were looking at that, I wouldn't say my asthma is controlled, because a lot of those questions I can answer "Yes I have to wake up in the night to take my inhaler" or "Yes, it prevented me from doing activities that I think I should be able to do." But it is almost kind of like a norm for me. (Betty)

Betty's parents decided to let her take more responsibility in her asthma management when she was in grade 3. At the same time, her mother always reminded her to bring her medication with her and asked her to increase her medication when she was not feeling well. Betty also received support from the Asthma Clinic and her family physician. She went to the Asthma Clinic for medical review about twice a year, where she discussed with her asthma specialist about her asthma management.

Asthma Management With Technology

Usability of Technology

Betty's Peak Expiratory Flow (PEF) was usually quite low. Although the respiratory therapist reset the warning values of the peak flow meter at the time of the first interview, Betty was still not able to get a peak flow reading without an exclamation mark. After she discussed her blowing technique on the phone with the respiratory therapist and read the instructions sent by the manufacturer, Betty tried for another few weeks and gave up.

Well the first couple of weeks, I'll say the first month, like, I'm trying and then I thought "No there's no way I'm going to blow over." So I stopped. (Betty)

The CareCompanion® was easy and quick to work with, but Betty also noted:

There's a couple of times when it was going off at the wrong time, so that's just more of a technical problem... (Betty)

Betty had a busy schedule. Although it only took her about two minutes everyday and it did not bother her most time, at times she found the CareCompanion® a “nuisance” when she “did not have time to do it” or when she “would like to forget it.” She thought it was partly because she chose the wrong time (7:00 in the morning) to do it. Both Betty and her mother hoped they could choose the time when the CareCompanion® went off. Although they could have asked the respiratory therapist to change the time anytime during the 3 months, they did not bother to call her.

There was probably a couple of weeks, out of the three months, there was probably two weeks, like sporadically, but all together it was probably two weeks when I’d like forget it or don’t have time to do it, it seemed like a nuisance.
(Betty)

... the timing, like for the...the timing should be synchronized properly. If we requested that it went off at seven thirty Monday to Friday and then weekends at night time...
(Betty’s mother)

Using the CareCompanion® was an “added responsibility” for Betty. She was concerned whether using the CareCompanion® would fit into her busy life.

...but to have this machine now, this is an added responsibility ... it hasn’t always worked out for her to be around to put the information in. But for her to add it on top of her daily ritual now...
(Betty’s mother)

... for people, I guess, that are really, really busy ‘cause it is kind of...it can be kind of inconvenient at times...
(Betty)

Betty suggested the CareCompanion® could be “more compact.” The CareCompanion® would keep beeping until the screen was pressed. This became “annoying” to Betty sometimes because her mother would “bang my room and yelled that the machine was going off.”

Using Technology

Betty was told to use the CareCompanion® from November 1, 2004 to January 31, 2005. However, she did not send any data after January 12, 2005. Betty was never able to send any peak flow data. The overall response rate for clinical questions was 48.9 % (Table 5). Apart from relatively low response rate during weekends, Betty's response rate was particularly low for month 3.

Table 5. Betty's CareCompanion® Usage Data

	Total days	Days symptom data sent (%)
Month 1	30	18 (60.0%)
Month 2	31	23 (74.2%)
Month 3	31	4 (13.3 %)
Total	92	45 (48.9%)

***Response Rate %=Days data sent/Total days**

At the end of the second interview, Betty said she would continue using the CareCompanion® if she could, but “maybe not everyday.” She thought “it was convenient to use” and “knowing that someone was looking at the results” was a comfort to her, although she did not know if there would be any benefit to her asthma management. Betty's mother believed it would be up to Betty to decide whether she would continue using the technology, although she did not feel Betty was “benefiting by doing the exercise.”

Technology and Personal Factors

The questions asked via the CareCompanion® were not personalized and would not change according to one's answers. Betty found her asthma had a "consistent pattern," which meant she often answered the questions with the same answers. It was frustrating doing so everyday and knowing her asthma status did not progress.

"How many times did you take it, your rescue medicine?"
and "did it interfere with your life" or whatever...so that
kind of really frustrated me 'cause you know, I kept
answering the same... knowing that it's not changing or
anything just kind of frustrated me... (Betty)

Betty's beliefs about the outcomes of taking specific asthma management actions did not change with the CareCompanion®. Betty got sick when she was using the CareCompanion® and adjusted her medication according to her action plan, but the action plan did not work:

Well, I actually had to go to the doctor and be put on
prescription medicine...so when I first got sick I tried
increasing my inhaler according to the plan, but it wasn't
working... (Betty)

Knowing "somebody was monitoring the results" made Betty more comfortable about her asthma management. Betty's mother also mentioned getting feedback from the health care provider if things went wrong would reassure them that everything was fine.

Technology and Environmental Factors

Data monitoring by the respiratory therapist was considered additional medical support for Betty and her family. Although Betty was not contacted over the three months, she would have been if she experienced an emergency situation.

Betty's mother shared some responsibility for Betty's asthma management using the CareCompanion®. She would remind Betty to use the CareCompanion® if Betty did not

hear the beep first. Sometimes the machine went off at a time when Betty was not at home, and Betty's mother had to press the screen to stop the beep.

Technology and Behavioural Factors

The CareCompanion® made Betty more alert to changes in her asthma symptoms:

... but I find that when I got sick it helped a lot ... 'cause I knew that I was getting worse ... (Betty)

Betty's mother was disappointed that peak flow meter did not work. She had expected that Betty would monitor her peak flow and she would get some indication of Betty's health from the peak flow readings.

Betty usually took her Symbicort® first thing in the morning and before she went to bed.

She did not think that the CareCompanion® helped her take Symbicort® more regularly.

However, it reminded her to take her reliever medication when she needed to:

...well usually when I do take it[medicine], I'll take before the machine goes off, like I'll take it right when I wake up, so when it asked me I'd go "oh I should take my medicine" and then end up doing something else, I'd already forgotten.... (Betty)

...the CareCompanion® usually said, like how many times you should take your rescue [reliever medication] and I'd get that like a lot. So that's like something I never forget to take, 'cause I always have that, but sometimes...like my regular inhaler... (Betty)

Betty thought her asthma had not been well controlled over the 3 months. This was supported by the data sent via the CareCompanion®. Of the 45 days when data were sent, limited physical activities were reported 13 times, waking up during the night were reported 8 times, and school absenteeism twice.

Case Summary for Betty

In summary (Table 6), Betty was aware of her asthma action plan but did not believe following the action plan would help control her asthma. She did not monitor her symptoms as suggested by her physician and sometimes forgot to take her medication. Her asthma was not well controlled.

Betty had technical problems with the peak flow meter and was not able to send any peak flow data. Although the CareCompanion® was easy and quick to use, it sometimes did not fit into her busy schedule very well. Her overall response rate in using the CareCompanion® was 48.9%, with a decline over time. Betty felt more confident about her asthma management because her data were monitored by the respiratory therapist. Managing asthma with the CareCompanion® also helped her be more alert to worsening signs of asthma and take reliever medication more often as needed. Betty would like to continue using the CareCompanion® even though she was not sure if she would benefit from using it.

Table 6. Technology Effect Matrix (Betty)

Themes and Categories	Without the CareCompanion®	With the CareCompanion®	Researcher's Notes
*Technical Problems	N/A	"it was really frustrating at first...[peak flow meter] didn't work properly..."	
*Time Taken	N/A	Two minutes	
*Flexibility	N/A	Did not like the time she originally chose. Hoped the schedule could be changed as requested.	
*Personalized Interaction	N/A	Betty had to answer the same questions with the same answers most of the time	
* Added Responsibility	N/A	One more thing to add to her busy schedule	
*Technology Aesthetics	N/A	"It's kind of big. I think it could be like a bit more compact" "that [the beep] was kind of annoying"	
Using Technology	N/A	Response rates: 48.9%/0% Would continue to use the CareCompanion® because it was convenient and "knowing somebody was looking at the results" was good.	
Personal Factors 1. Self-Efficacy 2. Outcome Expectation	1. "I guess always like remembering to take my medicine [is difficult] 'cause I know sometimes I forget." 2. Did not think following action plan would help asthma control. "I don't see any change happening."	1. Being monitored by the respiratory therapist made her more confident in her asthma management. 2. Did not change	Using technology also added frustration because she realized her asthma did not progress and no specific advice was provided. This was related to "personalized interaction", usability of the technology.
Environmental Factors 1. Access to Medical Advice 2. *Shared Responsibility	1. Twice-a-year regular check at the asthma clinic 2. Family supportive in asthma management	1. Being monitored and getting feedback from the health care professional provided extra support. 2. Mom had to wake her up if Betty was not around when the CareCompanion® went off.	
Behavioural factors 1. Symptom Monitoring 2. Measuring PEF/FEV1 3. Taking Medication 4. Following Action Plan	1. "...usually pretty good, ehm almost, now they've become kind of regular so not as much as maybe I should be..." 2. Did not measure PEF/FEV1 regularly 3. 4. Usually followed her action plan	1. "but I find that when I got sick it helped a lot. ...'cause I knew that I was getting worse" 2. Peak flow did not work 3. "...like rescue and I'd get that like a lot. So that's like something I never forget to take, 'cause I always have that, but sometimes...like my regular inhaler I forget to take" 4. Did not change	It helped Betty be more aware of worsening signs of asthma. She took reliever medication more often as needed but not the preventer medication.

*=emergent categories from data, i.e. not included in the template codes

N/A=Not Applicable

--=Not mentioned by interviewees

4.4.3 Case 3-Liz

Asthma Management Without Technology

Liz was a fifteen-year-old high school girl living with both of her parents and her sister.

Liz had been diagnosed with asthma since she was about two years old. She described asthma as “not bad” because:

You have to take time out to take your medicine and if you do it all right you should be okay...it doesn't severely affect my life, it's just when I have to do the odd things, like when I'm around a cat ...gross....but it's just kind of like a small annoyance as I would say. Like a cold that never goes away. (Liz)

At the time of the first interview, Liz took Symbicort® 400mcg twice daily, Singulair® 10mg once daily, and Bricanyl® as needed. Liz was not aware of her written action plan at the time of her first interview. Managing asthma meant “taking meds and avoiding cats” for her. She would increase her inhaled corticosteroids according to her physician's advice if her symptoms got worse. She knew symptoms like sneezing or feeling tight were signs to adjust her medication. When Liz was much younger, her mother used to ask her to measure her peak flow when she was really sick.

Managing asthma was not difficult in general, but remembering to take her medication was hard sometimes, as described during her first interview:

It depends...at one point in time I didn't take my medication for a week and then, that was difficult to breathe...[because]I didn't think I was sick...you'd rush in the morning and then you'd be out for a long time and then you'd come home and you wouldn't have time then and you'd be so tired you'd just go to bed and you'd die and then you'd wake up “Oh maybe I should take my medicine” and then you'd have to run again and you'd be at school going “Uh”. Took a lot of Ventolin [short acting β -2 receptor antagonists] during that week. (Liz)

Liz had quite severe asthma, but both Liz and her asthma specialist thought her asthma had been well controlled for quite long. Her last asthma attack was many years ago, when she was about six years old.

Liz goes to the Asthma Clinic for a regular medical check every six months. Every time she went there, her asthma specialist would “answer their questions and listen to their concerns,” and “do things like pulmonary function tests ... so let her know how things were going generally.”

Liz’s parents handed over the responsibility for managing asthma to Liz when her asthma seemed to be better controlled years ago. Liz was responsible for her daily asthma management; however, her parents were still there for her if she ran into problems.

They usually don’t do that much. They pay for the medication and then I just take care of myself.

(Liz)

Ehm, I buy the medication (laughter). I think we’re here, you know, so that if she does run into problems she knows that she’s going to let us know... (Liz’s mother)

Asthma Management With Technology

Usability of Technology

Liz thought trying to figure out how to blow the peak flow meter appropriately was “really neat.” She was able to measure her peak flow daily. Despite her efforts of trying to send her peak flow data through the CareCompanion®, she was never able to transfer the data due to technical problems.

Liz thought the CareCompanion® was easy and quick to use. It took one or two minutes each time. However, as described by her mother, it was still “one more thing to do.” She

chose to work with the CareCompanion® at 4:30 in the afternoon after school. She felt the timing always worked well for her.

Liz felt that the beep of the CareCompanion® “did get a little in the way after a while if you didn’t catch it.” But it did not bother her too much because “as soon as you pressed the button it would stop.” When Liz was asked how to make it more attractive to teenagers, she said maybe some stickers would be nice.

Using Technology

Liz used the CareCompanion® from November 5, 2004 to February 4, 2005. Liz was very consistent in transferring her clinical data (Table 7). Although she was not able to transfer the peak flow data through the CareCompanion®, she recorded her daily PEF/FEV1 data on a piece of paper.

Table 7. Liz’s CareCompanion® Usage Data

	Total days	Days symptom data sent (%)
Month 1	30	29 (96.7%)
Month 2	31	30 (96.8%)
Month 3	31	30 (96.8%)
Total	92	89 (96.7%)

***Response Rate %=Days data sent/Total days**

Liz would like to continue to use the CareCompanion® if she could:

Why not? Probably ’cause it makes you a little more aware of where you are with your asthma. Keeps you healthier.
(Liz)

Her mother was not sure if the CareCompanion® would be beneficial to Liz. She thought that the technology was more for those people who had less access to the health care facilities.

Technology and Personal Factors

Liz thought sending data to the respiratory therapist was “like there’s a camera watching you.” She did not expect to receive any feedback from the respiratory therapist. Liz’s mother thought being monitored by the respiratory therapist could provide the family more confidence in asthma management if they had known that they would be contacted when Liz ran into a problem.

Technology and Environmental Factors

The CareCompanion® was set up in the living room downstairs. Liz’s parents and sister would call her downstairs Liz if she was upstairs and did not hear the beep. Sometimes they had to press the CareCompanion® to stop the beeping if Liz was not at home. Being monitored everyday provided more medical support. However, Liz’s mother thought it was not a concern for them because Liz’s asthma was well controlled and they had easy access to various health care facilities, such as the Asthma Clinic and Liz’s family physician. She thought the CareCompanion® was more for those people who had less access to the health care system.

...I don’t know. [the CareCompanion®] was an interesting thing... I’m not sure it’s all that beneficial for us “cause we’re so close to go to the emergency care ...

(Liz’s mother)

Technology and Behavioural Factors

Measuring her peak flow and answering the questions daily made Liz more aware of her disease. Liz and her mother agreed it also reminded Liz to take her medication or to modify her medication when necessary:

Like if it [PEF] was once in the two hundreds or down in the red zone I would know that I should take a bit more medication...

(Liz)

Well I'm sure it would be a really good reminder, you know, so I would think it might be you missed one but you probably wouldn't miss two, because the machine would kick in and then you'd be "Oh yeah". (Liz's mother)

Case Summary for Liz

In summary (Table 8), Liz's asthma was better controlled as she grew up. She was not aware of a written action plan but she followed the advice provided by her asthma specialist and knew what to do if she noticed signs of worsening asthma. Liz thought remembering to take medication was difficult sometimes.

She thought the CareCompanion® was easy and quick to use. The time she chose to work with the CareCompanion® was convenient for her. She monitored her PEF/FEV1 everyday over the 3 months although she was not able to transfer the data. Liz used the CareCompanion® consistently over the 3 months, with an overall response rate of 96.7 %. The CareCompanion® made her more aware of her asthma and reminded her to take her medication or to modify her medication as needed. Liz would like to continue to use the CareCompanion® because she thought it made her more aware of her asthma and could make her healthier.

Table 8. Technology Effect Matrix (Liz)

Themes and Categories	Without the CareCompanion®	With the CareCompanion®	Researcher's Notes
*Technical Problems	N/A	Had problems with peak flow meter.	
*Time Taken	N/A	One or two minutes	
*Flexibility	N/A	--	CC fit into Liz's schedule well. She was happy with doing it everyday at 4:30 Pm. She didn't need to reschedule or unplug the unit very often.
* Personalized Interaction	N/A	--	
*Added Responsibility	N/A	"...one more thing to do"	
*Technology Aesthetics	N/A	"put some stickers on it"	
Using Technology	N/A	Response rates: 96.7%/0% Wanted to continue to use it because it made her more aware of her asthma.	
Personal Factors 1. Self-Efficacy 2. Outcome Expectation	1. Not difficult in general, although remembering to take medicine everyday was not easy 2. Taking medication and avoiding cats are important to achieve asthma control	1. Liz did not expect to hear from the RT; her mother thought it would provide families with more confidence although it was not important for Liz. 2. Did not change	
Environmental Factors 1. Medical Support 2. *Shared Responsibility	1. Twice-a-year regular check at the asthma clinic 2. Family supportive in asthma management.	1. Data monitoring is considered additional support but not important for Liz because she had easy access to health care facilities 2. Other people in the house were involved.	
Behavioural factors 1. Symptom Monitoring 2. Measuring PEF/FEV1 3. Taking Medication 4. Following Action Plan	1. "if I'm sneezing and feel like I'm getting really sick then I'll take something" 2. Did not measure regularly 3. Forgot to take medicine sometimes. 4. Would change medication according to her doctor's advice.	1. "...a little more aware of where you were with your asthma and how well you were doing" 2. Measured PEF regularly 3. Helped her take medication. 4. Indirectly affected how she followed her action plan by the above influences.	

*=emergent categories from data, i.e. not included in the template codes

N/A=Not Applicable

--=Not mentioned by interviewees

4.4.4 Case 4-Jane

Asthma Management Without Technology

Jane was 14 years old when she participated in the study. She lived with both her parents and two younger siblings. Her father has exercise-induced asthma.

Jane was diagnosed with asthma when she was very young and it felt like she had “had it forever.” Jane did not like the fact that she was not able to do sports as much as she would like to due to asthma. However asthma was not “a big deal” for her most of the time. She spoke about her understanding of asthma:

Oh your lungs like, you close up and ...[you have] some kind of tube in your throat or something, like it gets smaller and tighter. Not much (laughter). (Jane)

Jane thought managing asthma was about “taking puffers.” She believed as long as she took her medication regularly according to the asthma specialist, she would be able to control her asthma well. Jane took Symbicort® (ICS) 400mcg once daily and Bricanyl® (Short-acting β_2 -agonist) on an “as needed” basis. Although Jane did not have a written asthma action plan during the first interview, she would do what her asthma specialist had told her if there were signs of worsening asthma control:

Well, when my asthma gets worse I’m supposed to take, like right now I take two puffs[Symbicort®, ICS] once a day and if it get worse I’m supposed to take two puffs [Symbicort®, ICS] twice a day. (Jane)

Her mother noted Jane was very independent in her asthma management:

I pay for the drugs and I go get them (laughter). She’s the one who knows whether she needs more or whatever, like sometimes she’ll ask me and I’ll say “I don’t know – you figure it out yourself.” ‘cause I mean it’s how she breathes and all this. (Jane’s mother)

When was asked what was difficult in her asthma management, Jane said: “having to take my puffer all the time.” Although she usually remembered to take her medication, it was not unusual to lose her blue (Bricanyl®) puffers:

I don't forget [to take my medication] very often. I just...I have a lot of blue puffers 'cause I lose them a lot 'cause I bring it to school and then leave it at school and then I bring another one to school ... (Jane)

Jane's asthma was well controlled and her last asthma attack occurred when she was in grade four. Her asthma specialist noted that Jane's ICS dosage was “on the moderate to low side.” Her activity tolerance was good in general, except that she had to take Bricanyl® when she was playing sports, particularly in the fall.

Jane reported that most of her knowledge about asthma came from the Asthma Clinic. She goes to the Asthma Clinic every six months for a regular check-up and discusses her asthma management with the asthma specialist.

Managing Asthma With Technology

Usability of Technology

Jane was able to blow the peak flow meter appropriately. However, every time she put the meter in the cradle to transfer the data, the CareCompanion® said “measurement failed.” Jane discussed this with the respiratory therapist and was told not to continue after a few weeks.

The CareCompanion® started beeping at 7:30 in the morning, even during the weekend and holidays. Although Jane usually only spent 2 or 3 minutes working with the CareCompanion®, sometimes she would rather not do it.

...it was sort of like you got used to the schedule after a while and it was like a normal every morning thing, but every once in a while I'd like forget and it was annoying

when it woke me up early in the morning. (Jane)

Jane usually unplugged the CareCompanion® if she knew she would be away, but thought that was not very convenient because she might forget to plug it back in. She hoped there could be a more flexible and convenient way to do this. Her mom also talked about the flexibility in using the CareCompanion®.

I don't know if there would be a way to do this, but like if ... instead of having to unplug it you could just ...I don't know.... if you could just be like "Okay I'm going to be away for two days"... do something so you don't have to re-plug it when you got back 'cause I'd always forget to re-plug it. (Jane)

I don't think it's flexible enough. We had to call somebody, let's say for changing the time ...it would be nice if that could be controllable by us... 'okay, gone to sleep over' ... "Cancel the service right now" or...if it was... maybe portable... [If] she's going somewhere for two weeks...she takes it. (Jane's mother)

The CareCompanion® did not take too much room but was still "kind of bulky" and "there were a lot of long cords" that "sort of got in the way." Jane did not mind the beep, except that it was not loud enough for her sometimes.

Using Technology

Jane used the CareCompanion® consistently over 3 months, from November 9, 2004 to February 8, 2005 (Table 9), although she was unable to send her peak flow data.

Table 9. Jane's CareCompanion® Usage Data

	Total days	Days symptom data sent (%)
Month 1	30	28 (93.3%)
Month 2	31	30 (96.8%)
Month 3	31	28 (90.3%)
Total	92	86 (93.5%)

* **Response Rate % = Days data sent / Total days**

Jane would not continue to use the CareCompanion® because she thought using it everyday was “useless” to her and made her asthma “more of a big deal.” Her mother agreed that Jane did not need the CareCompanion® because she was able to manage her asthma well on her own.

Technology and Personal Factors

Jane thought it was nice that somebody knew how she was feeling because her data were monitored by the respiratory therapist. By checking the data everyday, the respiratory therapist would know if, by any chance, Jane was getting really sick. Jane felt more confident to manage her asthma in case of an emergency situation. Jane's mother commented:

I mean it didn't happen that we needed it that way, but if it were a matter of her asthma being out of control ...I guess somebody's like seeing it, overseeing it as opposed to always go to the doctor and... getting the results once every year type of thing...if somebody was worried about their asthma or if it wasn't as controlled then I think that gives them ...a more confident kind of approach but, it's not something that she [Jane] had trouble with.

(Jane's mother)

Technology and Environmental Factors

It was quite often that Jane's family members had to remind her to work with the CareCompanion® when it started beeping:

The beep wasn't loud enough for me but that's just because I'm not a morning person...I was eating breakfast but I was pretty much still asleep, so I couldn't hear it but my parents could.
(Jane)

The CareCompanion® provided additional medical support to the family. However, Jane's mother did not think they needed this. If Jane did not feel good, they would just go see their doctor.

... I don't think she needs it. As far as... being able to control and I mean, if really she fell off the chart I think we'd just go to the doctor and, even our GP, and he could, sometime, like right now, she just had a cold, and ...so she just increased her medication a little bit but....I think she's doing fine the way she's managing it.(Jane's mother)

Technology and Behavioural Factors

Jane was more aware of her asthma during the 3 months:

...so I had to actually think about [my symptoms] instead of just like "Hmmm I'm feeling a little wheezy today"
(Jane)

Jane thought she had always been good at taking her medication. Although sometimes the CareCompanion® reminded her to take her medication right away, most of the time she had taken her medicine in the morning before the CareCompanion® activated. Jane managed her asthma as advised by her asthma specialist. Using the CareCompanion® did not change what she would do otherwise:

'Cause it's ... if I need to take it...I know I need to...I'd just have taken it upon myself anyways, but it...yeah, if I was forgetful it would have helped me ...no...it would just like...it would just remind me to...no it would jut make me

think of my symptoms but it wouldn't help me [to actually do anything].
(Jane)

Jane had to use Bricanyl® when she caught a cold during the 3 months. Other than that, her asthma was well controlled. Her clinical data sent over the CareCompanion® indicated she had been limited in her physical activities for 3 days. She also reported using Bricanyl once a day for 6 days.

Case Summary for Jane

In summary (Table 10), Jane thought she managed her asthma well with or without the CareCompanion®. Managing asthma was about “taking puffs,” and generally was not difficult for Jane. Jane did not have a written action plan, but she followed her doctor’s advice about her asthma management.

She thought the CareCompanion® was easy and quick to use, although sometimes she did not feel like waking up early in the morning to do this. She sent data consistently over the 3 months, with an overall response rate of 93.5%. Using the CareCompanion® made her think about how she was doing but did not change what she would do to manage her asthma. Although Jane and her mother felt it was nice to have Jane’s data monitored by an expert, they did not think Jane needed it, because her asthma was already well controlled and they had easy access to health care facilities. Jane would not continue using the CareCompanion® because it added one more thing to do and it did not benefit her asthma management.

Table 10. Technology Effect Matrix (Jane)

Analytical Categories	Without the CareCompanion®	With the CareCompanion®	Researcher's Notes
*Technical Problems	N/A	Had problems with PFM. "at times she found it frustrating because it would give her the signal that either it didn't read the message or something that she wasn't sure" (mother)	
*Time Taken	N/A	Two minutes	
*Flexibility	N/A	Could change schedules and choose when to cancel the sessions; portable device	
*Personalized Interaction	N/A	--	
*Added Responsibility	N/A	The CareCompanion® made her asthma more of a big deal because she had something to do everyday.	
*Technology Aesthetics	N/A	"it didn't take much room....but still kind of bulky"	
Using Technology	N/A	Response rates: 96.6%/0% Would not continue to use the CareCompanion® because it was "useless" to her.	
Personal Factors 1. Self-Efficacy 2. Outcome Expectations	1. Managing asthma was not difficult although remembering to take medication everyday was not easy. 2. Taking puffers are important. Believed what she was doing with asthma management was fine	1. Being monitored gave her and her family reassurance in case of emergency situation. 2. Did not change	
Environmental Factors 1. Medical Support 2. *Shared Responsibility	1. Twice-a-year regular check at the asthma clinic 2. Family supportive in asthma management	1. Additional support provided by the CareCompanion, but might not be necessary for Jane. 2. Other people in the house had to remind her to go get the CareCompanion®	
Behavioural factors 1. Symptom Monitoring 2. Measuring PEF/FEV1 3. Taking Medication 4. Following Action Plan	1. Knew when her "asthma gets worse" 2. Did not measure PEF/FEV1 regularly 3. Did not forget to take medicine. 4. Followed advice given by her specialist.	1. "I had to actually think about how I was, you know." 2. Peak flow did not work 3. Reminded her to take her medication sometimes but most of the time she took her medication before working with the CareCompanion®. 4. "if I need to take it, like I know I need to, ..., I 'd just have taken it upon myself anyways"	Jane didn't forget to take her medicine and knew what to do upon herself. The CareCompanion® did not make any difference other than making her thinking more of her symptoms.

*=emergent categories from data, i.e. not included in the template codes

N/A=Not Applicable

--=Not mentioned by interviewee

4.4.5 Case 5-Rebecca

Asthma Management without Technology

Rebecca was a 16- year-old girl living with her parents and two younger siblings at the time of her initial interview in November, 2004. The initial interviews with Rebecca and her mother were conducted at her parents' house. When Rebecca turned 17 in January 2005, she moved out of the house to live with her boyfriend. The researcher met Rebecca in a small cafeteria close to her high school for the second interview in February, 2005. There was tension at the time of the second interview, when the researcher mentioned her mother. A few days later, the researcher called Rebecca's mother and completed a telephone interview. This big change in Rebecca's family made her a unique case in the study.

Rebecca had been diagnosed with asthma since she was about six years old and her asthma was well controlled. One thing that bothered her was physical activity restriction due to asthma:

Just like when it [asthma] stops me from doing the stuff
that I like to do, like sports. (Rebecca)

Rebecca was aware of her written action plan at the time of the first interview. According to her action plan, the most important part of her treatment was to “avoid environmental triggers.” However, Rebecca's parents were not able to convince her to get rid of the stuffed animals in her bedroom, which might trigger her asthma. To prevent dust mites as a possible asthma trigger for Rebecca, her mother vacuumed her bedroom at least once a week. She also regularly washed Rebecca's sheets, blankets, and stuffed animals. During the study period, Rebecca took Advair® (ICS and long-acting β_2 -agonist, preventer or controller) 250mcg once daily, Singulair® 10mg once daily, and Bricanyl®

as needed. She did not always remember to monitor her symptoms and take medication according to the action plan, which was with her parents at the time of the first interview.

Both her mother and her boyfriend reminded her quite often.

My action plan is with my mom and the doctors...if I don't remember it [action plan] my mom will like...remind me... yeah, I forgot a lot. My mom and my boyfriend always have to remind me [to take medication] (laughter).

(Rebecca)

At the time of the first interview, Rebecca seemed to be quite dependent on her parents for asthma management. Her specialist had the same impression about Rebecca.

... she [Rebecca]'s grown up somewhat more recently but she was always somewhat infantile... her mother's on her case all the time... difficulties have been in transferring frankly the management of asthma from her mother to her [Rebecca] ...she needs to be assertive with herself as well to take control and make decisions.

(Rebecca's asthma specialist)

Rebecca also received support from the Asthma Clinic. During the first interview, Rebecca said she went to the Asthma Clinic twice every year. Every time her asthma specialist would review her asthma status and action plan. The asthma specialist thought that the action plan would help Rebecca make decisions about her asthma management.

Asthma Management With Technology

Usability of Technology

Rebecca was not able to transfer the peak flow data through the CareCompanion® although sometimes she was able to blow the peak flow meter appropriately. Rebecca described this as an annoying experience: "I always had the exclamation mark and that was annoying ...I wasn't sure if I had done it right or wrong."

The CareCompanion® started beeping at 6:30 in the morning, after Rebecca's alarm clock went off. Rebecca thought it was very hard to wake up early every day. She thought that she should have scheduled it later than 6:30. Although she knew she could contact the respiratory therapist to change the schedule, she did not bother to call her.

Well it was like, hard waking up to the beeping every single day ...I have my alarm set so I'd have music and then it would be beeping for like five minutes later ...
Argggg ... (Rebecca)

The CareCompanion® was easy and quick to work with. It took Rebecca about 2 minutes to answer all the questions. On the other hand, using the CareCompanion® everyday was still an added responsibility. One had to be very involved and committed to do it, as Rebecca explained:

...sometimes it just got to be a pain in the butt. Just like trying to do everything over and over again. (Rebecca)

Overall, Rebecca thought the CareCompanion® was too big and the beeping was very annoying:

Man! It's big... It's just the beeping that was annoying...
make the sound of the beeping more pleasant...
(Rebecca)

Using Technology

Rebecca started using the CareCompanion® on November 8, 2004 (Table 11). She was not able to send her peak flow data due to the technical problems, however sent in clinical data quite consistently for the first month (83.3%). Rebecca stayed with her friends more often in December and the response rate declined. She moved out of her parents' house in January and did not finish her 3-month monitoring.

Table 11. Rebecca's CareCompanion® Usage Data

	Total days	Days symptom data sent (* %)
Month 1	30	25 (83.3%)
Month 2	31	3 (9.7%)
Month 3 (dropped out)	31	0
Total	92	28 (30.4%)

* **Response Rate % = Days data sent/Total days**

Rebecca did not know if she wanted to continue using the CareCompanion® on a daily basis. Rebecca's mother thought it was a good idea to have her asthma monitored by an expert. But she also believed that it would eventually be Rebecca's decision.

Yeah, if I could I think I would, because, like I say, if they run into trouble it's monitored and you could let them know "Start increasing medication", so I think it's a good idea, but whether she would or not, I don't know.

(Rebecca's mother)

Technology and Personal Factors

Rebecca thought using the CareCompanion "helped a lot" in her asthma management because it provided her with an option that would "either help you or you could ignore it." Rebecca was very dependent on her parents for her asthma management. She often forgot to take her medication and needed her parents and boyfriend to remind her. During the time she was using the CareCompanion®, Rebecca's parents did not help her with her asthma management as they used to. The CareCompanion® provided Rebecca with more confidence in managing her asthma by herself.

Technology and Environmental Factors

The CareCompanion® was set up in Rebecca’s bedroom upstairs and she would unplug it if she went to her friend’s house for a few days. Rebecca was planning to move out while she was using the CareCompanion®. She wanted to depend less on her parents, including her asthma management. During the second interview, when she was asked about the role of her mother in her asthma management, her response differed significantly from her first interview. Rebecca did not think her family, including her mother, did anything in her asthma management when she was using the CareCompanion®.

Rebecca’s mother agreed that she was not aware of what Rebecca was doing with the CareCompanion® because Rebecca kept her door closed and was not always home.

...because the machine was in her room and she always has the door closed and so I wouldn’t know. In the last month [I did] not really [do] anything [in her asthma management]. [Her asthma management with the CareCompanion®] doesn’t really have anything to do with me, because, like I said, it was all up to her... and it was in her room and it didn’t affect the [telephone] line...

(Rebecca’s mother)

Rebecca felt being monitored by the respiratory therapist “was interesting.” Her mother thought using the CareCompanion® was “a good idea because if anybody runs into trouble, you’ve got somebody that can come back to you and let you know.”

Technology and Behavioural Factors

Rebecca thought the CareCompanion® “helped a lot” in her asthma management and it made her more aware of how well her asthma was controlled. She took her medication more regularly without her parents reminding her.

It really helped. ‘Cause... it asks you if you slept, like woke up at night and if you took, like some of your puffer.

Well, it helped me like take my medications more often. I used to like forget a lot... (Rebecca)

Although the CareCompanion® asked questions about following her action plan, Rebecca did not think that helped her manage her asthma differently because she “didn’t really think about it.”

Case Summary for Rebecca

In summary (Table 12), Rebecca’s parents used to take charge of her asthma management, but this changed over time. She wanted to take control of, and make decision on her asthma management.

The CareCompanion® helped Rebecca be more aware of her asthma as well as take her medication more regularly without being reminded by her parents. Rebecca used the CareCompanion® consistently for the first month, with a response rate of 83.3%. Due to her family situation, Rebecca rarely used the CareCompanion® in December and did not send any data in January. She did not know if she wanted to continue using the CareCompanion® on a daily basis because it was sometimes “a pain in the butt” to wake up early in the morning and answer all the questions.

Table 12. Technology Effect Matrix (Rebecca)

Themes and Categories	Without the CareCompanion®	With the CareCompanion®	Researcher's Notes
*Technical Problems	N/A	Had problems with peak flow meter.	
*Time Taken	N/A	Two minutes	
*Flexibility	N/A	"I should have gotten it a little later"	
*Personalized Interaction	N/A	--	Although this was not mentioned in her interview, personalized interaction might help Rebecca follow her action plan better if more specific actions were provided.
*Added responsibility	N/A	"a pain in the butt. Just like trying to do everything over and over again"	
*Technology Aesthetics	N/A	Too big. Annoying beeping.	
Using Technology	N/A	Response rates: 30.8%/0% Didn't know if she wanted to use it everyday because it could be a pain in the butt to do the same thing over and over again.	
Personal Factors 1. Self-Efficacy 2. Outcome Expectation	1. Felt hard to remember to take medication and follow her action plan 2. Didn't think certain actions would lead to better asthma control (e.g. avoiding triggers)	1. Liked the fact of being asked about her asthma control and reminded of her medication. 2. Did not change	
Environmental Factors 1. Medical Support 2. *Shared Responsibility	1. Twice-a-year regular check at the asthma clinic 2. Family supportive in asthma management. Parents took charge of her asthma management.	1. Did not change for Rebecca but her mother felt they received additional medical support from the RT, who was monitoring the data. 2. Other people in the house were not involved	Rebecca turned to 17 and planned to move out of the house during the study. She took more responsibility for her asthma management. The technology did what her mother used to do: remind her to monitor symptoms and take medications.
Behavioural factors 1. Symptom Monitoring 2. Measuring PEF/FEV1 3. Taking Medication 4. Following Action Plan	1. Knew when symptoms got worse, often reminded by her mother. 2. Did not measure regularly 3. Forgot to take medication often 4. Would change medication according to action plan if reminded by her mother	1. "...it asks you have... you are doing and stuff, that was good." 2. Peak flow did not work 3. Helped her take medicine more often. 4. Did not help "I didn't really think about it"	

*=emergent categories from data, i.e. not included in the template codes

N/A=Not Applicable

--=Not mentioned by interviewee

4.4.6 Case 6-Christina

Asthma Management Without Technology

Christina was a fifteen-year-old girl living with her parents, grand parents, and a younger sister. She played soccer and went swimming every week. At the time of her second interview, she had joined a school band and played trumpet in the band.

Christina was diagnosed with asthma in the Asthma Clinic in 1992, approximately 12 years ago. For the first few years she had many difficulties controlling her asthma, however, it has been well controlled in the last 6-7 years. Being short of breath and having to stop doing whatever she was doing were the bad things about having asthma. Christina thought avoiding triggers, monitoring symptoms, and taking medications were very important strategies to achieve better asthma control. Managing asthma was not difficult for Christina because she had been living with asthma for a long time. Taking medication was part of her routine. Although Christina did not have a written action plan, she knew quite well how to manage her asthma. At the time of the first interview, Christina took Symbicort® 200mcg twice daily, Foradil® (long-acting β_2 agonist, preventer or controller) 12mcg twice daily, and Ventolin® as needed.

To manage it you have to always know ... don't forget to take your asthma medication...when you can't do anymore ...sports or something. You have to monitor yourself so you know when you can't do it anymore so you don't go all the way to the end and then have an asthma attack, you have to do your best, you have to be able to take care of yourself and take away all those things that trigger asthma.
(Christina)

Christina went to the Asthma Clinic every six months, where her asthma specialist encouraged her to discuss what she would do to manage her asthma and decided what to

do through discussion. Christina thought the asthma specialist “is really helpful when it comes to regular check-ups.”

Christina’s asthma specialist thought her parents tended to be “a bit more involved than was necessary.” However, Christina appreciated their support and encouragement in her asthma management.

Always encouraging, always, you know, asking “did you take your puffers today.” When I have a cold or something they ask “Are you preserving your energy, do you need another puff?”
(Christina)

Managing Asthma With Technology

Usability of Technology

The first CareCompanion® sometimes turned on “at a random time and stopped at one or two questions.” So after 2 weeks Christina called the respiratory therapist and had it exchanged for another one. She also found blowing the peak flow meter very hard.

Although she was able to have a correct peak flow reading sometimes, she was not able to transfer the data through the CareCompanion®. Christina found having these technical problems very frustrating.

The CareCompanion® was easy to work with and it took her about 3 to 6 minutes everyday. Christina chose to answer the questions at 6:30 in the evening. She thought it fit well into her schedule after she “got used to it.”

The questions via the CareCompanion® did not change over the 3 months. Christina felt her answers to the questions presented by the CareCompanion® had been the same over the three months due to her stable and well controlled asthma.

Well most times, like, the answer to my questions were the same ‘cause my asthma is always the same all the way throughout the 3 months...
(Christina)

Using Technology

Christina used the CareCompanion® from November 11, 2004 to February 10, 2005, although at first it did not work properly. Christina started with the new CareCompanion® on November 27, 2005.

Christina was unable to send her peak flow data due to the technical problems. Although she “tried to do it close to every day,” the data generated by the software showed that her overall response rate of sending clinical data was 39.1% (Table 13). The response rate for the first month was low partly due to the technical problems with the first CareCompanion®.

Table 13. Christina’s CareCompanion® Usage Data

	Total days	Days symptom data sent (*%)
Month 1	30	8 (26.7 %)
Month 2	31	12 (48.4%)
Month 3	31	10 (32.3 %)
Overall	92	30 (39.1%)

***Response Rate % = Days data sent/Total days**

Christina would be willing to continue using the CareCompanion® because it might potentially benefit her asthma management and it fit well into her schedule. She thought she would also benefit from using the peak flow meter if it worked properly.

Technology and Personal Factors

Christina was confident about her asthma management and did not expect the respiratory therapist to provide feedback if something went wrong with her. Her father thought the fact that her data was monitored could be “a plus.” He thought Christina would be taken care of if something did happen with her.

Technology and Environmental Factors

The CareCompanion® was set up in a room downstairs in the basement, where Christina's grandparents lived. They would call her downstairs if it started beeping and she was not there. Christina sometimes had her soccer game from 6 to 8 PM and was not home every once in a while. In that case, the CareCompanion® would continue beeping for 30 minutes. Christina's father thought the beep did not bother them because it "wasn't very sharp."

Christina's father thought that the CareCompanion® provided them with additional medical support. Christina did not feel it was necessary in her case but agreed that the CareCompanion® could provide important medical support for people in "remote areas."

Technology and Behavioural Factors

Christina thought using the CareCompanion® was a good way to monitor one's symptoms:

I think this is a good way to keep track obviously...you don't actually go around and think that... how many times did I use my, my emergency medication or whatever.

(Christina)

However, Christina "didn't use it [emergency medication]" because her asthma "has been in control for a long time and it stayed the same." She thought "it would have made a difference if it was somebody who has differences in their asthma." The electronic data sent via the CareCompanion® supported that Christina's asthma had been stable and well controlled over the 3 months.

Christina believed that the CareCompanion® could remind asthma patients to take their medications more regularly. However, she did not forget to take her medication even without being reminded, so she thought it "wouldn't affect me very much."

When asked how use of the CareCompanion® affected her following the action plan, she said “it’s good for thinking about your actual action plan” but it did not affect her because she already knew exactly what to do without the reminder.

Case Summary for Christina

In summary (Table 14), Christina understood her asthma management very well. She believed that avoiding triggers, taking medications, and monitoring symptoms were important strategies to manage her asthma. She was confident in her asthma management and her asthma was well controlled.

The CareCompanion® was quick and easy to use. It fit well in Christina’s schedule.

Although the CareCompanion® could make asthma patients more aware of their symptoms and take their medications more regularly, it did not affect Christina’s asthma management because she was able to manage her asthma well without using the technology. Her overall response rate in using the CareCompanion® was 39.1%. She would be willing to continue using the CareCompanion® because she believed potentially it might benefit her asthma management, particularly if the peak flow meter could work properly.

Table 14. Technology Effect Matrix (Christina)

Themes and Categories	Without the CareCompanion®	With the CareCompanion®	Researcher's Notes
*Technical Problems	N/A	Had technical problems with peak flow meter and the first CareCompanion®	
*Time Taken	N/A	3-6 minutes	
* Personalized Interaction	N/A	Felt answering the same questions with the same answers.	
*Added Responsibility	N/A	--	
*Flexibility	N/A	--	Scheduling was not a problem for Christina because the time she chose was convenient and it fit well into her schedule.
*Technology Aesthetics	N/A	--	
*Using Technology	N/A	Response rates: 39.1%/0% Wanted to continue to use it because it could potentially benefit asthma patients	
Personal Factors 1. Self-Efficacy 2. Outcome Expectations	1. Asthma management was not difficult 2. Believed avoiding triggers, taking medications, and monitoring symptoms were important to achieve asthma control	1. Did not change for Christina although her father thought it was a plus that she would be taken care of if anything happened to her. 2. Did not change	
Environmental Factors 1. Medical Support 2. *Shared Responsibility	1. Twice-a-year regular check at the asthma clinic 2. Family supportive in asthma management.	1. Extra support for people in "remote areas" 2. Other people in the house were involved.	
Behavioural factors 1. Symptom Monitoring 2. Measuring PEF/FEV1 3. Taking Medication 4. Following Action Plan	1. Would be aware of worsening signs of asthma such as getting stuffy or short of breath 2. Did not measure regularly 3. Did not forget to take her medicine. 4. Would change medication according to her doctor's advice.	1 "...good way to get yourself thinking about asthma" 2. Did not make peak flow meter work but thought it would have been beneficial if she could make it work 3. Would have helped her if she forgot. 4. Would help people to think about their actual action plan but had not affected her.	Christina thought the CareCompanion® could benefit asthma patients in different ways. However it had not affected her asthma management because she was able to manage her asthma well without the CareCompanion®.

*=emergent categories from data, i.e. not included in the template codes

N/A=Not Applicable

--=Not mentioned by interviewees

4.5 Cross-Case Findings

The five themes and their corresponding categories are presented in 4.4.1-4.4.5, in the same sequence as they are presented in within-case findings: Usability of Technology, Using Technology, Technology and Personal Factors, Technology and Environmental Factors, Technology and Behavioural Factors. An exploration of relationships among the themes is discussed in 4.4.6.

4.5.1 Usability of Technology

The CareCompanion® with a peripheral device, the Piko-1 electronic peak flow meter, was the technology used in the study. Usability of Technology, an emergent theme from the data analysis, included six corresponding categories related to this theme: technical problems, time taken, personalized interaction, flexibility, added responsibility, and aesthetics.

4.5.1.1 Technical Problems

Technical problems were major barriers to the use of the peak flow meter for most participants in the study. All six teens and their parents spoke about their frustrations with the peak flow meter technical problems. Only one teen in the study (Anna) was eventually able to measure PEF/FEV1 and transfer the data via the CareCompanion®. The remainder of participants did not succeed in sending the peak flow data either because they were not able to use the appropriate blowing techniques to measure their PEF/FEV1 (n=2), or they were not able to transfer the data via the CareCompanion® (n=3). Most of them found it hard to make it work appropriately and gave up after a few weeks. When they were asked to measure their peak flow, most of them just pressed the “skip” button.

Although peak flow data transfer through the CareCompanion® was a problem, the CareCompanion® itself worked properly most of the time. As the first participant of the study, Anna was not able to use the CareCompanion until a separate telephone line was installed at the respiratory therapist's house. Although Christina had technical problems with her first CareCompanion® and was not able to send data sometimes, she did not encounter technical problems with the second CareCompanion®.

4.5.1.2 Time taken

All six teenagers and their parents agreed that the CareCompanion® was easy and quick to use. It took approximately 1-6 minutes to answer the questions, try the peak flow meter, and send the data.

4.5.1.3 Personalized Interaction

The CareCompanion® was programmed in a way that the same set of questions was posed to all individuals in spite of difference in their asthma management behaviour and disease status. After a while, some teens in the study felt they were answering the same questions with the same answers over and over again. Individual customized questions were preferred, as a more efficient means for communicating, motivating, and guiding the teens in their efforts to manage asthma. As Anna's father noted: "there's no reason why it couldn't say 'Hi [Anna's real name].'" For Rebecca, who was less certain about what her action plan was, a general reminder such as "please follow your action plan" did not help her take necessary actions. More specific messages based on her asthma management might be more helpful.

4.5.1.4 Flexibility

Most teenagers and their parents talked about flexibility of using the CareCompanion®.

Once the CareCompanion® was set to beep at a certain time of the day, unless the respiratory therapist changed the schedule at her end, it would beep at the same time everyday.

Some participants mentioned that they had to unplug and plug the CareCompanion® back in if they were away for a few days. Rather than having to unplug it, they hoped they could just skip one or two sessions when they were away. It was noted that a portable device would work better.

Four teens originally chose to work with the CareCompanion® early in the morning. However, they felt annoyed that the CareCompanion® started beeping early in the morning during weekends and holidays. Although all the participants were told at the beginning of the study that they could contact the respiratory therapist to change the schedule if they wanted to, no one bothered to do that. They preferred the flexibility to schedule the time by themselves. As Jane's mother suggested: "it would be nice to be controllable by us, like 'gone to sleepover', you know like 'cancel the service right now'..."

4.5.1.5 Added Responsibility

Using the CareCompanion® everyday was an added responsibility. For those who scheduled the CareCompanion® in the morning, waking up early and answering the questions everyday could be "a pain in the butt" (Rebecca). It was an "added thing to worry about" (Betty's mother). Jane noted using CareCompanion® everyday "almost made it (managing asthma) like more of a big deal 'cause every day I had to do things."

4.5.1.6 Aesthetics

All six teens talked about the shape, size, or beep of the CareCompanion®. The technology was considered too big by most teens and the sound or length of the beep seemed to be annoying to most of them. They believed most teens would prefer to use something more appealing in appearance.

4.5.2 Using Technology

Response rates to the CareCompanion® varied among participants, ranging from 30.4 % to 96.7 % (Table 15). Only Anna was able to transfer PEF/FEV1 data through the CareCompanion®. Her response rate in reporting lung function data was 18%.

Sometimes Christina was not able to send data due to technical problems of the first CareCompanion®. This partly contributed to her lower response rates compared to other participants. Rebecca's overall response rate was low because she moved out of her parents' house in January and did not finish the 3-month monitoring.

Most participants used the CareCompanion® quite consistently; however, response rates during weekends and days around Christmas and New Year's Eve were low for some participants. Betty's response rate declined significantly over time and Rebecca used the CareCompanion® for less than 2 months.

Table 15. CareCompanion® Usage Data (All Cases)

Participant	Total Days	Days Symptom Data Sent (*%)
Anna	92	38 (41.3%)
Betty	92	45 (48.9%)
Liz	92	89 (96.7%)
Jane	92	86 (93.5%)
Rebecca	92	28 (30.4%)
Christina	92	30 (39.1%)

* **Response Rate % = Days data sent / Total days**

Three participants (Betty, Christina, and Liz) would be willing to continue using the CareCompanion®. Most parents thought it would be up to their children to decide whether or not to continue using the CareCompanion®. Most of them did not consider it necessary for their teens to use the CareCompanion® on a daily basis.

4.5.3 Technology and Personal Factors

This theme includes findings related to the effect of technology on personal factors related to asthma management. Personal factors reside within an individual and include psychological features such as beliefs and attitudes in asthma management. The theme contains two major categories: self-efficacy and outcome expectations.

4.5.3.1 Self-efficacy

Self-efficacy refers to a person's perceived ability to engage in a specific behaviour with an anticipated outcome (Bandura, 1995). In the study context, self-efficacy was the teen's belief that she was capable of taking certain actions related to her asthma self-management. All six teens in the study had been diagnosed with asthma for more than 10 years and generally felt it was not difficult to manage. Most of them believed they knew how to manage their asthma and were confident in performing most tasks following their doctors' advice. However, most of them reported difficulty in remembering to take their medications every day.

The CareCompanion® played a role in reassuring some teenagers and their parents about asthma management during the 3 months. Self-efficacy varies greatly depending on the particular task one is performing (Bandura, 1995). Most teens and their parents felt knowing the respiratory therapist was monitoring the data provided the teens and the families more confidence in their asthma management. More specifically, they felt that

they would be taken care of if a bad asthma attack happened. However, many of them also emphasized that it was not necessary in their cases because their asthma was well controlled and stable. For Rebecca, who was not good at monitoring symptoms and taking medication on her own, the CareCompanion® made her more confident in performing these tasks without being reminded by her parents.

4.5.3.2 Outcome Expectations

Outcome expectation refers to the belief that undertaking a specific behaviour will lead to a particular outcome (Clark, 1999). In the context of the study, outcome expectation was the teen's belief that undertaking specific actions as advised by her asthma specialist would lead to better asthma control. The teens in the study thought differently about how well the specific disease management strategies they used (i.e. following action plan, taking medication regularly, etc.) contributed to their asthma control. Five out of the six teens had their asthma well controlled and felt the asthma strategies they were undertaking now contributed to a better asthma control.

Taking a specific disease management action was influenced by the teen's outcome expectation of the specific action. When the teen believed that taking her medication or following her action plan would benefit her, she was more likely to do so consistently. Anna followed her action plan because she believed it was very important to keep their asthma under control. On the contrary, Betty did not think following her action plan had helped her asthma control. Rather than strictly following her action plan, she did not monitor her symptoms everyday as suggested by her asthma specialist.

After the participants had managed their asthma using the CareCompanion® for 3 months, none of them reported seeing a difference in how engaging in certain actions was

connected to the outcomes. Apparently using the CareCompanion® did not influence outcome expectations for the teens.

4.5.4 Technology and Environmental Factors

This theme presents findings related to the effect of technology on social or physical environment that can affect a person's behaviour in relation to asthma management. Two categories in this theme are explored in more detail, including medical support and shared responsibility (between family members).

4.5.4.1 Medical Support

The six teens in the study went for regular check-ups at the Asthma Clinic every 6 to 12 months and agreed they had easy access to a variety of health care facilities. No additional medical advice was provided through using the CareCompanion®, although as outlined in the research protocol, the respiratory therapist would have contacted the participants under emergency situations if this was necessary.

The participant's expectation of getting feedback from the respiratory therapist varied and appeared to be related to her confidence in asthma management, her disease status, and access to health care facilities. Some teens noted they did not expect to receive any feedback from the respiratory therapist because they would recognize signs of worsening asthma and respond without additional instructions. However, being monitored by the respiratory therapist was perceived as an extra source of medical support by other teens and their parents. With an easy access to health care facilities, most participants could seek help at the emergency department; but immediate feedback from the respiratory therapist would promote early identification of an emergent status change.

4.5.4.2 Shared Responsibility

All the teens had very supportive families. Although most of them took responsibility for their asthma self-management, their parents were always ready to help them.

For most teens in the study, using the CareCompanion® was a responsibility shared by the whole family. Five of the six teens set up the CareCompanion® in a family area. The CareCompanion® made sounds that demanded attention and therefore got other people in the family involved in the process. All five teens noted that their parents or siblings had to go get them when they were not around the machine. If they were gone for the weekend, other people in the house had to press the button to stop the beep. Therefore additional family support was required to use the CareCompanion® in the teen's daily asthma self-management. While none of the parents complained about this added responsibility, some suggested that it should first be communicated to everybody in the family.

Rebecca was the only teen who did not involve her family members while working with the CareCompanion®. Her machine was originally set up in her bedroom upstairs. Due to her family situation during the time she was using the CareCompanion®, she often kept her bedroom door closed and the process did not affect other people in the house.

4.5.5 Technology and Behavioural Factors

The behaviour studied was the teens' use of asthma self-management strategies. Self-management strategies comprise the individual's means to keep the disease and its effects under control (Clark, et al., 2001), which in this study included avoiding asthma triggers, monitoring symptoms, taking daily preventer medication including ICS and LTRA, taking reliever medication as needed, and following their action plans. These strategies

were effective or ineffective, were taken with or without the help of a written action plan. Four categories are discussed under this theme: monitoring symptoms, measuring PEF/FEV1, taking medication, and following action plan.

4.5.5.1 Monitoring Symptoms

Recognizing early warning symptoms or triggering situations is important in asthma self-management. In response to a question at the initial interviews, participants cited the common symptoms such as feeling tight, shortness of breath, and wheezing as early signs of worsening asthma.

All the teens somehow monitored their symptoms, usually by paying attention to some of the early signs of worsening asthma. Most of them noted using the CareCompanion® made them more aware of how well they were doing:

I think that...it's just a good way to get me thinking about asthma, 'cause before the three months I just....I just take my medication and I just go on with life. I didn't really actually stop to think about my asthma or what I did about asthma...it's just a way of being aware and keep...to pay attention to your asthma. (Christina)

By contrast, as one of the most “well-organized” and “compliant” patients who was already aware of her disease status, Anna did not see any change in awareness of her asthma when using the CareCompanion®. She thought she knew about her asthma for “pretty much entire life,” so “pressing buttons and reading things” did not make her more aware of it.

4.5.5.2 Measuring PEF/FEV1

Anna was the only participant who was able to send the PEF/FEV1 data. Liz was not able to transfer the data but she measured her PEF/FEV1 everyday and wrote it down on a piece of paper. Both of them felt measuring PEF/FEV1 daily helped them know better

where they were with their asthma. Although the other teens did not successfully measure their PEF/FEV1, some mentioned it might have been helpful if they had managed to do it.

4.5.5.3 Taking Medication

Once a day the CareCompanion® reminded the teens to take their medications. The study teens were taking their medications in a once- or twice-daily regimen. During their first interviews, most teens said remembering to take their medications every single day was hard, although some had less difficulty than others. Two of them (Liz and Rebecca) said they took their preventer medication more often when using the CareCompanion®. Jane usually remembered to take medication on her own; the CareCompanion® only reminded her a few times. Using the CareCompanion® reminded Betty to take her reliever medication more often because she was more aware of her symptom changes, but not the preventer medication.

The other 2 teens did not think the CareCompanion® had affected them. They agreed the CareCompanion® could be useful for somebody who sometimes forgot to take her medication, but they also believed they took their medications quite consistently without being reminded.

4.5.5.4 Following Action Plan

In the context of this study, an asthma action plan might or might not be in a written format. It was developed by the asthma specialist and the patient herself, including information about avoiding trigger, when and how to modify medication, and when to seek emergency help.

The CareCompanion® reminded the teens to follow their action plans once a day by asking the same question: “Did you need to use your action plan?” Although some of them said it made them think about what they should do, none of them thought it changed their use of management strategies. However, by making them more aware of their symptoms and reminding them to take their medications, the CareCompanion® indirectly affected how they followed their action plans.

4.5.6 Exploring the Relationships among Themes

Themes, corresponding categories, and specific context for each of the six cases were displayed in a partially ordered meta-matrix in order to facilitate further cross-case analysis and to understand how the themes fit together (Table 16). The matrix suggested the participants’ asthma self-management behaviours and asthma control without the technology varied. They encountered several common usability issues, yet some found the technology easier to use than others. Themes related to roles of technology varied slightly as they were manifested across the cases. Usability of the technology affected use of the technology as well as how technology influenced the participants’ asthma management. Both technology usability and their perceived benefits of the technology appeared to influence the participants’ decisions about continuing to use the CareCompanion®.

Table 16. Partially-ordered Technology Effect Meta-Matrix (All cases)

Case	Without the CareCompanion®	With the CareCompanion®				
		Usability	Personal Factors	Environmental Factors	Behavioural Factors	Using Technology
Anna	<ul style="list-style-type: none"> -Asthma well controlled and stable -Highly confident in asthma management -Believed action plan would lead to better asthma control -Good family/medical support -Following action plan strictly -well controlled 	<ul style="list-style-type: none"> -technical problems, resolved later on -personalized interaction -Flexibility in setting schedules -size, look, beep 	No change	<ul style="list-style-type: none"> -Family shared responsibility -Extra medical support via the CareCompanion® not needed. 	Monitored PEF/FEV1	<ul style="list-style-type: none"> <50% Would not use it in the future because “it didn’t do that much.”
Betty	<ul style="list-style-type: none"> -Asthma not well controlled but stable -Didn’t believe action plan worked -Confident in asthma management in general -Good family/medical support -Sometimes forgot to take medications or monitor symptoms -not well controlled 	<ul style="list-style-type: none"> -technical problems with PFM -personalized interaction -flexibility in setting schedules -added responsibility to her busy schedule - size, beep 	<ul style="list-style-type: none"> -Felt more confident in asthma management -No change in outcome expectations 	<ul style="list-style-type: none"> -Family shared responsibility -Being monitored daily provided extra medical support 	<ul style="list-style-type: none"> -More alert to worsening signs -Took “rescue medications” but not ICS more regularly 	<ul style="list-style-type: none"> 48.9% Would continue using the CareCompanion® (maybe “not everyday”), because it was easy to use and she was monitored by the RT
Liz	<ul style="list-style-type: none"> -Asthma well controlled and stable -Confident in asthma management in general -Good family/medical support -Sometimes forgot to take medications -well controlled 	<ul style="list-style-type: none"> -technical problems in sending PEF data, but was able to measure PEF -time chosen was good, flexibility not an issue -added responsibility 	-No change	<ul style="list-style-type: none"> -Family shared responsibility -Being monitored daily was considered additional medical support but not important for Liz 	<ul style="list-style-type: none"> -More aware of her asthma -Took medications more regularly Measured PEF/FEV1 	<ul style="list-style-type: none"> 96.7% Would continue using the CareCompanion® because it made her more aware of her asthma.
Jane	<ul style="list-style-type: none"> -Asthma well controlled and stable -Confident in asthma management in general -Believed taking medication was important -Good family/medical support -Did not forget to take medication -well controlled 	<ul style="list-style-type: none"> -technical problems with PFM -flexibility in scheduling -“made asthma more of a big deal” -size, beep 	<ul style="list-style-type: none"> -Felt more confident in case of emergency -No change 	<ul style="list-style-type: none"> -Family shared responsibility -The CareCompanion provided additional medical support but not necessary for Jane 	<ul style="list-style-type: none"> -Monitored symptoms better -Reminded her to take medications sometimes 	<ul style="list-style-type: none"> 96.6% Would not continue using the CareCompanion® because it did not do much and made asthma a bigger deal
Rebecca	<ul style="list-style-type: none"> -Asthma well controlled and stable -Not confident in asthma management, very dependent on her parents -Good family/medical support -Forgot to monitor symptoms/take medication very often -well controlled 	<ul style="list-style-type: none"> -technical problems with PFM -flexibility in scheduling -“a pain in the butt” to get up early everyday -size, beep 	<ul style="list-style-type: none"> -More confident in asthma management -No change in outcome expectations 	<ul style="list-style-type: none"> -Family did not share any responsibility for using technology. Instead, the CareCompanion® did what her parents used to do to remind her 	<ul style="list-style-type: none"> -Monitored her symptoms better -Took medication more regularly 	<ul style="list-style-type: none"> 30.8% Would not continue using the CareCompanion® because it was “a pain in the butt” to get up early and do it everyday
Christina	<ul style="list-style-type: none"> -Asthma well controlled and stable -Confident in asthma management -Believed taking medication and - monitoring symptoms were important -Good at following action plan -well controlled 	<ul style="list-style-type: none"> -technical problems with CareCompanion®, resolved later; problems with PFM -Personalized interaction 	-No change	<ul style="list-style-type: none"> -Family shared responsibility -Could provide additional medical support to people in remote areas 	No change for her case but believed it could help other people with asthma.	<ul style="list-style-type: none"> 39.1% Would continue using the CareCompanion® because it was potentially beneficial, particularly if peak flow worked)

A few subsequent displays were generated to further explore the relationships among categories of most interest. Table 17 is a case-ordered meta-matrix, which illustrates cases from high to low self-efficacy. Participants who had higher confidence and better compliance in their asthma management without using the technology reported less behaviour changes with the technology. They also appeared not to feel more confident in asthma management, knowing the respiratory therapist was monitoring the data everyday. This suggests that participants with better compliance and self-management behaviour might benefit less from the technology. As well, status of asthma control seemed to influence how technology affected one's behaviour.

Table 17. Case-Ordered Technology Effect Meta-Matrix (All Cases)

Asthma self-management without technology Self-efficacy and compliance to action plan	Technology and Behavioural Factors	Technology and Environmental Factors	Technology and Personal Factors
High :			
Anna	1. Monitored PEF	1. family shared responsibility 2. did not expect extra support	Did not change
Jane	1. More aware of symptoms 2. Reminded to take medication, only “sometimes”	1. family shared responsibility 2. did not expect extra support in her case	Felt more confident in case of emergency situation
Christina	No change in her case but believed it could potential help a patient be more aware of her symptoms, take medication more regularly, monitor one’s PEF, and follow one’s action plan better.	1. family shared responsibility 2. did not expect extra support in her case	Did not change
Median:			
Liz	1. More aware of symptoms 2. Took medication more regularly 3. Monitored PEF	1. family shared responsibility 2. did not expect extra support in her case	Did not change
Betty	1. More aware of symptoms 2. Took “rescue medication” more often	1. family shared responsibility 2. expected extra medical support under an emergency situation	Felt more confident in asthma management
Low:			
Rebecca	1. More aware of symptoms 2. Took medication more often	1. family did not share responsibility 2. did not expect extra support in her case	Felt more confident in asthma management

4.5.7 Summary

The teens' asthma management strategies without using technology, including asthma control, self-efficacy, and asthma management behaviours, were found in multiple sources of data. All three aspects of management influenced roles of technology in their asthma management. For example, several participants felt their asthma management was not affected by the CareCompanion® because they were able to manage well without the technology.

This study also found that the teen's use of the CareCompanion® and her intention to continue using it were based on perceived benefits and usability of the technology. The perceived benefits found in the study included the effect of technology on personal, environmental, and behavioural factors related to asthma management. Therefore, these three factors reciprocally influenced the teen's use of the technology.

CHAPTER FIVE: DISCUSSION

This research sought to understand the role of home telehealth technology in teens' asthma management. Findings suggested various aspects of asthma management, including status of asthma control, self-efficacy, access to health care facilities and asthma management behaviours prior to using the technology influenced the role of this technology in teens' disease management. A better understanding of these results required a second look at the underlying literature in this field.

This chapter begins with a discussion of the findings as they relate to the research questions posed at the beginning of the study as well as within the context of current literature. The strengths and limitations of the study are discussed. Finally, the implications for practice and recommendations for future research are provided.

5.1 Research Questions

The central research question of this study was: What was the role of home telehealth technology in teens' asthma management? A conceptual framework (Figure 2) focusing on influence of technology on three Social Cognitive Theory factors guided data collection and analysis. The role of the CareCompanion® in influencing personal, environmental, and behavioural factors related to the teens' asthma management was identified.

The central research question was further explored through three more specific subquestions:

4. How did teens manage asthma without using home telehealth technology?
5. What happened in the 3-month period?
 - a) How did the home telehealth technology work?

- b) How did the technology influence teens' asthma self-management?
 - c) How did the technology influence their daily life?
6. How did home telehealth technology influence teens' perceptions of asthma management?

Findings related to each of the three more specific research questions as well as the central research question are discussed in sections 5.1.1 to 5.1.4, and where possible, are situated in the current literature.

5.1.1 Subquestion 1: How did Teens Manage Asthma without Using Home Telehealth Technology?

Before the six teens used the CareCompanion®, interviews were conducted with the teens, their parents, and their asthma specialists. By collecting data from different sources, we intended to gain a comprehensive understanding of these teens' asthma management prior to using the technology.

Social Cognitive Theory explains behaviour in terms of a triadic, dynamic and reciprocal interaction of the environment, personal factors, and behaviour (Bandura, 1995). Furthermore, this theory emphasizes that the motivation to change derives mainly from self-efficacy and outcome expectations. In the context of asthma management, patients' self-efficacy and outcome expectations related to specific behaviours may influence their asthma self-management behaviours; external support from health care providers and families is a weaker source of influence.

In our study, all the six teens had supportive families and easy access to medical facilities. They all had been diagnosed with asthma for more than 10 years. Except for one teen, they were responsible for and generally felt capable in their asthma management. The

teen that was not very confident in managing asthma on her own tended to monitor her symptoms less regularly and forgot to take her medication more often. Outcome expectations varied among the six teens, and seemed to influence how they followed advice from their asthma specialists. They took an action more consistently if they believed it would lead to better asthma control.

5.1.2 Subquestion 2: What Happened in the 3-month Period (during Use of Technology)?

Subquestion 2a: How did the technology work?

The CareCompanion® was approved for use in Canada. According to the Medical Devices Regulations, “a medical device shall perform as intended; a medical device that is part of a system shall be compatible with every other component or part of the system with which it interacts and shall not adversely affect the performance of that system” (Department of Justices Canada, 1998).

In the context of our study, the peak flow meter was a peripheral that was part of the CareCompanion® system for the purpose of measuring teens’ lung functions. Given that the CareCompanion® was approved for use in Canada, we expected it had been beta tested and proven to be effective. During the study, all the six teens had difficulties with their peak flow meters. Although we contacted the manufacturer for assistance, they did not provide sufficient technical support to solve the problems with peak flow meters. Five of the six participants were still not able to send their PEF/FEV1 data.

In spite of the fact that all the teens noted the CareCompanion® was easy and quick to use, its usage over the 3 months ranged from 30% to 97%. This was less than expected given a relatively well-motivated group of teens with asthma.

Schneider, Schwartz, and Fast (1995) suggested that users should be able to access the information or program as often as they wish, making their particular version of a program more or less intensive. Some study teens identified lack of flexibility as one of the barriers to use of this technology. Most participants in the study noted they wished they could have scheduled the CareCompanion® at their end whenever they wanted. For the participants with busy schedules who could not commit to using the technology at regular fixed times, flexible access to the CareCompanion® was particularly important. Communication technology provides an easier way to produce personalized interaction, which can be adjusted to participants' efficacy level, the unique impediments in their lives, and the progress they are making (Bandura, 2004). Interactivity, the capacity both to gather data from users and provide personalized feedback, is an advantage of the new technologies. It may increase the probability of the message being read and considered (Owen et al., 2002). Studies have suggested that individually tailored information was more effective in changing attitudes and behaviour (Brug, Steenhuis, van Assema, & de Vries, 1996, DeBusk et al., 1994).

Personalized interaction was not provided by the CareCompanion® in our study. The participants received the same set of questions and reminders regardless of their current behavioural status and asthma control. Study findings agree with the literature; although many of them did not expect direct feedback from the respiratory therapist, they preferred to receive messages from the CareCompanion® that were tailored to their disease status and individual needs. As stated by some participants, the questions and reminders never changed and they did not think about the messages sent by the CareCompanion® after a while. A general reminder question about the action plan did not help one participant use

asthma management strategies differently because she did not pay much attention to it.

The study suggests that individualized feedback based on asthma patients' disease status and personal needs may be more likely to be attended to. This personalized interaction may help patients identify their early status changes and respond according to their action plans.

Aesthetics, such as size, shape and sound of the technology were mentioned by most teens in our study. It is not too surprising that a group of female teens with asthma related perception of physical appeal to their satisfaction with the technology.

Subquestion 2b: How did the technology influence teens' asthma self-management?

Social Cognitive Theory suggests that a program developed to change health behaviour should not focus on behaviour in isolation but focus instead on changes in the environment and in the individual as well (Clark & Valerio, 2003). In the context of asthma management, knowledge or behavioural capability is insufficient to lead to change in behaviour and improved health outcomes of asthmatic patients (Boulet et al., 1999). To achieve behavioural changes, the patient's asthma-specific self-efficacy beliefs and outcome expectancies should be increased, and more social support by important others should be established, in order to increase the intentions towards self-management behaviour.

The CareCompanion® was programmed to present questions related to asthma control on the touch screen and to record responses. It also asked each teen to measure her peak flow, take her medication, and follow her action plan. The CareCompanion® automatically telephoned the respiratory therapist's number and transferred the data daily.

Theoretically, the CareCompanion® may provide asthma patients with environmental support (feedback from the respiratory therapist under emergency situations), improve patient's self-efficacy and outcome expectations (sending positive reinforcement messages, facilitating interaction between health care professionals and the patient, and letting the patient experience successful behaviour), and therefore change her asthma self-management behaviour.

Most participants in the study reported some behaviour changes in their asthma management when they were using the CareCompanion®. Changes in environmental factors including family and medical support as well as their confidence in disease management were also observed in the study.

Subquestion 2c: How did the technology influence teens' daily life?

Many participants discussed the impact of using the CareCompanion® on their daily life. Ease of use meant "free of effort" in a broad sense, which was not only related to technical features of the technology, but also meant no extra burden on their lives. Their decisions about future use of the technology were related to how well it fit into their everyday lives. One participant thought using the CareCompanion® made her asthma "more of a big deal" because she had one extra thing to do every day. Another participant worried that using the CareCompanion® daily might be difficult in her busy schedule. The CareCompanion® assisted one participant to take her medication more regularly; however, she still did not want to use the technology on a daily basis because it was "a pain in the butt" to wake up early every morning. The study findings indicate that recognizing the need for total readjustment in the teenager's lifestyle was as important as the perceived usefulness and ease of use of the technology.

5.1.3 Subquestion 3: How did Home Telehealth Technology Influence Teens’

Perceptions of Asthma Management?

One objective of using the CareCompanion® was to help teens monitor their symptoms and therefore make better decisions in their own asthma management. However, this objective was not met in some cases. The teens and their parents were told at the beginning of the study that they would be contacted if their responses indicated emergency situations. Although early recognition and intervention of acute asthma exacerbations were the key steps in their action plans, some of them noted they expected to hear from the respiratory therapist if asthma emergency occurred. It was surprising that given the technology was meant to increase self-efficacy, it easily created a “dependency” on the promise of an expert’s monitoring of emergency situations.

A previous study reported that asthma patients did not show strong preferences for having a major role in decision making, although the current asthma management guidelines emphasize enhancing patient self-management through increased autonomy in decision making (Gibson, Talbot, Toneguzzi, 1995). Ryan et al. (2005) recently published a study using mobile phone technology with an electronic peak flow meter in asthma patients. Patients measured their peak flow and sent data via the cell phone. They had immediate feedback in the form of asthma trend analysis from the server, but no intervention was offered over the 9-month study period. At the end of study, patients reported that enhanced ability to monitor peak flow increased their autonomy and understanding of asthma management.

The difference between technologies in these 2 studies may explain why patients felt different about their responsibilities in their own disease management. In our study, the

teens' trust in the respiratory therapist made them feel safer, even though the respiratory therapist probably could not identify early signs of asthma exacerbations without seeing peak flow data; in the cell phone study, technology promoted autonomy in asthma management by sending patients disease trend and encouraging them to make decisions on their own.

5.1.4 Central Question: What was the Role of Home Telehealth Technology in Teens' Asthma Management?

The role of the CareCompanion® in influencing factors related to teens' asthma management included the following:

- Personal (self-efficacy)
- Environmental (shared responsibility between family members and additional medical support)
- Behavioural (symptom monitoring, monitoring lung functions and taking medications).

The results of the study also suggested usability of technology, use of technology, and the role of technology in teens' asthma management influence, and are influenced by, each other.

Many self-management programs involving technology, including the CareCompanion® system, are designed to be utilized over time and user adherence to the intervention schedule is therefore necessary (Farzanfar, Frishkopf, Migneault, & Friedman, 2005).

The role of technology in disease management would be very limited if the technology is not accepted and used.

Research in the area of user acceptance of new technology has resulted in several theoretical models, including Theory of Reasoned Action (Ajzen, 1980), Technology Acceptance Model (Davis, 1989), Theory of Planned Behaviour (Ajzen, 1991).

These theoretical models all focus on individual's behavioural intentions to predict use.

Theory of Reasoned Action suggests that an individual's intention to adopt a technology is determined by personal interests and social influence (Ajzen, 1980). Technology

Acceptance Model and Theory of Planned Behaviour are both adaptations of Theory of Reasoned Action, with Technology Acceptance Model specifically tailored for modeling user acceptance of information systems. This model identified perceived usefulness and perceived ease of use as key factors that influence attitude toward technology use.

Although the key constructs in this model have been operationalized primarily through quantitative studies to predict usage of technology, the two constructs, perceived usefulness and perceived ease of use or usability, appear to best describe data collected in this study.

In this study, perceived usefulness and usability of the CareCompanion® were often tied to the teens' intention to use the technology. Three of the six participants would not continue to use the CareCompanion® due to either perceived lack of benefits or its extra burden on their daily life. Three participants would like to continue using the CareCompanion® because they thought it could potentially improve their health and it was simple and easy to use.

Perceived usefulness is also influenced somewhat by usability (Davis, 1989). Response time, flexibility, and technical problems including breakdowns or crashes have been proposed to have both direct and indirect effects on technology acceptance (Karsh, 2004).

Technical problems were major barriers to using the Piko-1 electronic peak flow meter in this study. Most participants were not able to use the Piko-1, and therefore did not benefit from monitoring peak flow daily. Although the technology was available, it could not be used as intended and therefore had a limited role in the participants' asthma management.

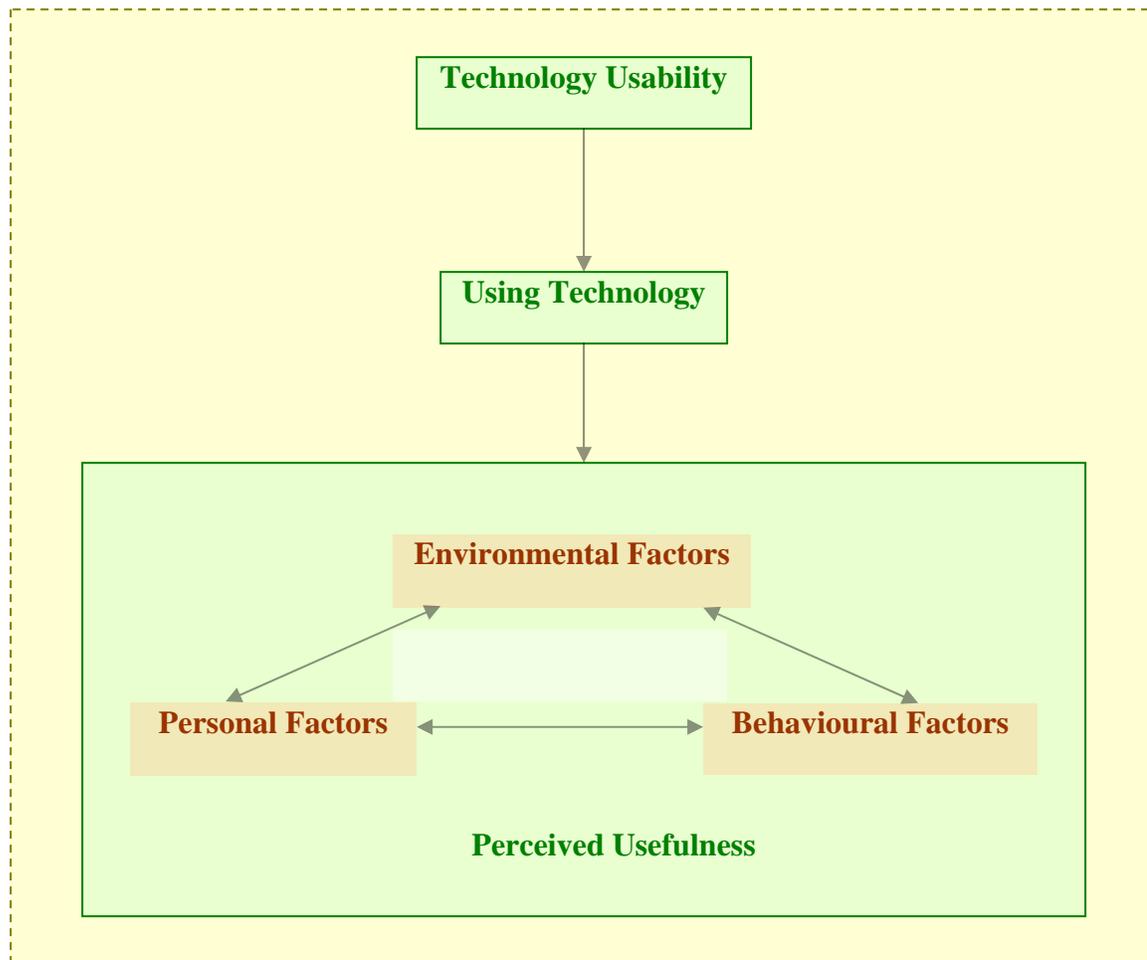
Even when the CareCompanion® was properly used, roles of technology varied among the six teens with asthma. The diversity suggested that their status of asthma control, self-efficacy in asthma management, access to health care facilities, and asthma management behaviours influenced the role of technology in their disease management. For example, participants who often forgot to take their medications found the CareCompanion® very helpful in reminding them to take medications more regularly; while for those who took medications consistently without being reminded, the daily technology reminder was not helpful. Most participants noted the technology would have made a bigger difference if their access to health care facilities had been less easy.

5.2 Revised Conceptual Framework

At the beginning of the study, a conceptual framework (Figure 2), adapted from Social Cognitive Theory, was used to help guide data collection and analysis. The conceptual framework reflected an expectation that using technology might affect one or more of the three factors related to asthma management and therefore change the asthma management behaviour. Throughout the study, the researcher gained an appreciation of the relationships between usability of technology and use of technology, as well as the role of technology in the three asthma management factors.

The revised conceptual framework (Figure 5) combines Social Cognitive Theory and Technology Acceptance Model. It attempts to capture the influence of the five themes on each other as well as situate the themes within the context of asthma status and asthma management.

Figure 5. Revised Conceptual Framework



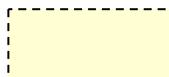
Social Cognitive Theory Factors:



Technology Acceptance Model Factors:



Context:



5.3 Study Strengths and Limitations

5.3.1 Strengths

Although a number of studies have been done to demonstrate the feasibility of home telehealth technology in asthma management, few explored the role of home telehealth technology in teens' asthma management. It might be difficult to identify all the relevant variables in a more structured design at the beginning of the study. The study methods allowed the researcher to raise questions and concerns and to explore relationships among themes. The interviews were flexible and additional questions were created during the interview, allowing flexibility for the researcher to probe for details and for the participants to discuss issues. Multiple interviews with the same participant were likely to be richer because of the opportunity to ask additional questions and to get feedback on previously obtained information (Reinharz, 1992). The qualitative data provided information about context and processes related to the role of the CareCompanion® in teens' asthma management.

5.3.2 Limitations

The first limitation is that this was the researcher's first time conducting qualitative interviews. The interview data might have been different had it been collected by someone with more experience in qualitative research interviews.

The second limitation is that the study investigated the role of the CareCompanion® only in participants who fell within the characteristics of our sampling frame. Recruitment was restricted to within Calgary for easier study management. It is likely that people living in areas outside Calgary would have more limited access to asthma specialists and other

medical support. Lack of access to health care facilities may influence the role of technology in their asthma management differently.

Finally, among the patients who met the study sampling criteria, those who were considered more likely to participate and stay in the study were approached first.

Therefore, study participants may have been more “compliant” than most teenagers with asthma. They were motivated enough to participate in a study like this and their experience in asthma management using the CareCompanion® may be different from other teens.

5.4 Implications for Practice and Future Research

5.4.1 Implications for Practice

Although a number of home telehealth vendors were contacted when we planned the study, the CareCompanion® was the only one of two with approval for use in Canada. We designed the study based on the assumption that the CareCompanion with its peripheral, Piko-1 electronic peak flow meter, worked properly. However, the peak flow meter did not work for five of the six teens in the study, and the manufacture did not provide sufficient technical support to solve the problems.

Our experience with the CareCompanion® indicates that regulatory approval is not always a guarantee of technology effectiveness or quality. Ongoing data collection enables the manufacturers to improve their technology, as well as helps health care providers and health policy makers to evaluate a new technology. All participants in this study agreed that the CareCompanion® was easy and quick to use, but most of them identified some aspects of the technology that needed to be improved.

First, the CareCompanion® is designed for monitoring physiologic parameters as well as sending health related questions and reminders. In this study, the only peripheral used was the peak flow meter. However, other peripherals such as blood pressure cuffs were also attached to the patient unit, which made it “bulky”. From the user’s perspective, the device should be compact and include only peripherals that are needed. Second, most participants found the alarm beep “annoying” because the sound was unpleasant and could last for up to 30 minutes if the screen was not touched. It would be more appealing if the user could choose a sound they like and decide how long it lasted. Third, it is important to provide personalized feedback via the CareCompanion®. Interactions based on users’ disease status and personal needs are more likely to be attended to. The more recent version of the software provides a “branch set” option for the questions asked by the CareCompanion®. Therefore, questions vary depending on the answer to the previous question. For example, if a patient does not have worsening signs of asthma, she would not be asked to adjust her medication according to the action plan. Finally, users should be given more flexibility in their use of the CareCompanion®. This may include flexibility of the frequency and the schedule of the monitoring sessions. The new version of the CareCompanion® has an “ad hoc” reporting feature, which adds some of this flexibility. Participants can choose when they want to send in data. If not done by a certain time of the day, it then can be set to beep.

Despite the fact that all the participants had asthma for more than 10 years and had used peak flow meters before, most of them encountered technical problems with the Piko-1 electronic peak flow meter. This suggested the technology might present a challenge even for the patients with prior exposure to similar technologies. Health professionals need to

provide sufficient training and education on how to use technology appropriately. The study also found that use of home telehealth technology in teens with asthma could involve everyone in the family, and from an education perspective, information has to be communicated to all family members.

Some teens expected the respiratory therapist would provide them with advice under emergency situations. Trust in health care professionals made the teens feel safer; while in reality the safety did not exist in our study due to the technical problems. Clinicians and researchers should be aware of the possible negative impact of the technology on their patients. Patient education with information related to the goal of the technology in their asthma management and potential technology problems may be useful.

Status of asthma control, confidence in managing asthma, access to health care facilities, and asthma management behaviours all influenced roles of the technology in asthma management. As cited by most participants in the study, they did not as much benefit from the technology because their asthma was stable and well controlled over the 3 months. The study also suggested that teens who felt more capable of managing their asthma were able to manage their asthma without the technology and were less likely to benefit from the technology. Additional clinical and other criteria are necessary to determine which teens with asthma are more motivated to use the technology and likely to benefit from using it.

5.4.2 Implications for Future Research

Although we assumed that the technology had been tested before regulatory approval was granted, the Piko-1 electronic peak flow meter did not work for most of the study participants. This suggests that pilot study to test the usability of an approved technology

in a particular environment with a particular group of patients, is very important. For the CareCompanion®, pilot testing of the technology should be conducted in a researcher's own environment whenever a new peripheral is introduced in a study. This multiple case study identified some themes related to the role of technology in female teens with asthma. Further exploration of why and how technology might influence asthma management in, for example, teens with different levels of self-efficacy and/or asthma control is needed. An explanatory case study may be able to answer these types of questions.

After the role of technology in teens with asthma is better understood, and technology is tested in the researcher's own environment, we can then move to the second stage, to test the health outcomes of using the technology in clinical settings. Results from these studies would provide evidence of clinical effectiveness of the technology in teens' asthma management.

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APPENDIX A. ASTHMA SELF-MANAGEMENT PLAN (SAMPLE)



Last Name: Patient First Name: Sample
Date of Birth: 12/Dec/1990 Age: 12 yrs 6 mth
ACH: 1-23-45-67 PHN:

Scheduled Clinic Date:

Action Plan

Today, Sample was seen by Dr. Spier.

1. THE MOST IMPORTANT PART OF YOUR TREATMENT IS AVOIDING ENVIRONMENTAL TRIGGERS, SUCH AS: CIGARETTE SMOKE, CATS, DOGS, HORSES.

Your Asthma is in Control When:

1. There is no cough or wheeze.
2. Your asthma does not limit your physical activities.
3. Your need for additional reliever medication is less than 4 per week.
4. You are still able to attend school or special events every day.
5. Your peak flow reading is 216 (90%).

2. Your daily medication controllers/preventers are:

Medication	Amount (mcg/mg)	Puffs/ doses	Times/Day	Device
Pulmicort (brown)	200	1	2	Turbuhaler

Peak Flow Meter:

Your personal best peak flow is 240
80% of personal best is: 192
60% of personal best is: 144
50% of personal best is: 120

3. Your Reliever Medication is:

Medication	Amount (mcg/mg)	Puffs/ doses	Frequency	Device
Bricanyl (blue)	500	1	before exercise	Turbuhaler

First Signs: At the first signs of a respiratory infection (a cold), or for worsening asthma control or peak flows less than 192:

Increase Pulmicort (brown) 200 mcg/mg to 2 puff(s) 2 time(s) a day for at least 5 day(s) or until your asthma is controlled.

If respiratory difficulty add reliever medication:

Start Bricanyl (blue) 500 mcg/mg 1-2 puff(s) every 3-4 hrs as needed.

No Improvement: If no improvement after 3 days, or if peak flows less than 144 on two occasions:

Call your family physician and Start Prednisone 10 mcg once a day for 4 day(s).

Other:

Please let me know if there are any problems next week

Followup appointment with Usual Physician - Dr. Doctor Sample in 1 months.

Followup appointment with Asthma Clinic in 3 months.

Please call Secretary to make an appointment.

Susie Springhetti, Clinical Resource Nurse 943-7324
Marianne Mundy, Clinical Resource Nurse 943-2287
Lori Fairservice, Clinical Resource Nurse 943-7324
Lillian Serak, Secretary 943-7328

APPENDIX B. CARECOMPANION® QUESTIONS**Questions presented on the CareCompanion® screen and their original versions:**

1. Did you awaken last night due to asthma? Yes/No
2. How many times did you use rescue med? 0,1,2,3,>3

(Original: How many times did you use your rescue medication in the past 24 hours?)

3. Did you miss school yesterday? Yes/No
4. Were you limited in physical activity? Yes/No

(Original: Were you limited in exercise/physical activity in the past 24 hours?)

5. How well was asthma controlled in the past 24 hrs? 1-5 scale, 1 is very poor
6. Did asthma interfere with your life? Yes/No
7. Do you need to use your plan? Yes/No

(Original question: Do you need to take action according to your plan?)

Reminder:

1. Please take your medication.

* The CareCompanion® presented 7 questions and 1 reminder per each monitoring session. The questions asked about participants' asthma control in past 24 hours. The participants were instructed how to interpret these questions at the first interviews. Some questions were rephrased because the CareCompanion® had a restriction on total amount of words per each question.

APPENDIX C. INTERVIEW PROTOCOL

Interview protocol for teens after 3 months

Date of Interview _____

Time of Interview _____

Place of Interview _____

Interviewee _____

Interviewer _____

Research Purpose

This research is to explore the role of home telehealth technology (the CareCompanion® with electronic peak flow meter).

Consent

I want to remind you that, even though you agreed to participate in the research, if at any time you feel uncomfortable or choose not to continue, you are free to decline to answer a question.

This interview will be up to an hour. It will be audiotape recorded. Later it will be typed and we will analyze the data. Your name will not be used in the final report and the audiotapes will be destroyed after the final report is written.

You may stop the interview at any time if you want. You can withdraw at any time without jeopardizing your health care.

Questions

1. Now you have finished 3 months monitoring with the CareCompanion®. Could you tell me something about your experience with the CareCompanion® and the electronic peak flow meter in the last 3 months? (Probes: how did the technology work?)
 - How easy was it to work with the technologies?
 - How long did you spend everyday with the equipment?
 - How many times did you measure PFM and answer the questions everyday? When?

- How did the peak flow meters work? (¹*How many times did you try before you gave up? How did you feel when you were not able to transfer the data?*)
 - How did the CareCompanion® work? If there were problems, what technical problems did you have? Can you give me an example of the problem you had? What did you do when you have a problem?
 - *How did it fit in your life? (How did the CareCompanion fit into your schedule? What happened when you were not home and it started beeping?)*
2. Can you describe 2 or 3 things about CareCompanion that you like and 2 or 3 things that you don't like and give me some examples. (*e.g. beep, look, size, etc.*)
 3. Let's talk about your asthma management in the last 3 months. (probes: use of asthma management strategies with the CareCompanion®, behaviour changes)
 - Can you describe your asthma management with the CareCompanion in the last 3 months?
 4. Asthma management goals.
 - What bothers you most by having asthma? Or what goal do you want to achieve by managing your asthma?
 - Do you think using the CareCompanion® helped your achieve your asthma management goal? Why? (Probes: Does the technology match personal goals of asthma management)
 5. How did your asthma self-management work using the CareCompanion® in the last 3 months? (Probes Outcome **expectations** about asthma management using CareCompanion®)

¹ Questions in italic were formulated after a few interviews.

APPENDIX D. ETHICAL APPROVAL



FACULTY OF | UNIVERSITY OF
MEDICINE | CALGARY

2004-03-12

Dr. M.A. Hebert
Department of Community Health Sciences
HMREB
Calgary, Alberta

OFFICE OF MEDICAL BIOETHICS
Room 93, Heritage Medical Research Bldg
3330 Hospital Drive NW
Calgary, AB, Canada T2N 4N1
Telephone: (403) 220-7990
Fax: (403) 283-8524
Email: omb@ucalgary.ca

Dear Dr. Hebert:

RE: Can Home Telehealth Technology Support Disease Management in Teens with Asthma?

Grant-ID: 17548

The above-noted thesis proposal, revised consent form (Version 3, dated March 9, 2004), and interview protocols have been submitted for Committee review and found to be ethically acceptable.

Please note that this approval is subject to the following conditions:

- (1) access to personal identifiable health information was not requested in this submission;
- (2) a copy of the informed consent form must have been given to each research subject, if required for this study;
- (3) a Progress Report must be submitted by 2005-03-12, containing the following information:
 - i) the number of subjects recruited;
 - ii) a description of any protocol modification;
 - iii) any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
 - iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
 - v) a copy of the current informed consent form;
 - vi) the expected date of termination of this project.
- (4) a Final Report must be submitted at the termination of the project.

Please note that you have been named as a principal collaborator on this study because students are not permitted to serve as principal investigators. Please accept the Board's best wishes for success in your research.

Yours sincerely,

Christopher J. Doig, MD, MSc, FRCPC



Chair, Conjoint Health Research Ethics Board

CJD/am

c.c. Child Health Research Committee Dr. T. Noseworthy (information) Research Services Pin Cai
Office of Information & Privacy Commissioner

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APPENDIX E. INFORMED CONSENT FORM



FACULTY OF MEDICINE

Health Telematics Unit
 Health Sciences Centre, G204
 Telephone: (403) 220-7452
 Fax: (403) 270-8025
 Email: hebert@ucalgary.ca

TITLE: Can Home Telehealth Technology Support Disease Management in Teens with Asthma?

SPONSOR: None.

INVESTIGATORS:

Principal Investigator:

Dr. Marilynne Hebert – Assistant professor, Health Telematics Unit, Department of Community Sciences, Faculty of Medicine, University of Calgary

Co-Investigators:

- Pin Cai – Graduate student, Department of Community Health Sciences, Faculty of Medicine, University of Calgary
- Dr Sheldon Spier - Associate Professor, Department of Pediatrics, Faculty of Medicine, University of Calgary
- Sybil Young- Outreach [Services](#) Manager, Southern Alberta Child & Youth Health Network, Alberta Children's Hospital

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your child's participation will involve.

If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND



CareCompanion (Size: 20×40cm)

Home telehealth is a relatively new way to deliver home care services, using new technologies. In this study, a CareCompanion (the equipment shown in the above picture) with a peak flow meter will be located in [your](#) home and a computer in the nurse or physician's office. Information will be sent over the telephone line.

Home telehealth technology has been helpful in monitoring chronic disease including diabetes and asthma. Several studies in asthma (including one in teens) demonstrated that data could be successfully transferred, and that users accepted the technology. However, there is limited information on how the technology might influence teens' ability to follow their asthma action plans (e.g. measuring peak expiratory flow (PEF), monitoring symptoms, taking medications), and therefore improve their asthma control.

6 teenagers with asthma will be recruited for the study from Alberta Children's Hospital Asthma Clinic.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to explore adolescents' experiences of asthma management using home telehealth technology (CareCompanion).

WHAT WOULD MY CHILD HAVE TO DO?

Your child will monitor and report their symptoms and PEF daily using CareCompanion for 3 months. He/she will send the data daily via a telephone line to a computer in a nurse's office. It will take about 10 minutes to complete data transmission. The nurse will track and trend symptoms and PEF values. Your child is expected to continue to take action according to their asthma self-management plans. Follow up will only be initiated under emergency situations.

You and your child will be interviewed separately before and after the 3-month monitoring. Each interview will be up to 1.5 hours. The discussion will be audio tape recorded and later transcribed. All the audio tapes will be destroyed when the report is complete. [Your or your child's names](#) will not be used in the final report.

WHAT ARE THE RISKS?

There are no known risks associated with the study.

ARE THERE ANY BENEFITS FOR MY CHILD?

If you agree for your child to participate in this study there may or may not be a direct medical benefit to them. The study will provide close monitoring of your child's asthma. Their asthma may be improved during the study but there is no guarantee that this research will help them. The information we get from this study may help us to provide better management in the future for adolescent patients with asthma.

DOES MY CHILD HAVE TO PARTICIPATE?

Your child's participation in the study is voluntary. If your child does not take part in this study, he/she will continue to receive routine asthma care services. You and your child

are free to withdraw at any time without jeopardizing your child's health care. To withdraw simply tell [the respiratory therapist](#) that you no longer wish to participate.

If new information becomes available that might affect you and your child's willingness to participate in the study, you will be informed as soon as possible.

WHAT ELSE DOES MY CHILD'S PARTICIPATION INVOLVE?

Although it may not be legally required, your child's agreement to participate will be sought. Your child will not be enrolled in the study unless he/she wants to participate.

WILL WE BE PAID FOR PARTICIPATING, OR DO WE HAVE TO PAY FOR ANYTHING?

On completion of the study, your child will receive a \$40 honorarium.

You will not have to pay for anything related to this research. The CareCompanion will be installed at the beginning of the study and removed at the end of the 3 months. It plugs directly into the existing phone line and does not interfere with other telephone functions.

WILL MY CHILD'S RECORDS BE KEPT PRIVATE?

All information that is collected from you and your child will be kept private. This means your child's name will not appear in any information shared among research team members or published in the results. All of the information you and your child contribute will be identified with subject initial and not your child's name. Only your child's pediatrician and the co-investigator who will interview you and your child will have access to the name and number key to check for accuracy. All of the information we collect will be kept in a locked cabinet. All tapes will be destroyed at the end of the project. You should note, however, that the researchers may be required to grant access to the information to any legally authorized party or to the Ethics Board for audit purpose.

**CONSENT TO THE DISCLOSURE OF INDIVIDUALLY IDENTIFYING
HEALTH INFORMATION**

To install and remove the CareCompanion from your home for the purposes of your child's participating in the study, you will be asked to authorize the name and address of your child to be disclosed by _____, name of asthma clinic nurse, in accordance with section 34 the *Health Information Act*, to _____, study personnel of the project.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your child's participation in the research project and agree to his/her participation as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw your child from the study at any time without jeopardizing their health care. If you have further questions concerning matters related to this research, please contact:

Dr. Marilynne Hebert at 403-220-7452

-or-

Dr. Sheldon Spier at 403-943-7503

If you have any questions concerning your child's rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

Parent/Guardian's Name (Printed)

Signature and Date

Child's Name (Printed)

Signature and Date

Investigator/Delegate's Name (Printed)

Signature and Date

Witness' Name (Printed)

Signature and Date

The investigator or a member of the research team will, as appropriate, explain to your child the research and his or her involvement. They will seek your child's ongoing cooperation throughout the study.

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.