Clinical User-Experience Evaluation of Type 2 Diabetes Patients using an In-Home Monitoring Device: Complementing a Telemedicine Clinical Trial with HCI Evaluation

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Thesis submitted by

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Statement on the Contribution of Others

The research described and presented in this thesis was undertaken by the author under supervision of Dr. Trina Myers and Professor Ian Atkinson. Frequent advice was received from Dr. Muriel Soden from a healthcare perspective. Occasional advice was received from Dr. Dianna Madden and Dr. Tim Marsh.

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"*There is no desire that anyone holds for any other reason than that they believe they will feel better in the achievement of it. Whether it is a material object, a physical state of being, a relationship, a condition, or a circumstance - at the heart of every desire is the desire to feel good.*" -- (Abraham Hicks). I commenced this PhD with the desire to feel good. I have felt mostly joy all along the way. Thank you Universe!

List of Publications

Jalil S, Myers T, Atkinson I (2015), 'A Meta-Synthesis of Behavioral Outcomes from Telemedicine Clinical Trials for Type 2 Diabetes and the Clinical User-Experience Evaluation (CUE).', Journal of Medical Systems 39 (3):1-21.

Jalil S, Hardy D, Myers T, Atkinson I (2014), 'But it doesn't go with the décor: domesticating a telemedicine diabetes intervention in the home.', *Proceedings of the 26th Australian Computer-Human Interaction Conference on Designing Futures: the Future of Design,* Sydney, Australia, 2-5 December 2014. ACM, pp. 280-289.

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Jalil S, (2013), 'Persuasion for in-home technology intervened healthcare of chronic disease: Case of diabetes type 2.', *Adjunct Proceedings (Doctoral Consortium) of 8th International Conference on Persuasive Technology (Persuasive-2013)*, Sydney, Australia, April 3-5.

I dedicate this work to—

my parents Shamsun Nahar Nadira & Abdul Jalil Thanda.

Love transcends time, dimensions, space and reality.

Abstract

A worldwide demographic shift is in progress. The percentage of the population that is ageing (those over the age of 64 years) is projected to more than double in the next four decades. People aged over 64 have a higher burden of disease, so the demand for medical care will increase. Unfortunately, the present healthcare models will be inadequate to handle the demands of the ageing population.

One proposed remedy is to provide in-home assisted healthcare with technology-intervened approaches. Telemedicine, telehealth and e-health are part of current technological approaches that provide clinical treatment through a technology intervention. These technology interventions are evaluated through clinical trials, which are common procedures in evidence based medical science.

Clinical trials are targeted to measure only improvements in medical conditions and the treatment's cost effectiveness. They do not investigate patients' experiences with these technologies. However, the effectiveness of a technology also depends on the interaction pattern between the technology and its users, especially the patients. The discipline of Human-Computer Interaction (HCI) provides various user-centred evaluation methods to assess user interaction and satisfaction with a technology.

As a component of this qualitative research study, I developed a novel research methodology - the Clinical User-Experience Evaluation (CUE). The CUE is a HCI user-evaluation technique that complements a wider medical clinical trial. This clinical trial investigated medical improvements and cost effectiveness of telemedicine in-home monitoring technology for type 2 diabetes patients in the Townsville region in Australia. The clinical trial was governed by the Townsville-Mackay Medicare Locals (TMML). The CUE investigated how patients interacted with in-home monitoring technology that was being used as part of TMML's clinical trial.

The CUE consisted of three stages: 1) a contextual inquiry, 2) a semi-structrued interview and 3) an anonymous survey. I defined the precise stages of CUE to separate it from the activities of the clinical trial, which were conducted by clinical researchers/nurses. The CUE uses an ethnographic approach. I carried out the CUE in the field with nine type 2 diabetes patients. In addition, I interviewed two nurses to complement the patients' interviews.

Stage 1 of CUE was a contextual inquiry that was performed *in-situ* at a patient's home. Patients used the technology with the think-aloud method during this stage, during regularly scheduled times for using the technology.

Stage 2 of CUE was a semi-structured qualitative inquiry to understand patients' experience and expectations. In addition, questions that arose during stage 1 and any topic mentioned by the patients were explored. The interview took place directly after stage 1, while perceptions were still fresh in the mind of the patients.

Stage 3 was a semi-anonymous survey to encourage patients' candor. I observed certain patterns of behaviour among the patients in this clinical trial, during the first two stages. I developed a semi-anonymous survey to verify these observations by obtaining patients' opinions. This survey in stage 3 was conducted online eight months after stage 2.

Prior to the implementation of the CUE, I conducted a meta-synthesis of past clinical trials of type 2 diabetes. The meta-synthesis demonstrated that past telemedicine technologies had positive behavioural outcomes on patients. Therefore, implementation of CUE held promises of new findings in a traditional clinical trial.

Data from CUE was analysed and presented as the following topics in this thesis.

1. Patients' experience of using the device;

2. A User-Centred Design for type 2 diabetes patients;

3. Domestication of the technology; and

4. Hidden Hypotheses by patients and nurses-- this part presents my observations about the assumptions that the patients made about the trial and the assumptions that the nurses made about the patients and the technology. I call these assumptions "hidden hypotheses".

Key analytical findings from the CUE depicted that patients value the benefits of in-home monitoring but the current device did not possess all functionalities that type 2 diabetes patients require. The User-Centred Design (UCD) methodologically confirmed the functionalities the in-home monitoring device should contain, to meet the expectations of type 2 diabetes patients. Analysis on the domestication of the device showed that patients did not change the location of the device after the initial placement. The hidden hypotheses disclosed some causes of why patient feedback about technology may remain hidden in a medical clinical trial.

List of Abbreviations

T2D	Type 2 Diabetes
IT	Information Technology
ICT	Information and Communication Technology
CUE	Clinical User-Experience Evaluation
TMML	Townsville-Mackay Medicare Locals
NBN	National Broadband Network
HCI	Human-Computer Interaction
PD	Participatory Design
PT	Persuasive Technology
UCD	User-Centred Design
CD	Contextual Design
ADSL	Asymmetric Digital Subscriber Line
RCT	Randomised Controlled Trial
CSIRO	The Commonwealth Scientific and Industrial Research Organisation

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Chapter 1. Introduction

The world is in the midst of a profound demographic shift. Advances in health and medical science have improved the life expectancy of humans. As a result, the proportion of the ageing population (those above 64 years of age), in comparison to the proportion of the younger population, is increasing. The United Nations' report titled *World Population Ageing 1950–2050* stated in 2001 that by 2050 the number of people throughout the world aged over 64 would exceed the younger population for the first time in the history of humankind. The reversal in the proportions of the young to the ageing began in 1998 in the more developed regions of the world [1]. The proportion of the global ageing population was 8% in 1950, 10% in 2000, 11% in 2012 and is projected to reach 22% by 2050 [2].

Demand for health care will increase with this demographic shift. Physical and sensory deficits commonly accompany ageing, so hospital visits will increase. The demographic shift will create unprecedented demands on healthcare for ageing and independent living, because this is the first time in human history that a shift like this has occurred. However, the existing healthcare models are not designed to handle the burden of the projected demographic changes [3]. A predicted lack of doctors, nurses and hospital beds for the projected patient numbers will generate unsustainable social and economic consequences.

Type 2 Diabetes (T2D) is one of the most dangerous chronic diseases for both the general and the ageing population [4]. T2D is a condition where the body essentially develops immunity to insulin (produced by the pancreas) and, as a result, blood glucose levels are under-regulated. Intensive management of blood glucose levels, through medical intervention or lifestyle adaptations (better diet and

increased exercise), has been shown to reduce complications in T2D [4].

T2D is currently one of the world's fastest growing diseases; the prevalence of T2D rose from 171 million affected in 2000 to 366 million affected in 2011 worldwide [5]. 1.1 million Australians were diagnosed with T2D in 2013. By 2031, 3.3 million Australians will have T2D[4]. Currently, 1.5 billion Australian dollars are spent on the direct costs of diabetes per year, while the indirect costs are as high as 14.6 billion dollars [4].

Opportunely, we live in interesting times for technological advancements in personal data collection. Technologies such as smartphone apps, Fitbits, Nike Fuelband, GPS devices, and physical activity trackers with accelerometers allow individuals to track all aspects of their daily lives, such as the number of steps they take, the food they eat, how much sleep they get, their heart rate, and their mood. Tracking activities help individuals learn about themselves and assist to take action to remain healthier. Such tracking of data about one's activity is known as *Quantified-Self* [6, 7]. Health data that used to be explained only by medical professionals are today easily available to individuals. Individuals are showing a great interest in these technologies. This phenomenal change in public culture is known as the "*Quantified-Self Movement*".

Although individuals have only recently become interested in their own health through the quantified-self movement, the medical community has been providing medical advice and care to individuals through *Information and Communications Technology* (ICT) since the 1950s [8]. Modern technological innovations such as ubiquitous and wireless sensors promise better means for providing medical care from the medical professionals to individuals at home.

In-home monitoring through technology-intervened treatments presents one possible way to provide ambulatory health care and

consequently reduce the number of hospital visits in the future ageing population. In the past, technology-intervened treatments were used mostly for chronic illnesses such as cardiopulmonary disease, asthma and heart failure, but they are now increasingly used for diabetes monitoring [9]. In the scientific literature, technology-intervened treatments are referred to as telemedicine, telehealth, e-health, etc.

Telemedicine is the use of ICT to provide clinical treatments over distances [10]. *Telehealth* is defined by the *American Telemedicine Association* (ATA) as closely associated with telemedicine but as also encompassing a broader range of remote healthcare methods, not always involved in clinical services [11]. *E-health* is an emerging field at the intersection of medical informatics, public health and business, and refers to health services and information delivered or enhanced through the Internet and related technologies [12].

Technology-intervened treatments, like telemedicine, hold promise for the management of chronic diseases from home [13]. With the advent of the availability of inexpensive wireless sensor networks [14, 15], technology-intervened treatments are increasing rapidly. A paradigm shift in healthcare is in progress.

1.1 Evaluation of Telemedicine: Problems and limitations

A strong challenge remains ahead for technology-intervened treatments. These treatments belong in a cross-disciplinary area where *Information Technology* (IT) meets medical science. Telemedicine technology first requires approval from a regulatory body regarding its safety for humans. The *Therapeutic Goods Administration* (TGA) is the regulatory body for therapeutic goods (including medicines, medical devices, gene technology and blood products) in Australia. In the USA, the equivalent regulatory body is the *Food and Drug Administration*

(FDA). Once a telemedicine device receives approval from the TGA, it goes to a clinical trial.

A clinical trial is an evaluation to gather data for *Evidence Based Practice* (EBP). Medical science uses EBP to determine the effectiveness of a treatment through clinical trials. Clinical trials are conducted on large samples of homogenous patients, for long periods ranging over a year. Larger samples help provide stronger evidence in clinical trials. For example, clinical trials of T2D emphasise comparing blood glucose and other medical conditions at baseline with those at the end of the trial and at specific intervals. These trials often run for at least six months, and up to a year. For a T2D telemedicine clinical trial to be considered effective it must provide quantitative evidence that the patient's condition improved and that the intervention was cost-effective.

Telemedicine technology remains a 'black box' during evaluation through clinical trials. What happens when patients use the technologies remains obscure during these trials. Systematic reviews have shown that clinical trials assess what went in (e.g. baseline measures) and what came out (e.g. post-intervention measures), but what happens inside the interventions (e.g. such as how patients felt about using the device) and the development of the interventions (e.g. not achieving a match between technology and context) – are rarely a focus of attention [16]. For example, in a clinical trial of T2D, the long term blood glucose Hb1Ac of patients at baseline is compared against Hb1Ac at the end of the trial. Improvements in Hb1Ac, along with additional health parameters, help the clinical researchers to conclude whether a telemedicine technology for T2D was effective or not.

Clinical trials do not investigate what type of technology was used, effects of the technology on the patients, how patients interact with these technologies or how patients feel when using these technologies. Investigations of interactions between the patient and the technology are important because failure to use a technology by

patients or an adverse response to the technology from patients can cause patients to withdraw from a clinical trial and, more importantly, to refuse to use such technologies in future. A disregard for the needs of patients and professionals, social-cultural habits and the complex nature of healthcare systems results in relatively low impact and uptake of telemedicine and e-health technologies [17].

Results of a clinical trial may prove that a device is effective but patients' satisfaction with the device, and the possibility of future adoption of the device, remains uncertain. For example, when an in-home monitoring device is given to a patient for a long period, such as six months to one year, it becomes a part of the patient's domestic life. This technology is not merely a treatment like a drug. However, clinical trials generally do not investigate or report on the interaction the patients have with a device. Therefore, important findings about how a patient feels about the device, what barriers the patients experience, and how enjoyable s/he finds the experience of using the device, remain unknown.

Clinical trials are time-consuming and take several years to be completed with sufficient evidence. By the time a clinical trial has determined that a telemedicine device is "effective", the technological markets may have several advanced alternatives readily available. Technology, on the other hand, is a rapidly evolving industry.

In summary,

- Clinical trials only check medical improvements and cost effectiveness of interventions;
- Patients' experience as users of the technology is not captured in clinical trials, possibly due to disciplinary differences;
- Patients' experiences of using the technology are paramount because even though a technology may be proved effective by the clinical trial, patients may still refuse to use it due to their unsatisfactory experience with it;

- Results regarding the use of the technology may remain diluted and/or lost with the clinical trial data;
- Clinical trials are time-consuming, taking several years for a complete evaluation; and
- Failure to use technology may be driven by patient preference/adverse response in clinical trials.

1.2 The Research Question

While clinical trials are limited in their ability to evaluate telemedicine devices from the patients' perspective, they are effective in determining the medical benefits and cost effectiveness of the devices. Clinical trials are not designed to show how patients use, or how they feel about using, a telemedicine device. Therefore, new methods of evaluation are needed to understand how patients use a telemedicine device during a clinical trial.

Thus the research question that guides this thesis is –

How to evaluate technology-intervened treatments (such as telemedicine) during a clinical trial, to understand patients' use and experiences with the device?

This research question has been separated into the following sub-queries:

Q1. How do patients use a telemedicine device?

Q2. How do patients feel while using a telemedicine device?

Q3. Which function, designs of the device satisfies/dissatisfies the patients?

Q4. How to evaluate traditional clinical trials so they can evaluate questions Q1-Q3?

New ways of evaluation are needed to resolve the problems and limitations in traditional clinical trials with telemedicine devices. The

following section presents the motivation to provide a possible solution to the research question.

1.3 Motivation

While patients' experiences with a technology may remain unknown in a clinical trial, investigation of experiences of humans with a technology is a common practice in *Human-Computer Interaction* (HCI). HCI studies the design, implementation and evaluation of technologies and systems. HCI and *IT* are intersecting fields as they both conduct research with technology. A patient who uses a technology-intervened treatment is a "user" of the system in HCI, which puts strong emphasis on understanding users and evaluating use of technology to inform human-centred technology design.

Participatory Design (PD) is a popular HCI methodology that engages potential users and stakeholders with the technological design team during the design, implementation and evaluation of a technology. PD does not simply investigate a situation with users, but also calls for action to ameliorate the situation [18]. Researchers and participants engage in systematic, iterative cycles. Each cycle consists of planning, acting, observing and reflecting prior to the next cycle. The method facilitates direct participation in a dynamic inquiry process [19, 20].

Another popular practice in HCI is the use of *ethnography* in IT, such as *Contextual Design* and *Applied Ethnography*. In these approaches, users are observed in their current context of work and the activities they perform. This action is extended by further interviewing. The knowledge from observation and interviews then guides the designers and researchers to create a *User-Centred Design* (UCD) for the technology or the system.

Practices in HCI involve humans and prioritise designing technology for humans. Currently, clinical trials lack a way to evaluate

and understand patients' uses of a technology, such as telemedicine (as described in section 1.1). In this research, I was inspired by HCI methods and opted to bring them to clinical trials in EBP to develop a deeper understanding of patients' behaviour.

1.4 A Possible Solution

To answer the research question, I developed an evaluation methodology for technology-intervened treatments, motivated by HCI empirical evaluation methods. The following sections present further details.

1.4.1 Approach

Telemedicine is the discipline where technology and medical science meet. Telemedicine lies at the intersection of medical science and IT; it provides medical care determined by medical science using technology developed by information technologists/biomedical engineers. Surprisingly, evaluation of telemedicine is undertaken only from the medical science perspective (Figure 1-1). Why cannot a telemedicine device be additionally evaluated from the technology use perspective, in the same way that the discipline of HCI performs its evaluations?

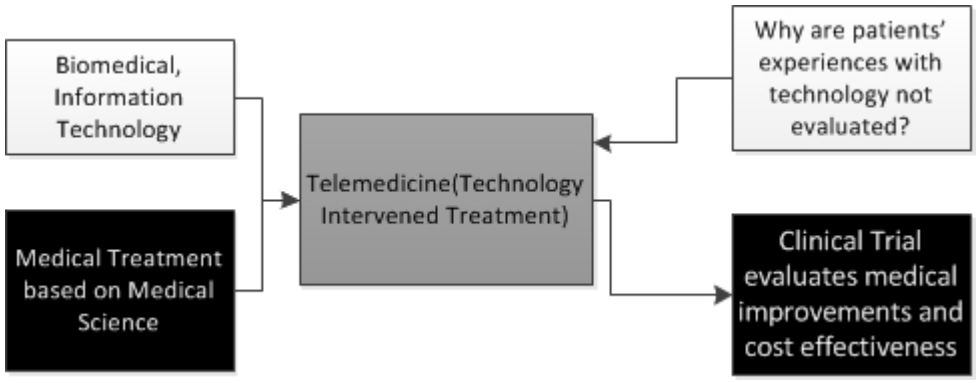

Figure 1-1. Current state of telemedicine evaluation with clinical trial

Hence, this research takes an approach towards a technology use perspective evaluation as seen in empirical user-evaluation methods in HCI (Figure 1-2).

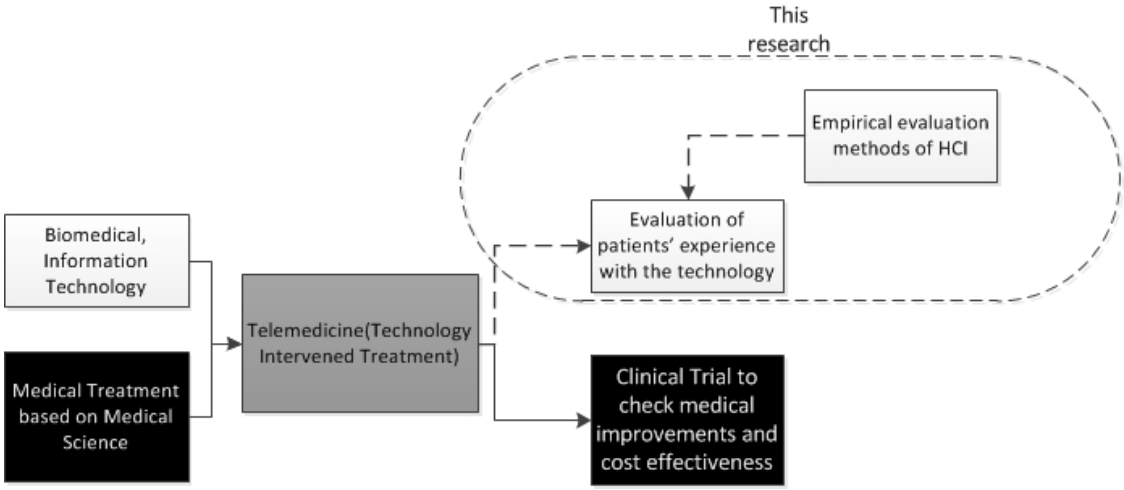

Figure 1-2. The approach taken in this research to evaluate telemedicine technology

However, cautious steps are needed when developing a new methodology to work with a clinical trial. *How*, *when*, *who* and *what* will be tested should be carefully considered, in order to blend appropriately with a clinical trial. Clinical trial protocols must be respected, as clinical trials measure the health benefits that are the lifesaving aspects of a telemedicine device.

I have developed a method called the *Clinical User-experience Evaluation* (CUE) (Figure 1-3) for this research. The CUE investigates how patients in a clinical trial interact with a device and patients' experiences of using the device. All clinical trial protocols were considered when developing this methodology and careful consideration was given to decide *how*, *when*, *who* and *what* will be investigated with this new methodology, in order that it would not interfere with or impede a clinical trial.

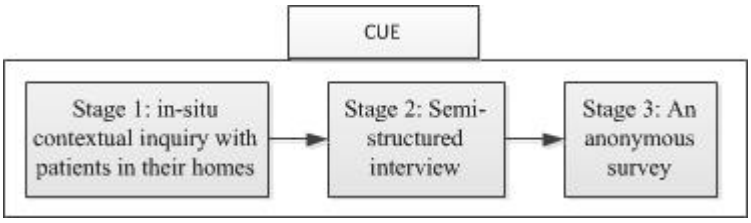

Figure 1-3. The Clinical User-experience Evaluation methodology

The CUE was implemented within a clinical trial, in a real world situation. This clinical trial was conducted by *Townsville-Mackay Medicare Locals (TMML)* in North Queensland in Australia. TMML provides health services to Townsville and surrounds. In this clinical trial, the TMML tested whether online monitoring of patients was effective in improving their diabetes, and also whether it was feasible and acceptable to the patients and their health professionals [21]. 210 patients were recruited in Townsville, Mackay and Brisbane. The project budget was 3 million Australian dollars.

The CUE was conducted in conjunction with TMML's clinical trial of a telemedicine in-home monitoring device for T2D.

1.4.2 Scope

This research explores patient experience in the post-rollout phase. A real world case of T2D patients who used a telemedicine device to manage their T2D from home is presented. This research is solely interested in the patients' use of the telemedicine technology. Generally, the term "user" would represent anyone who uses the telemedicine device, including medical professionals such as nurses, doctors, etc. and the patients. However, the patients' perspective is most important in this study. Notably, the terms *user* and *patient* are used interchangeably in the context of this thesis.

Every participant in the CUE is a T2D patient who was enrolled in the clinical trial by TMML. In most of the thesis I use the term *patients*, but also occasionally refer to them as *participants*, in a context

where necessary, i.e. during research methodology and recruitment. All participants are T2D patients in this research.

I was not involved in the clinical trial or its outcomes: the clinical researcher/nurses led that work. I positioned myself as an observer, able to ask questions of the actual participants in the absence of the clinical researchers. These observations, along with my recommendations, were sent back to the medical researchers for improvements in the future. My position was neutral.

1.4.3 Steps of the solution

1.4.3.1 Clinical trial and meta-synthesis

This research started with a literature review of clinical trials of type 2 diabetes and telemedicine interventions published since 1990, before formulating the CUE method and implementation. Clinical trials were selected specifically for T2D patients' technology use or experience.

1.4.3.2 Contacting past authors

I contacted 26 authors of clinical trial papers through personal email and enquired whether data related to patients' technology use and experience were part of their unpublished data set.

1.4.3.3 Developing the CUE methodology to fit a clinical trial

Next, I developed the CUE and defined it to meet clinical trial protocols. I proposed the CUE to the TMML. I received ethics approval from James Cook University to conduct human research.

1.4.3.4 Implementing the CUE

At this stage, I met nine patients enrolled in the clinical trial of TMML and carried out the CUE with each of them.

1.4.3.5 Findings and Analysis

The findings were then reported, analysed and validated with interviews from two nurses and an anonymous survey online (stage 3 of CUE).

1.5 Research Contribution

This research contributes to the areas of healthcare, healthcare for T2D, telemedicine evaluation, IT evaluation, and HCI. This research particularly answers the question: "*is there any benefit in understanding patients inside a clinical trial?*" and provides evidence that significant benefits are gained from this kind of evaluation.

1.5.1 A New Methodology the CUE

This research provided a new qualitative methodology, the CUE, to be used in conjunction with a clinical trial. The CUE specified the roles of the CUE researcher and the clinical trial researchers and research protocols to conduct the CUE. CUE can provide evaluation from the technology use and the patients' perspective during a clinical trial.

1.5.2 Evidence that CUE works with clinical trial

The case study of the CUE in a T2D clinical trial showed that the CUE works without obstructing a medical clinical trial. In this research, the clinical trial was solely about T2D.

1.5.3 Bridges the gap between IT and Medical Science through HCI

This research is a novel approach where a clinical trial and HCI researcher works in an evaluation from two different perspectives. The research demonstrates the need for a holistic approach to evaluate

telemedical systems (encompassing both the medical clinical trial and technology user experience evaluation).

1.5.4 Domestication of telemedicine

This research provided evidence and knowledge on how a telemedicine device for T2D is domesticated by patients. This research is the first example to provide evidence of domestication of a telemedicine device as compared to domestication of other technologies by users.

1.5.5 Design Implications for a telemedicine device for T2D

The CUE revealed data to provide future design implications and considerations to develop a patient-centered telemedicine device for T2D patients. Findings of this research can inform future telemedicine T2D development that thoroughly meets patients' requirements and expectations.

1.5.6 Promises of Persuasive Technology

This research signifies that telemedicine can immensely benefit to collaborate with Persuasive Technology to influence patients' behaviour. Evidence from this research show that Persuasive Technology and telemedicine can work together to provide better benefits to T2D patients.

1.5.7 Hidden Hypotheses to explain hidden assumptions of researchers

Finally, telemedicine, healthcare researchers and IT/HCI researchers would benefit from understanding the concept of "hidden hypotheses" in clinical trials so that participants and researchers may work with hidden beliefs that an outside observer may identify and flesh out. Hidden hypotheses could explain why the participants and the researchers do certain things the way they do them.

1.6 Use of the personal pronoun

Though traditionally personal pronouns are not the convention in scientific publications, modern researchers have used them in *Computer Science*, *IT* and *HCI*. In this thesis, I would like to use "I" because this thesis uses an ethnographic approach; my thoughts need to be separated, and not diluted in the thesis as a fact or universal truth. Use of "I" articulates what an author's thought process is and helps portray an author's journey, juggling between choices during a research project. Moreover, this thesis is an exploration into an area between two disciplines. Experiences and observations of the author need to be articulated with the use of "I".

1.7 Thesis Structure

This thesis is structured in eight chapters as shown below.

Chapter 1: Introduction

This chapter introduces this research.

Chapter 2: Research Background

This chapter presents the literature concerning demography shift, telemedicine, clinical trials, HCI, type 2 diabetes and costs.

Chapter 3: Methodology

This chapter presents the rationale for the CUE methodology followed by details of its development.

Chapter 4: Implementation of the CUE

This chapter presents all details about participants, the fieldwork process and human research ethics.

Chapter 5: Findings of CUE

This chapter reports the results of the CUE.

Chapter 6: Analysis and Discussions

This chapter presents the analysis of the findings about patient feedback on the device, a UCD for T2D telemedicine, and domestication of the device in patients' homes.

Chapter 7: Analysis: Hidden Hypotheses in the Clinical Trial

This chapter presents the analysis of the hidden suppositions that the patients and the nurses had about this clinical trial.

Chapter 8: Conclusion

This chapter presents concluding remarks, future work and contributions of this research.

1.8 Conclusion

This chapter introduced the readers to a future global situation that has been prompted by a fundamental demographic shift. Technology such as telemedicine will increasingly be used to meet future healthcare demands that will be caused by this shift. Some problems and limitations exist in the current evaluation methods for telemedicine, such as clinical trials.

A general research question was posed to address this problem. This question was broken down into sub-queries to define the scope of the investigation. The solution approach of this research is CUE, which is a qualitative evaluation from an HCI perspective. CUE was inspired by the ethnographic approach in HCI to complement a clinical trial.

The research process began with an investigation of traditional clinical trials of telemedicine and of T2D and their limitations. To provide a solution, existing evaluation methods of HCI were investigated. Next, the CUE methodology was developed and implemented in a real clinical trial.

The findings from the CUE were fruitful. Thorough knowledge of how patients use the telemedicine device and the patients' true voice was heard through the CUE. Analysis of the findings provided interesting knowledge on how a telemedicine for T2D patients could be designed and built effectively to help patients. Overall, CUE provided a significant way to complement telemedicine clinical trials.

Chapter 2. Research Background

This chapter presents the existing background literature and puts this research in context with that literature. This chapter elaborates the ideas outlined in chapter 1 and explains the future situation with telemedicine technology for T2D, as described in the literature. Sections 2.1 to 2.4 explore the major points raised in the background. Next, section 2.5 provides a discussion to summarise the situation and directs readers to the specific data available from clinical trials, which is elaborated in section 2.6. Section 2.6 provides a meta-synthesis through a systematic literature review of clinical trials. Finally, section 2.7 discusses and concludes the stance taken in this research.

2.1 World Demographic Shift

The world is going through a major demographic shift. The percentage of the population which is ageing (those who are above the age of 64) was 8% in 1950; this percentage is projected to more than double by reaching 22% by 2050 [2]. Australia's aged population will rise from 13% to 25% by 2056 [22]. In the United Kingdom, 10 million people are over 64 years old as of 2010 and this number will have nearly doubled to around 19 million by 2050 [23]. By 2050 the US population aged sixty-five and older is projected to reach 89 million -- more than double the 40.5 million elderly people in 2010 [24].

Three of the major challenges that may arise from the increase in the ageing population are -- additional demands on healthcare, a change in the patient versus the available healthcare ratio, and increasing healthcare costs.

The first challenge, the increasing demands on healthcare, will occur because the ageing population has a higher burden of disease

than the population on the whole. Burden of disease is a measurement to assess and compare the relative impact of disease on a population [25]. An increased percentage of ageing population requires higher levels of medical care.

The second challenge will be the change in the patient-to-healthcare ratio. The demographic shift will reduce the patient-to-doctor, patient-to-nurse and patient-to-hospital bed ratios. The ageing population exerts demands on the present healthcare models through higher incidence of chronic diseases [26] and the need for long term care and assistance of elderly people [27]. The current healthcare models will be inadequate to meet the demands of the future population shifts.

The third challenge will be higher healthcare costs. As the demand for healthcare increases, healthcare costs will continue to rise. Population ageing will tend to lower both labour-force participation and savings rates, thereby creating a future slowing of economic growth [28].

Healthcare models need to be decentralised from hospitals to meet the medical demands of the ageing population in an economically viable manner [3, 27]. Future healthcare systems will be enabled to manage patients from their homes through in-home monitoring technologies [29]. Telemedicine, telehealth and e-health are technological interventions that are presently in practice for remotely delivering healthcare to patients. The next section explores these technology-intervened treatments.

2.2 Technology-intervened treatments: Telemedicine, telehealth and e-health

Telemedicine is not new. It was introduced more than half a century ago [10]. Telemedicine refers to the use of communications and

IT to provide clinical treatments over distances. Fast growing ICT has helped telemedicine to grow and continuously redefine itself over time.

There is now a wide range of technologies available for telemedicine, spanning the entire spectrum of ICT [30-32]. For example, Sood *et al.* (2007) collected 104 peer reviewed definitions of telemedicine to ultimately define it as follows:

Telemedicine being a subset of telehealth, uses communications networks for delivery of healthcare services and medical education from one geographical location to another, primarily to address challenges like uneven distribution and shortage of infrastructural and human resources.

In 2010, the *World Health Organisation* (WHO) defined telemedicine as:

The delivery of health care services, where distance is a critical factor, by all health care professionals using information and communication technologies for exchange of valid information for diagnosis, treatment and prevention of disease and injuries, research and evaluation, and for the continuing education of health care providers.

Telehealth is defined by the ATA as closely associated with telemedicine. Telehealth is often used to encompass a broader definition of remote healthcare that does not always involve clinical services. Videoconferencing, transmission of still images, e-health including patient portals, remote monitoring of vital signs, continuing medical education and nursing call centres are all considered to be included[34].

The term e-health originated when the Internet was becoming widespread. It can be viewed as a type of e-commerce. According to Eysenbach (2001) [35], the term e-health was used more commonly by industrial and commercial enterprises than by academics and was created to be aligned with other “e” words such as e-commerce, e-business, e-solutions, etc. Eysenbach’s definition of e-health is:

E-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology [35].

The definitions of e-health were so variable in the academic literature that Oh *et al.* (2005) carried out a systematic review of e-health definitions from 1999 to 2004 [36]. The review found that the term e-health encompassed a set of disparate concepts, including health, technology, and commerce. It identified 51 unique published definitions, which included the concepts of health, technology and commerce with varying degrees of emphasis. Another systematic review carried out by Pagliari *et al.* (2005), mapped the contents of e-health topics and found that the concept extended across stakeholder groups, including providers, patients, citizens, organisations, managers, academics and policymakers[37]. They noticed a tendency for an inclusive model to predominate in Europe and a narrower consumer focused one in the USA, but finally concluded that e-health is well represented by the global definition suggested by Eysenbach (2001). They suggested a slightly adapted definition, as follows:

E-health is an emerging field of medical informatics, referring to the organisation and delivery of health services and information using the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a new way of working, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology. [37]

According to the WHO [38], e-health is the transfer of health resources and health care by electronic means. It encompasses three main areas:

- The delivery of health information, for health professionals and health consumers, through the Internet and telecommunications.
- Using the power of IT and e-commerce to improve public health services, e.g. through the education and training of health workers.
- The use of e-commerce and e-business practices in health systems management.

2.2.1 Comparison between telemedicine, telehealth and e-health

Telemedicine and telehealth existed before the advent of the Internet and continued to make improvements through the medium of the Internet, while e-health emerged after the birth of the Internet. The goal of telemedicine is therapeutic between a doctor or healthcare provider and a patient. The concept of telehealth additionally includes meetings between GPs (General Practitioner) and administrative staff, education and training of GPs and other stakeholders involved in treatment, public health improvement and prevention, and information sharing etc. Therefore, telehealth's motives are preventive, curative and promotive in health services. Telemedicine is a subset of telehealth [10].

E-health encompasses both telehealth and telemedicine. E-health could be seen as the growth of telemedicine and telehealth. It is not explicitly mentioned whether it is compulsory to include the terms "telemedicine" and "telehealth" when talking about e-health. In the literature, e-health's scope is broader than telehealth and telemedicine.

Telemedicine has been applied to treat various medical conditions - Heart disease management [39], [40], [41] [42], [43], diabetes [44] [45], [46] elderly care [47, 48], loneliness for disabled people [49], disability [50] and mental health [51] [52] -- are a few examples.

2.3 Type 2 diabetes and telemedicine

Diabetes patients have overwhelmed the healthcare system for decades [53]. On average people with diabetes are three times more likely to be hospitalised than non-diabetic individuals [54]. T2D is the most common chronic illness that threatens the well-being of the ageing population. Diabetes is one of the most dangerous chronic diseases that may be compounded by serious complications resulting in various organ involvements.

There are two main forms of diabetes: type 1 and type 2. In addition, there is gestational diabetes, which occurs in pregnant women. Gestational diabetes is a marker for development of T2D later in life. Type 1 diabetes causes the pancreas to cease producing insulin. Without insulin, the body's cells lose the ability to regulate glucose uptake of the cells and the body burns its own fats as a substitute. This is potentially life threatening if not treated [4]. Patients with type 1 diabetes accumulate dangerous chemical substances in their blood from the burning of fat if not treated with daily injections of insulin. T2D is more common than type 1 and is the most common chronic illness that threatens the well-being of the ageing population. T2D accounts for 85-90% of all people with diabetes [4]. While it usually affects older adults, younger people, even children, are now developing T2D. The pancreas makes some insulin in T2D patients but the body essentially develops immunity to insulin and the amounts produced are not enough to regulate blood glucose. This affliction can initially be managed with healthy eating and regular physical activity but over time, many patients also need medication or insulin injections.

There is currently no cure for T2D so the recommended treatment is day-to-day management [4]. T2D treatments involve diet control, exercise, home blood glucose testing, and in some cases, oral medication with or without insulin. Effective individualised treatments may also incorporate psychosocial, lifestyle and other medical

interventions [55]. Diabetes needs strict control of the blood glucose level by balancing within a triangle known as the diabetes triangle (Figure 2-1), which consists of food, exercise and insulin (or medication) as the three corners [56]. In reality, this model is more plastic and dynamic than the triangle shape envisages [57]. Patients' decisions sway in this triangle during their daily activities and if there is an imbalance, fluctuations in glucose level occur [58]. These fluctuations in the blood can cause hypoglycaemia, a lack of blood sugar, or hyperglycaemia, which is excessive blood sugar. Both hypoglycaemia and hyperglycaemia are acute conditions because they can cause physical and psychological effects that could range from mild to life threatening. Education, awareness and involvement of patients can help to prevent potential effects [59].

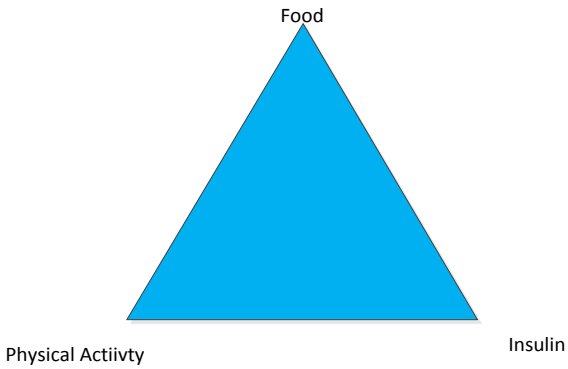

Figure 2-1. The diabetes triangle: clinical model of diabetes management [57, 60]

T2D is a chronic disease that causes serious complications in elderly patients. Although younger populations of first world countries are at risk, the prevalence of T2D is now increasing in older populations at alarming rates. Healthcare systems have struggled with the overwhelming number of patients suffering from diabetes [5]. In the year 2000, medical studies projected the total diabetic population to rise from 171 million in 2000 to 366 million in 2030 worldwide [61].

However, the present figures show that the earlier predicted figures were reached in only ten years instead of thirty years. In 2012 approximately 371 million people worldwide are diabetic, while a total of 4.8 million deaths were due to diabetes, with the treatment costs to be approximately 471 billion USD [5]. This significant increase is attributed to the demographic shift in the proportion of people over 64 years of age [62] where 2.5 million of the diabetes related deaths were from the 60 to 79 age group [5].

The total annual global health expenditure for diabetes in 2010 was estimated to fall between $376.0 and $672.2 billion USD. This accounted for 12% of the world's total health expenditure. In 2010, the global average expenditure related to diabetes per capita was $1330.00 USD [63]. Significantly, the economic cost of diabetes varies in different parts of the world. For example, in Bangladesh, the cost of one diabetic patient for one year is $28 USD, in China $193 USD, compared to the high costs of $8,478 USD in the United States and in Norway $9,208 USD [5]. Notably, the quality of treatment differs vastly depending on a country's healthcare system.

2.4 Randomised Clinical Trials

Clinical Trials explore whether a medical strategy, treatment, or device is safe and effective for humans. Clinical Trials also may show which medical approaches work best for certain illnesses or groups of people. A *Randomised Controlled Trial* (RCT) is a clinical trial in which participants are assigned to a study group. In a randomised controlled trial, participants are assigned to treatment conditions at random (i.e., they have an equal probability of being assigned to any group). RCT is a subset of Clinical Trial.

The primary goal of conducting an RCT is to test whether an intervention works by comparing it to a control condition, usually

either no intervention or an alternative intervention. RCTs produce the best data available for health care decision making [64].

The first instance of RCT occurred with a random allocation of patients to experimental and control conditions and is attributed to James Lind, a naval surgeon, in 1747. Lind randomly assigned 12 sailors to 6 different candidate treatments (2 patients per candidate treatment) for scurvy. The two patients who were given lemons and oranges recovered most quickly, suggesting a beneficial effect of citrus. The first RCT in medicine is credited to Sir A. Bradford Hill, an epidemiologist for England's Medical Research Council. The RCT was published in the British Medical Journal in 1948. It tested whether streptomycin is effective in treating tuberculosis. Because the drug was in short supply, Hill devised randomisation partly as a strategy to keep doctors from trying to manoeuvre their patients into the streptomycin arm of the trial. Earlier in his career, Hill believed that simply alternating the assignment of hospital admissions to drug versus control worked well enough. Later he recognised that simple alternation led to selection bias because the sequence was too easy to predict. That realisation led to the use of a random numbers table to generate the numeric series by which patients would be assigned to conditions [65].

Clinical Trials follow strict scientific standards [66]. These standards protect patients and help produce reliable study results. If an approach appears promising, the next step possibly involves animal testing. This demonstrates how the approach affects a living body and whether it is harmful. An approach that works well in the lab for animals may not always work well in humans. Thus, research in humans is done in clinical trials [64].

Clinical Trials start with small groups of patients to find out whether a new approach causes any harm. In later phases of clinical trials, researchers learn more about the new approach's risks and benefits. Three findings of a clinical trial are possible. A clinical trial may find that the strategy, device or treatment

- improves patient outcomes;
- offers no benefit; or
- causes unexpected harm

Clinical trials are a key research tool for advancing medical knowledge and patient care. RCTs are conducted for two reasons: first, if doctors do not know whether a new approach works well in people and is safe; and second, if doctors do not know which treatments or strategies work best for certain illnesses or groups of people.

Every clinical trial follows a protocol [64]. The protocol outlines what will be done during the clinical trial and why. The trial is led by a principal investigator, who is often a doctor. The principal investigator prepares the protocol for the clinical trial.

Key information in a protocol includes

- how many patients will take part in the clinical trial;
- who is eligible to take part in the clinical trial;
- what tests patients will get and how often they will get them;
- what type of data will be collected during the clinical trial; and
- detailed information about the treatment plan.

2.5 Discussion on Evaluation of Telemedicine

In the past, clinical trials have traditionally been used to assess drugs or treatment plans. With the invention of new technologies, clinical trials are now being used for assessment of treatments through technologies too. Clinical trials that assess devices generally compare various devices or compare a technology-intervened treatment with another form of treatment.

Chronic diseases require daily interaction with a telemedicine device. For example, T2D patients are required to use their

telemedicine devices at least two times a day. Daily use of these devices, make a telemedicine device part of the patients' daily life. The patient's capability of use is important because results may vary depending on the technological skills of the patients. Training is required with technology-intervened treatments to ensure the patient's capability and engagement. Contrarily, there is no training required with drugs and their effects are at the pharmacological, immunological and metabolic levels. Because the user has frequent or regular interaction with the technologies, especially in the case of T2D interventions, the feelings of these users towards the technologies are almost as important towards successful outcomes as in the case of drugs.

Unfortunately, clinical trials do not consider the interaction of patients with a device. The effectiveness of a telemedicine treatment can be compromised by the bad interaction design of a device. Therefore, understanding patients' interactions with a device during a clinical trial is critical to determining the effectiveness of the device in patients' lives.

On the contrary, understanding user-experience and designing user-centred technology is an extremely common practice in the discipline of *HCI*. User-experience refers to, *how a product behaves and is used by people in the real world* [20]. Every product that is used by someone has a user-experience: newspapers, ketchup bottles, reclining armchairs, cardigan sweaters [67]. How people feel when holding a product, using it, opening it, closing it – are all part of user-experience.

HCI techniques have many methods of evaluation, some are analytical and focus on the system with a set criteria while others are empirical and involve people using the system. Contextual design, interviews, observations, participatory design, and ethnography are effective techniques in performing empirical evaluations. HCI mandates that anyone who uses a system be classed as a user, so transcending the HCI empirical evaluation methods to technology-intervened

treatments, the “user” classification includes doctors, nurses, care providers as well as the patients. In the scope of this thesis, a user is a patient.

Computer systems are developed through a *User-Centred Design* (UCD) in HCI as opposed to the traditional software engineering and computer science approach where the functionality is the initial concentration. UCD keeps the human users and their goals central to design and evaluation [68].

HCI possesses examples of using qualitative research methods, which are common practice in an aim to generate richer knowledge about users. Qualitative research has been used by Dalcher [69] to understand major ICT and *Information System* (IS) failures in the United States. Dalcher [69] practices qualitative research in software engineering processes and argues that “knowledge is deeply bound to its original context and thus enables for a *contextually correct understanding”*. Effective capturing of a precise context is the only way to discover information about the informer´s position, perspective and relationship with the environment. To understand IS failures, Dalcher urges that any useful information must therefore be accompanied by additional contextual information that will shed light on its utility, validity and relevance and any methods adopted need to identify such contextual knowledge [69, 70]. In the following section this research explores the process of bringing HCI evaluation into a clinical trial.

2.6 An Investigation into Clinical Trials from the patients’ perspective

To answer the research question a new methodology needs to be developed combining HCI evaluation within a medical clinical trial. Prior to the development of a methodology another matter needed to be resolved. A literature survey was necessary to search for evidence of the patient (as a user) of telemedicine in clinical trials.

I conducted a meta-synthesis through an investigation of past telemedicine clinical trials of T2D [71]. The "meta-synthesis" formed new concepts from systematically reviewed qualitative data gathered from clinical trials. This meta-synthesis is presented in section 2.6.1.

The meta-synthesis searched for evidence (if any) of patient-technology and patient behaviour due to the use of telemedicine technology. Telemedicine treatments fall into two domains; the domain of medical science for their utilisation in healthcare and the domain of IT for the technology design and user-evaluation. The term "user" in telemedicine would refer to doctors, nurses, patients, and caregivers, all of whom use the technology and make up the user group. However, only the patients use telemedicine as a form of treatment for life altering illnesses.

This meta-synthesis focused predominantly on patients as the most important users because their well-being depends on the proper use of the technology. Patients' feelings, comfort, partiality, and ease of use are very important factors to gauge the success rate of a technology. This investigation focuses on the patients' perspective and the non-medical factors of improvement through telemedicine, telehealth and e-health for the treatment of T2D.

2.6.1 A Meta-synthesis of literature of T2D clinical trials

This meta-synthesis was conducted to understand the patients' perspective of telemedicine devices. I asked two questions:

1. How effective have telemedicine services been for the treatment of T2D?; and
2. What non-medical improvements did telemedicine provide for T2D patients?

2.6.1.1 Methodology of the systematic review for the meta-synthesis

The meta-synthesis involved a methodology of systematic review that comprised of four iterative steps[71]. This is described in (Figure 2-2):

Step 1 - *Pubmed, Science Direct* and *Google scholar* were searched for literature on clinical trials of T2D telemedicine. No limits were posed on sample population size, intervention type and clinical trial design. The keywords used to search were - “type 2 diabetes”, “clinical trial”, “telemedicine”, “e-health”, “telehealth”, “telecare”, “telemonitoring”, “technology”.

Step 2 - All variations of technological intervention for T2D treatments were included. No limits were posed on the type of technology.

Step 3 - Each paper was analysed systematically in the following order to extract content for the meta-synthesis.

Methodology;

Conclusion;

Discussion; and

Results.

The extracted contents were :

- The type of diabetes (type 1 and/or 2);
- The behavioural outcomes;
- The patient dropouts;
- The type of technology used;
- The contents about patients’ non-medical conditions;
- The patients’ feelings comments about the technology; and
- The patients’ difficulty or ease with the technology.

Not all of the papers contained contents of the above bullet list.

Step 4 –Search results most often yielded type 1 diabetes, clinical trial design and clinical trial planning for telemedicine, so the following exclusion criteria were used to filter the results (Figure 2-2):

Papers that were about ICT and diabetes care but were not clinical trials were excluded since this is not a review of the available technology;

Only papers on T2D were included. Papers on telemedicine clinical trials on type 1 diabetes were excluded. However, papers that considered both types 1 and 2 diabetes patients were included but only information on T2D was analysed;

Papers that only published the plan, proposal or study design of a clinical trial that has not yet commenced were excluded; and

Papers that were published in languages other than English were also excluded from this review.

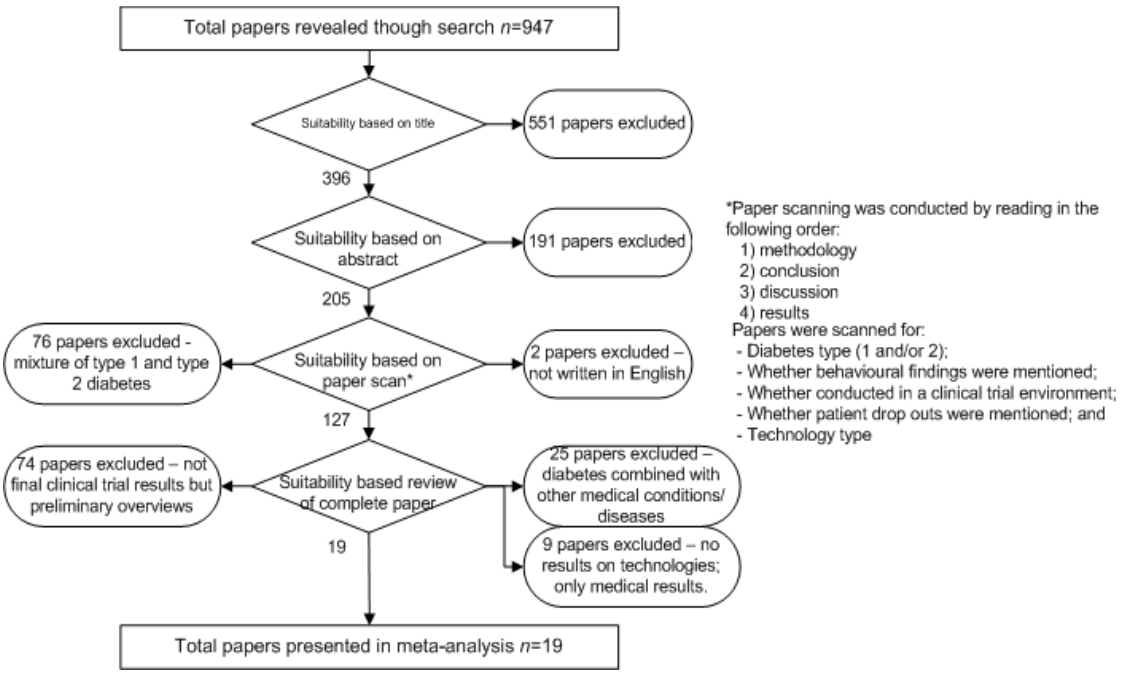

Figure 2-2. Systematic review methodology [71]

2.6.2 Findings

Nineteen clinical trials of technology-intervened treatments of T2D were included in the final selection of the meta-synthesis based on the

methodology described in section 2.6.1.1. The findings are presented in sections 2.6.2.1 to 2.6.2.3.

2.6.2.1 Types of T2D telemedicine technology

A classification of telemedicine technology that has been used in a clinical trial for T2D is presented in Figure 2.3. The technologies range from uncomplicated, where patients and clinicians communicate through phone, email or SMS (short message service), to complex web-based frameworks that require connection to the Internet. The different technology categories include:

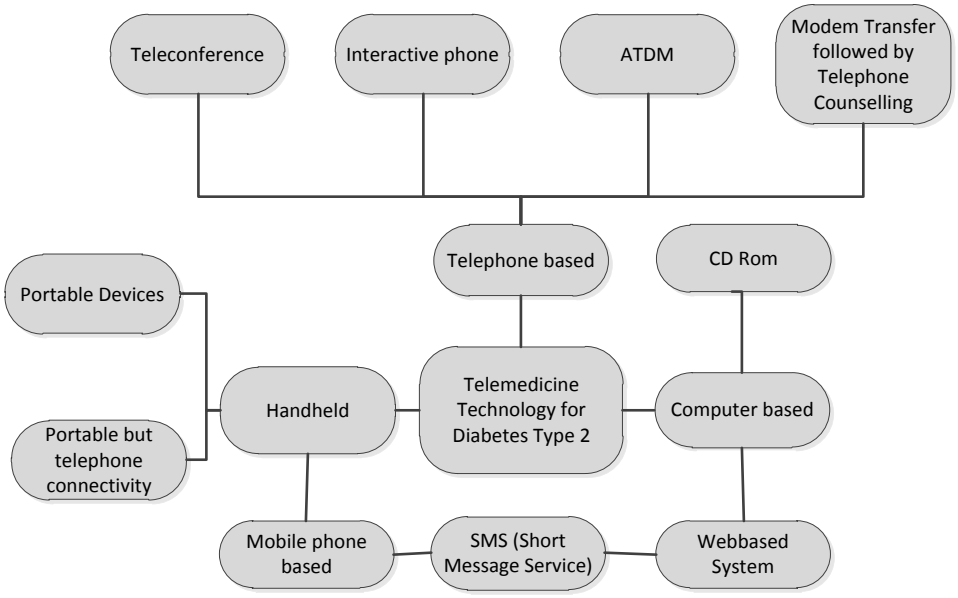

Figure 2-3. Categorisation of telemedicine devices in the systematic review [71]

- Handheld portable devices - devices that are easy for the patient to carry and automatically record time, date and blood glucose levels [72, 73]. For example, sample recommendations such as "Please, decrease the long acting insulin by two units", "Please add one tablet of sulfonylurea in the evening", "Lack of exercise may be the cause of the aggravated glucose level" and "Your glucose control seems to be good" etc., can be sent using the mobile phone SMS service [74];

- Transfer of data via modem followed by telephone counselling - methods used in earlier periods before the Internet was widely available [75];
- *Automated Telephone Disease Management* (ATDM) – a telephone-based system where patients receive calls at predetermined times and listen to self-management tips navigated via the telephone keypad [76] and the modern version where phone calls are automated to emulate the conversation with a physician [77];
- Glucometer modem transfer followed by graphical report generation [78];
- Data entry of touch tone telephone followed by voice message from clinicians [79];
- Interactive programs on CD Rom to educate on self-management [38];
- Web-based programs on self-management including chat room forums to enlist strangers as supporters [80] the iCare Desktop, the Health Buddy appliance web interfaces [81], web-based diabetes management systems [82] and the *Internet Based Glucose Monitoring System* (IBGMS) [83],;
- Teleconferencing - a person to person connection via telephone [84]; and
- Pro-active call centre treatment support - a telephone-based system where conversation is not automatic like the ATDM. The conversation takes place with trained non-medical operators [85].

2.6.2.2 Lack of data on dropout reasons

Dropouts of patients in a clinical trial are a common occurrence. How many of these patients drop out due to the difficulty of using the technology, proves to be a valuable question from the HCI perspective. Therefore, dropouts were examined in this meta-synthesis carefully.

The reasons for participant withdrawal, shown in Table 2-1, were not reported in the majority of the reviewed trials. Two withdrawals were reported by Rutten *et al.* [72] due to lack of motivation to adhere to the self-monitoring. Cherry *et al.* [81] and Biermann *et al.* [75] did not report any dropouts. Izquierdo *et al.*[84] reported several patients who did not send the data in time. As a result they were withdrawn by default. The following studies reported a large number of dropouts. For example, 10 by Shultz *et al.* [78], 43 by Glasgow and Toobert [38] and 37 by McKay *et al.* [80]; but the reasons for dropouts were not reported. Patients' inability to use the blood glucose meter and disappointment with the intervention resulted in four dropouts from 60 patients in a study by Williams, *et al.* [77]. The study by Meneghini *et al.* [79] had 77 withdrawals. This was the only paper that raised a question for future researchers to investigate reasons that cause patients to not use a technology in a clinical trial.

Fortunately, one clinical trial was sufficiently comprehensive to report the dropouts. The study by Young *et al.* [85] recorded and published the reasons for dropout and withdrawal. There were 83 dropouts in the intervention group with an additional 22 for call centre–related reasons. The reasons reported included: eight participants were not able to cope with the calls; four participants were unhappy with the advice given; three dropped out due to the travel required; three changed their minds; and two were too busy to use the intervention.

Table 2-1. Number of dropouts in clinical trials of T2D [71]

Study/Location	**Number of Participants**	**Number of dropouts**
Rutten *et al.* 1990 - Netherlands	149 of 171 eligible type 2 diabetic patients (Rutten *et al.* 1990)	2 withdrawals due to lack of motivation
Meneghini *et al.* 1998 - Florida USA	187 type 1 and type 2 diabetes	77 withdrawals- authors propose to question the reason in future [79]
Piette *et al.* 2000 - California USA	280 type 2 diabetes	5 refused follow up. 8 refused data collection- reasons not reported [76]
Glasgow and Toobert, 2000 Oregon USA	320 of 419 eligible type 2 diabetes (76% enrolment)	43 withdrawals - reason not reported [38]
Biermann *et al.* 2000 Germany	46 type 1 and type 2 diabetes	No dropouts reported [75]
Tsang *et al.* 2001 - China	20 initial patients	1 withdrawal- reason not reported [73]
Mackay et al.2002 - Oregon USA	160 of 265 eligible type 2 diabetes (61% enrolment) all were novice computer users	37 withdrawals- reason not reported [80]
Cherry *et al.* 2002 - Texas USA	169 type 1 and type 2	Withdrawals not reported [81]
Izquierdo *et al.* 2003 - New York USA	56 type 2	1 due to failing consequent appointments. 8 due to lack of time [84]
Young *et al.* 2005 - Salford, UK	591 type 2	83 dropouts with an additional 22 (5.6%) for not being able to cope with the number of calls. 4 not happy with the advice given, 3 changed their minds, 3 due to travelling and 2 were too busy. [85]
Cho *et al.* 2006- Seoul, South Korea	40 type 2	Not reported [83]
Kim and Kim, 2008-Seoul, South Korea	18 type 2	Not reported [74]
Bujnowska-Fedak *et al.* 2011- Poland	50 type 2	3 dropouts; 2 for being disinterested with the technology [86]
Williams *et al.* 2012- Brisbane, Australia	60 type 2	4 dropouts; unable to use the blood glucose meter and disappointed with the technology [77]
[87]- Iran	39 SMS type 2, 41 telephone type 2	3 dropouts [87]
[88]-Several states, USA	405 type 2	[88]54 dropouts- reasons not reported
Pressman *et al.* [89]-California, USA	118 type 2	[89]9% of the 118 patients dropped out-reasons not reported

2.6.2.3 Behavioural improvements from the use of telemedicine

This meta-synthesis assessed the effectiveness of telemedicine for T2D patients from the results reported in the clinical trials. Most of the reviewed papers were randomised clinical trials where the blood glucose is measured initially as a baseline. This is followed by another measurement after a certain period after the intervention. The baseline and post-intervention results are then compared between the control groups.

This meta-synthesis extracted information solely from the publications about clinical trials, regardless of the specific applied design methods. Thus only the available results and conclusions about the effectiveness of telemedicine treatment were assessed.

Surprisingly, the results were mixed; not all trials agreed that telemedicine for T2D treatment was effective. These mixed results are consistent with the results from [13] who conducted a systematic review of reviews on the impacts and costs of telemedicine. Ekeland's study reported on eighty heterogeneous studies of which only twenty-one stated telemedicine was effective. Eighteen other studies stated that telemedicine was promising, while others raised questions for further investigation of the benefits of telemedicine.

Significantly, this meta-synthesis found that every clinical trial showed noteworthy positive behavioural outcomes of telemedicine. The trials concluded that even though telemedicine does not definitely improve medical conditions, it incites positive behavioural change. The literature urges the need for further investigations on behavioural outcomes due to the limited evidence currently available.

In their publications, authors reported behavioural improvements in the clinical trials; however assessing behavioural improvements did not fall within the scope of the clinical trials. Therefore, the authors of

many papers mentioned that behavioural outcomes are worth investigating in future to determine conclusive results. Some authors also mentioned that study design was limited. Table 2-2 [71] summarises the effectiveness of clinical trials in terms of physical and behavioural improvements.

Table 2-2. Effectiveness of clinical trials- physical improvements, behavioural improvements and need for further investigation [71]

Study	**Physical Improvement**	**Behavioural Improvement**	**Further Investigation Needed?**
Rutten *et al.* 1990	Yes - Weight and/or glucose.	Yes.	No - Concluded to be effective.
Shultz *et al.* 1991	Yes - Blood glucose level significantly dropped.	Yes - Adherence to dietary guidelines and well-being.	No - Concluded to be very effective.
Meneghini *et al.* 1998	Yes - Reduced blood glucose and frequency of consults.	Yes.	No – Concluded to be effective.
Piette *et al.* 2000	Nil improvement in blood. Some improvement in weight.	Yes - Self-management and awareness.	Yes - Effective management and behaviour but no results for improved blood glucose.
Glasgow and Toobert, 2000	No.	Yes.	Yes - Effective but further studies for a longer period required.
Biermann *et al.* 2000	No - Same as normal treatment.	Yes - Satisfied with lifestyle.	No - Concluded to be effective.
Tsang *et al.* 2001	Yes - Decrease in blood glucose.	Yes - Dietary behaviour improvement.	No - Concluded to be effective.
Mckay *et al.* 2002	No – little improvement in blood glucose.	Yes - Perceived positive personal social support. Dietary behaviour improved.	No - Concluded to be effective.
Cherry *et al.* 2002	Not mentioned.	Yes - Self-management and quality of life improved.	No - Concluded to be effective.
Montori *et al.* 2002	No.	Yes - Better self-reporting behaviour.	Yes - Further studies needed.
Izquierdo *et al.* 2003	Yes - Blood glucose reduced.	Yes.	No - Concluded to be effective.

Young *et al.* 2005	Yes- but not the level that authors expected.	Yes - Lifestyle changes and adherence to treatment.	No- Concluded effective for Caucasians but urged further investigations for other ethnic groups.
Cho *et al.* 2006	Yes - significant improvements.	Yes - Self-management improved - attributed to the recommendations received from medical staff.	No - Concluded to be very effective.
Kim and Kim, 2008	Yes- significant improvements.	Yes - Enthusiasm and motivation in self-management.	No - Concluded to be very effective.
Bujnowska-Fedak *et al.* 2011	Yes.	Yes - Perceived improvement about blood glucose, diet and diabetes. Improved mental health.	No - Concluded that only patients who are aware of their diabetes gain benefits from the system.
Williams *et al.* 2012	Yes.	Yes - Improved adherence to self-care and mental health improvement.	No - Concluded to be effective.
Zolfghary *et al.* 2012	Yes. Significant improvements.	Yes - Patients showed an increase in physical exercise, diabetic medication intake and diet adherence.	No - Concluded to be very effective.
Tang *et al.* 2013	Yes.	Yes - Continuous engagement was demonstrated.	Yes - further studies needed if nurses can maintain this
Pressman *et al.* 2014	No.	No.	Yes - additional studies are needed

Three specific behavioural improvements of the patients were seen in the clinical trials (Figure 2-4). The improvements are:

1. Activity improvement,
2. Awareness improvement, and
3. Satisfaction

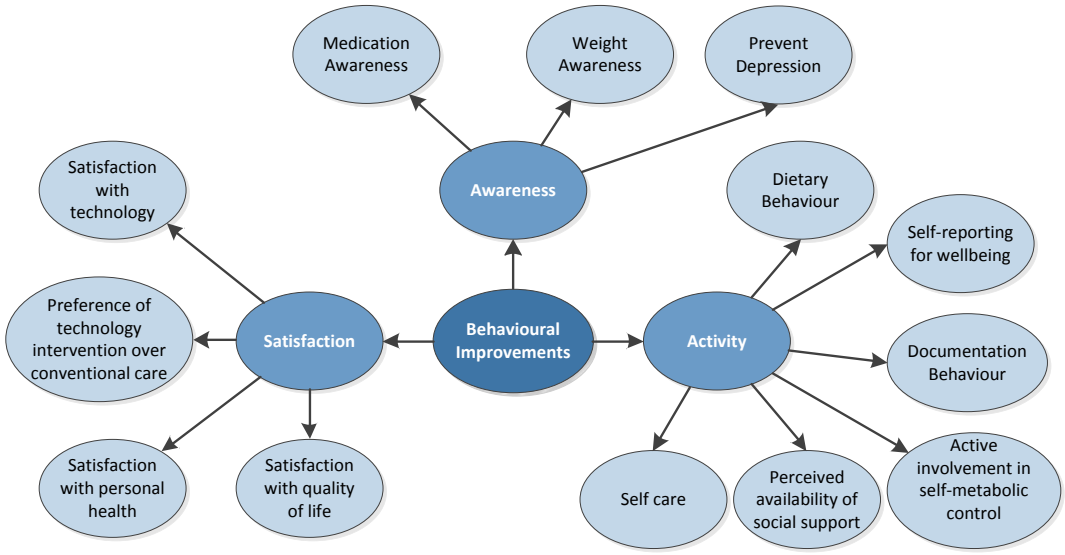

Figure 2-4. Behavioural improvements of patients from clinical trial

Activity improvement refers to activities that the patients adopted due to the technology intervention. *Awareness improvement* refers to the informed state-of-mind about living with T2D, that the patients achieved after using the telemedicine intervention. *Satisfaction* refers to the participants' pleasure and fulfilment from using the technology intervention.

Behavioural outcomes from the 19 clinical trials of this meta-synthesis are presented in the following list:

- Rutten *et al.* [72] reported overall improvement of all the patients in personal health care and quality of life. The participation stimulated the patients to keep closer control of blood glucose levels and increased their motivation for maintaining good levels.
- Shultz *et al.* [78] showed that using telemedicine helped patients adhere to a dietary plan and other healthy habits. The study did not mention the types of other healthy habits.
- Meneghini *et al.* [79] reported patients grew into active participants and got involved in metabolic control. Additionally, Meneghini *et al.* [79] have urged the importance of the

psychological foundation, possible system dependencies, and personality traits are contributing factors in the various behaviours that require further study.

- Piette *et al.* [76] found multiple improvements. The study stated that the automated telephone assessment resulted in improved self-care and weight monitoring for patients even though the interaction with the nurse was less than six minutes per month. This system also allowed patients to enforce healthy behaviour.
- Glasgow and Toobert [38] found evidence of improvements in the dietary behaviour of the patients. This clinical trial is the first of its kind to consider the social cognitive-environmental model in an intervention.
- Biermann *et al.* [75] observed that patients were enthusiastic about sending data. The patients preferred telemanagement rather to daily logging with pen and book, which was the traditional way of treatment.
- Montori *et al.* [82] showed a better way of self-reporting and documenting to improve the well-being of the patients.
- Izquierdo *et al.* [84] measured the stress levels of diabetes patients through teleconferencing. They found that patients' quality of life improved by reducing the diabetes related stress; consequently this helped the patients to manage the illness better.
- Cherry *et al.* [81] showed that patients' overall quality of life was improved. This improvement was evidenced by the SF-12 survey. The survey indicated a change of self-management behaviour.
- McKay *et al.* [80] showed that social support is also important for self-management and awareness, where improvements in patients' perceived availability of social support was relative to participants who only had computer access to information about

diabetes. Connecting with other T2D patients helped patients to engage better in self-management.

- Tsang *et al.* [73] reported that dietary awareness was generated after use of the technology.
- Young *et al.* [85] published the behavioural outcomes in a companion article separate from the medical results of the clinical trial. The companion article reported participants receiving the intervention continued to report high levels of satisfaction with their treatment after a year. More than 90% of the patients strongly agreed or agreed that the telecarer approach was acceptable. Qualitative comments from the companion article pointed to the importance of a personalised service; increased feelings of well-being, including confidence and self-control; help with problem-solving; and patients developing rapport and a strong bond with the telecarers [90].
- Cho *et al.* [83] presented a surprising result. The study expected the majority of patients' questions to be about drug dosage during the 30 month trial. However, they discovered that the contrary was true. Only 20% of the time, patients actually sought advice for glucose dose adjustment. Instead, the authors found that 41% of the recommendations made were for patients seeking encouragement and problem assessment and 30% of patients asked for some sort of counselling.
- Kim and Kim [74] attributed the significant physical improvement of patients to their behavioural changes. Patients were found to have more contact with caregivers through SMS and Internet based messages, which improved their enthusiasm, motivation and engagement in blood glucose monitoring.
- Bujnowska-Fedak, *et al.* [86] found that patients who used the system alone benefitted with an increased quality of life score

shown in the surveys that indicates better mental health and higher prevention of depression.

- Zolfaghari, *et al.* [87] found that both SMS and telephone intervention led to significant improvements in behaviour.
- Tang *et al.*[88] found physical improvements through behaviour change and attributed it to the Hawthorne effect, where patients are influenced by their awareness of being observed. The authors aimed to understand factors that might predict patient engagement.

The behavioural improvements in this meta-synthesis show positive results in T2D treatments and comply with the diabetes treatment based on the diabetes triangle that consists of diet, exercise and medication. The compliance is only towards the two corners of food and insulin, since the technology interventions did not have physical activity monitoring functions. Yet there was awareness of weight management. Improvements in dietary behaviour and medicine are positive indicators that these telemedicine technologies are moving towards patient improvement. Furthermore, satisfaction with the technology by patients in the trial shows promise for these kinds of interventions. The behavioural outcomes are positive, although the medical outcomes in terms of blood glucose are not always positive.

2.7 Discussion of Research Background

As seen from the literature, two key findings of the meta-synthesis of T2D clinical trials are –

1. lack of data on patient dropouts; and
2. positive behavioural outcomes in patients from using a telemedicine technology

Patient withdrawals from clinical trials is common [91]. Notably, the reasons for patient withdrawals are often not collected by clinical researchers or published, even though the numbers of withdrawals

influence the statistics and outcomes. This practice is common because the objective of clinical trials is to discover improvements, particularly, medical conditions and cost effectiveness of telemedicine.

Clinical trials do not investigate how patients interact and use a technology. Understanding patients' use of a technology is crucial because that influences the success or failure of an in-home monitoring technology [92]. Users discontinue the use of any technology if they have unpleasant experiences or difficulties [93], similarly patients may possibly drop out of a clinical trial due to the telemedicine technology. From a patient's perspective, a reason for dropout could relate to user-experience and interaction issues such as difficulty of use, the complexity level higher than the patient's skill level and/or the patient's confidence level, and willingness to adopt a technology. Unless the technology designers know the exact reason that a patient may have refused to use an in-home monitoring technology, future designs of such technologies cannot be modified. Bardram [94] argued that *"the clinical benefit of a healthcare technology might be diluted significantly if the patient finds the technology hard to use"*. System complexity and poorly crafted interfaces can cause negative emotional responses in the user, which lead to experiences of confusion, frustration, and failure [95].

This meta-synthesis concluded that every clinical trial showed noteworthy positive behavioural outcomes of telemedicine for T2D patients. Even though clinical trials focus on improvements in patients' medical conditions, authors reported positive behavioural changes. For example, one clinical trial study in the meta-synthesis by Bujnowska-Fedak, *et al.* [86] reported that patients who operated the technology by themselves gained greater benefits from the medical treatments than those who could not or would not use the technology. The study reported that only 35% of patients could use the technology without assistance and they gained more benefits from the telemedicine treatment in comparison to the rest of the patients. Moreover, another

clinical trial by Meneghini *et al.* [79] urged the importance of studying three factors -- the patients' psychological foundation, possible system dependencies, and personality traits. The study predicted that these could be contributing factors in the various behaviours of patients and require further study.

Clinical trials do not investigate how patients use an in-home monitoring telemedicine device, therefore authors of several clinical trials clearly stressed the need for further investigations on the influences of a telemedicine device on patients. Clinical trials are not adequate to discover how patients use in-home monitoring devices such as telemedicine. Thus, this thesis addresses the research question -- **"*How to evaluate technology-intervened treatments (such as telemedicine) during a clinical trial, to understand patients' use of the device and experiences with the device?*"**

A new methodology is required. To evaluate areas that are not in the scope of clinical trials, use of technology from a user's (patient's) perspective needs to be examined. Evaluation methods from the HCI discipline are specifically targeted towards understanding users and uses of technology. Therefore this research attempts to complement a medical clinical trial with HCI evaluation. Chapter 3 describes the defining process of the methodology to answer the research question.

Chapter 3. Methodology

This chapter outlines the development of the methodology to answer the research question. Section 3.1 presents the rationale behind the research methodology that originated from the meta-synthesis of the systematic literature review in the previous chapter. Section 3.2 explores the development of the methodology. Section 3.3 suggests some possible benefits of the new methodology.

3.1 Rationale behind the research method

To answer the research question, "How to evaluate technology-intervened treatments (such as telemedicine) during a clinical trial, to understand the patients' use of and experiences with the device?", a new approach is necessary to understand how patients use a device and what their experiences are, during a clinical trial. As a prelude to the research design, I conducted a meta-synthesis to investigate the published clinical trials of T2D and summarised these in section 2.6.1. Two key findings (section 2.7) of the meta-synthesis of T2D clinical trials were–

Finding 1) lack of data on patient dropouts; and

Finding 2) positive behavioural outcomes in patients from using a telemedicine technology

An investigation into Finding 1 is presented in section 3.1.1. A summary of Finding 2 is presented in section 3.1.2.

3.1.1 Investigation of why dropouts were not reported

During the meta-synthesis of technology-intervened T2D clinical trials from 1990 to the present, I looked specifically for data regarding patient interaction with telemedicine devices. The term “dropouts” was used throughout the literature, to denote patients who do not continue

for the entire length of the trial. There are several reasons for dropout; e.g. medical conditions (degradation of health or death), self–withdrawal or relocation, or disqualification from the trial due to failure to comply with conditions.

The majority of the clinical trials did not investigate whether the dropouts were related to difficulties with the use of the device, however a few did. For example, one clinical trial reported two dropouts due to being disinterested with the device, but did not report why this may have occurred [86]. However, an earlier study by Meneghini *et al.* (1998) with 77 dropouts suggested that the reasons behind patients not using the system in a clinical trial should be investigated in future research [79]. The large number of 77 dropouts legitimately raised the point in the authors' minds.

The lack of data about withdrawal and/or dropouts could be due to the following assumptions:

(1) the reasons were not investigated;

(2) the reasons were investigated but not published; or

(3) the reasons were out of the scope of the clinical trials.

At this stage, I decided to contact the authors of telemedicine clinical trials for T2D papers, to further investigate the reasons. I emailed the corresponding author and co-authors of 26 clinical trial papers. I received responses from two authors, both from studies published pre-2000 (see Appendix A). Both responders have given permission by email to use their quotes.

The corresponding author [72] stated that reasons for withdrawal were not recorded. He concluded the email with "*I cannot remember whether they* (patients) *dropped out from the study because of not being able to handle the technology, but I can hardly imagine. I have no detailed information anymore*" (personal email Guy Rutten). This response

supports the assumption that an investigation into the reasons for patient withdrawal from the study was beyond the scope of the project.

The second reply was from [96]. He agreed that the interaction of patients with a device needs further investigation. He added, "*With regards to the study you mention, we had only one drop out among the families, and that was due to their having to move outside the city."* He went on to note that many of the mothers of the paediatric patients were disinclined to end the trial as they appreciated having their children's blood glucose data monitored remotely. "*They expressed great comfort knowing that someone was watching over them"* (personal email David G. Marrero).

3.1.2 Behavioural improvements in clinical trials for T2D patients

The findings on behavioural improvements in the meta-synthesis (in section 2.6.2.3) show positive results in T2D treatments. Evidence of awareness of weight management, improvements in dietary behaviour and medicine intake, are positive indicators that these telemedicine technologies are supporting patient improvement even though the blood glucose improvements were not consistent. Behavioural modification following use of a telemedicine device may be positive although the medical condition itself may not improve due to the use of the telemedicine device.

The clinical trials were predominantly concerned with the medical improvements of patients using the intervention. The clinical trials reported unpredicted behavioural improvements (section 2.6.2.3). This evidence highlights the importance of evaluating patients' interactions and experiences with a telemedicine technology.

3.2 Development of a Methodology

The next question to be addressed relates to "how to capture the patients' use of a telemedicine device during a clinical trial?" Opportunely, the HCI discipline has a plethora of case studies and methods to capture the interaction of humans with a technology. HCI can contribute to the understanding of a patient's interaction in clinical trials. The following section presents an overview of such methods in HCI.

3.2.1 An overview of prevalent methods in HCI

HCI is an interdisciplinary area of *computer science*, *behavioural sciences*, *psychology*, *human factors* and several other disciplines. Three decades of field work in HCI demonstrate that the discipline tends to be highly divergent in its choice of methods and approaches. HCI practitioners and researchers, individually and/or collectively, attempt to combine different methods and perspectives of the above mentioned disciplines. Sometimes they additionally bring their own disciplinary background and skills to contribute to HCI.

A primary focus of HCI is on the users – the humans who use a system or technology. Understanding users and their needs are a seminal part of HCI work. Due to HCI practitioners' diversity, there are many different approaches to organising and conducting the design, development and evaluation of systems. Brief overviews of six prevalent methods in HCI are discussed in sections 3.2.1.1 to 3.2.1.6.

I chose to focus on these six methods of HCI because these are the major methodologies. First, these are the most commonly used research methods in HCI. Participatory design and co-design are rapidly expanding in practice and in publications, while applied ethnography and contextual design are widely used methods in the commercial sectors and publications. Contextual design in particular has gained wide popularity due to its structured methodological steps.

3.2.1.1 Ethnography

Ethnography arose within the discipline of anthropology. Anthropology had previously documented what members of other cultures *did*, while ethnography suggested that through daily participation in everyday life, one could come to understand the *experience* of the members of those cultures through their actions.

Ethnography advocated long term and immersive fieldwork combining observation with participation, unlike surveys and interviews. Ethnography expanded as a discipline with *Computer-Supported Cooperative Work* (CSCW) as an area of inquiry. CSCW placed an amplified emphasis on the social organisation of activity and on methodological approaches by which that social organisation might be understood. Ethnography has proved to be an important tool in CSCW.

Ethnography draws attention to social and cultural aspects of communication and cooperation between people. Ethnography helps researchers and designers in the field, to study and understand how people use their current products or how people perform certain tasks. Lucy Suchman pioneered this approach in the ICT industry with her studies on how people used Xerox copiers [97]. Movies of people struggling with these machines brought ethnography to the engineers at Xerox. Ethnography eventually helped the engineers to redesign and improve the copiers [98].

Field studies are a particularly promising approach for understanding users' implicit and non-verbal needs [99]. Ethnography is especially relevant for the design, redesign and evaluation of ICT applications for CSCW [100, 101].

Ethnography is gaining popularity in the commercial settings of market research and product development. Ethnography and participatory design have been combined to create better designs by

some researchers [102, 103] for example, by combining observations, interviews and participatory workshops.

3.2.1.2 Contextual Design

Contextual Design [107] is an ethnographic approach to finding the specific needs of users in a work situation. It is a technique in which users and their work processes are observed with comparatively less time and with more specificity. It is an application of ethnography which helps researchers and designers to observe people in a natural context (often a work context), to discuss and interpret their observations in a multidisciplinary project-team setting, and to directly apply their findings for formulating recommendations and requirements for an improved or new ICT application.

CD advocates several perspectives along which observations and interpretations can be organised. CD finds what users do; why they do it, how they communicate; the roles that power and culture play; the artefacts which they use; and their physical environment [107].

In CD, knowledge about users is gathered by the project-team members and brought into the development process and transformed into product requirements. [133] argued that because of this transfer and the concern with creating an ICT application, there can be a risk that project-team members foreground their own knowledge *about* users (which would be based on interactions *with* users) over knowledge *from* users. The developers of CD, Karen Holzblatt and Hugh Beyer have established the *InContext Foundation*, which practices the CD methodology to design customer centred systems (www.incent.com).

3.2.1.3 Participatory design (PD)

The *Participatory Design* (PD) movement arose in the late 1960s and early 1970s in Scandinavia. It was initiated by academics who worked with people from trade unions. PD strived for more democratic

values in the workplace and for worker emancipation, as offices became automated by computers [104-106]. Details of the history of PD can be found in [18].

In PD, people who will be using a system, are given a role in the design, evaluation and implementation of the system. PD involves users in the research and design process. Involving users in design decisions is not difficult although cultural differences can become acute when users and designers are asked to work together to produce a specification for a system [20].

3.2.1.4 Lead user approach

Many ideas of new products or services originate in the minds and hands of innovative users [108-110] and do not always come from professional researchers or designers. Lead users are defined [111] as people who have two distinguishing characteristics:

1. They are at the leading edge of an important market trend(s), and so are currently experiencing needs that will later be experienced by many users in that market; and

2. They anticipate relatively high benefits from obtaining a solution to their needs, and so may innovate.

Lead users experience a problem that a current product or service does not resolve. Consequently, they create innovative solutions, applications or modifications. Lead users may be invited by an organisation to help researchers and designers jointly develop improved or new products or services. The most important difference between the lead user approach and participatory design is that the lead user approach is oriented towards commercial goals rather than towards democracy or emancipation. Many examples of successfully involving lead users in product development relate to outdoor or extreme sports equipment (e.g. [112]; [113]; [114]; [115]). There are people who are so passionate about their sport that they improve their

equipment or develop superior equipment. For example, in the sport of tennis, Serena Williams has contributed to discussions with racquet designers [116] and outfit designers[117]. In practice, sometimes such lead users are hired by a firm for product development or marketing roles. Note that lead users may not be true representative of the actual users.

3.2.1.5 Empathic Design

Empathic design is part of a relatively new branch of UCD approaches that support design teams in building creative understanding of users and their everyday lives [118-120]. The founders of empathic design, including leading academics and design consultancies such as *IDEO* [121], have successfully explored empathic design in projects for and with clients in the industry. One noteworthy example is a design for visually impaired users [122].

Empathic design is a design research approach that is directed towards building creative understanding of users and their everyday lives for *New Product Development* (NPD). Creative understanding is the combination of a rich, cognitive and affective understanding, and the ability to translate this understanding into user-centred products and services [123]. It draws on information about the user and his/her everyday life, and it includes inspiration for design and empathy, or 'a feel' for the user [124]. The empathic design approach is considered most valuable in the early stages of NPD, when product opportunities need to be identified and product concepts developed [119].

In empathic design, researchers and designers attempt to move towards users' lives and their work, in an attempt to empathise with them and with their experiences and emotions. There are four principles of empathic design.

The first principle is balancing rationality and emotions in building an understanding of users' experiences. The second principle is to make empathic inferences about users and their possible futures.

In empathic design, people's feelings and experiences are thought to be best understood through empathy [125]. Empathy can be described as the ability to understand what it feels like to be another person – what that person's situation is like from his/her own perspective [126]. Empathic design calls upon designers' and researchers' empathic abilities in interpreting what people think, feel and dream, and in envisioning possible future situations of product use [118, 127].

The third principle is involving users as partners in NPD. In empathic design, designers and researchers continually develop and check their creative understanding of users' experiences in dialogues with users over time [118].

The fourth and last principle is the engagement of design team members as multidisciplinary experts in performing user research. In the article "*Design for experiencing: New tools*," [120] notice that the roles of designer and researcher are becoming mutually interdependent.

The success of empathic design depends on how user-focused the organisation is, how people within the organisation think and communicate about users [128], and to what extent they already practice the four principles of empathic design. Another key issue that has emerged in discussions with practitioners and seems to be as yet undecided in this relatively recent approach is how one can achieve empathy. Should a designer try to exclude his own experiences, and focus and connect to the other person's experiences? Or should a designer try to connect with his or her own experiences, inspired or informed by what s/he sees and hears from another person [127, 129].

3.2.1.6 Co-design

Co-design is an attempt to let users, researchers and designers cooperate creatively and jointly to explore ideas and concepts. Co-design can be thought of as a kind of participatory design, with additions from art and design traditions. In a participatory design, one

would typically involve a group of people who work together in professional tasks in their role as *workers* and design a product with which they will be working. Whereas in co-design, one can also invite people who do not yet know each other and design a product for a mass market or for non-work contexts. In co-design '*everyday people*' can become participants and co-creators rather than customers and users [130]. These users can contribute as '*experts of their experiences*' [129] to the research and design processes.

In traditional market research one typically tries to capture *'what people say'* via focus groups or interviews, and that in traditional ethnography one typically captures *'what people do'* via observation [132]. Accordingly, [132] advocates focusing on *'what people make'* and facilitating users, researchers and designers to jointly create things.

Use of *'generative tools'* are meant to establish *'a shared design language'* and to enable people to *'communicate visually and directly with each other*' [132]. The design language is generative in the sense that with it, people can express an infinite number of ideas (for example, dreams, insights, opportunities, etc.) through a limited set of stimulus items [131]. Examples of generative tools [132]are presented below.

- *tools for remembering* such as diary-style cards on which people can answer questions, e.g. '*what is your typical weekday evening like?*';
- *tools for thinking* which are meant to help brainstorming about questions, e.g. 'how do you expect your work to change in the future?';
- *tools for visioning* to facilitate creatively addressing questions or themes; and
- *tools for feeling* which are intended to come into contact and express one's emotions.

3.2.1.7 Discussion on the six HCI methods

A philosophical representation of HCI methods show two major existent tensions [133],[127]. The first tension is between the researcher's and designer's knowledge about a design against the users' knowledge of that design. Here, the terms '*researcher*' and '*designer*' do not imply people or occupation; the terms imply roles or activities. The same semantic meanings are carried out in this thesis by the terms '*designer*' and '*researcher*'.

The first tension is a gap between the researcher's/designer's world and the user's world [133,127]. Each world has its own knowledge and boundaries. Finding a balance between the two is a tough job [134]. In HCI practice, researchers/designers have to make a choice whether to move to the user's world or move the users to the researcher's/designer's world.

The second tension exists between research orientation and design orientation. The contrast between research orientation and design orientation causes this tension [133,127]. HCI methods can be aimed at understanding a present situation while they can also create a design for a future situation. This tension between the present and future occurs because HCI researchers target understanding the present and also designing for the future [19, 135, 136].

The second tension may be described as the differences between a concern for studying and describing current or past situations (archetypal for research), and a concern for exploring and visualising alternative or future situations (archetypal for design), as described by [137]. This tension can be understood as a tension between a concern for "*what now is*" versus a concern for "*what ought to be"* in future.

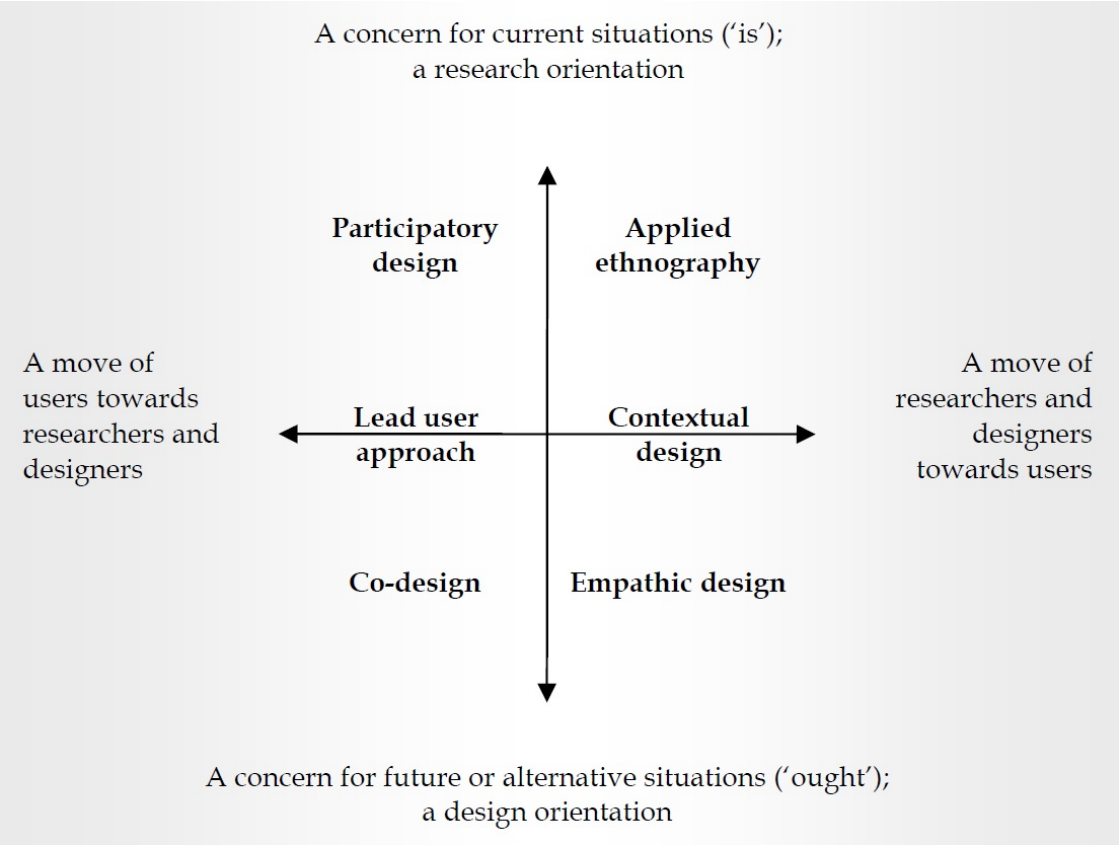

Figure 3-1. The six prevalent design approaches in HCI [133]

These two tensions are chosen as two axes the six prevalent methods of HCI are placed in the space between these axes (Figure 3-1)[133]. The first tension exists along the horizontal axis. Ethnography, contextual design and empathic design capture detail of users' worlds; researchers/designers move towards the users' environments to understand users and capture their activities. Then these methods translate the users' requirements to the design of systems. While participatory design, lead user approach and co-design move the users towards the researchers'/designers' worlds; researchers/designers come with some pre-conceived ideas and probe and provoke the users to interact and engage in the process. The aims of these methods are to revolutionise future design. Another differentiator between lead users and participatory design approach is that lead users may not be true representatives of ideal users.

Along the vertical axis the second tension exists. System development in HCI is done in multidisciplinary teams, which cause philosophical differences in development of a new technology. Researchers generally understand the current situation or *what now is* to provide a solution for it with technology. While designers often focus on *what ought to be* the design of a technology. Participatory design and applied ethnography work in the HCI shows many social science researchers being involved and consequently focusing on the present way of work and a design that reflects and supports the present work. Contrarily, co-design and empathic design lie on the vertical axis of how the future design should be [133]. Contextual design and lead user approach remain in a balanced position by neither focusing too much on current ways nor focusing too much on how the design should be in future; these approaches understand how users work in the present and additionally incorporate the future needs of the users.

3.2.2 Defining and developing a methodology

Several prevalent human-centred methods in HCI are available as shown in section 3.2.1. The choice of a method that suits the purpose of this research was made with regard to the following considerations.

3.2.2.1 Consideration 1

The rationales 3.1.1 and 3.1.2 showed that reasons for dropout due to technology use are not investigated in clinical trials and the authors mentioned that some trials found behavioural improvements among patients from the use of telemedicine devices. The new methodology must be able to capture these issues.

3.2.2.2 Consideration 2

In the six prevalent user-centred methods of HCI, a new technology or system is developed by the design, implementation and

evaluation conducted simultaneously and repeatedly with user involvement. These are best practices and start from the development stages till completion with variations as described in section 3.2.1.

Contrarily, technologies that are applied in health services and medicine, such as telemedicine, go through a process known as *Health Technology Assessment* (HTA), which consists of many multidisciplinary regulations -- medical, social, ethical and economic implications. The two step process of the HTA for telemedicine is that first a telemedicine device has to be approved by a regulatory body such as TGA in Australia, FDA in the USA, NHS in UK. In this step the regulatory bodies decide if a drug/device is safe for humans. Next, the telemedicine device needs to go through rigorous testing methods to prove its efficacy, which is done through clinical trials. Clinical trials are formal procedures that are followed in EBP to check safety and efficacy, which refers to the "capacity of a beneficial effect", and data for health intervention (drugs, devices etc.). Medical practitioners follow EBPs to find the best available evidence from medical science literature before a treatment decision is made by a clinician [138]. EBP supports the clinician in the decision on the risk and beneficial factors of a treatment for a particular patient [139, 140].

Clinical trial researchers are not creating or testing patients with a new probe, as done in PD or Co-design. Clinical trials are not discovering or exploring new technologies to suit humans. The telemedicine device has already passed regulatory boards and the clinical trials are searching for the medical benefits of the device for T2D patients. So, the new method ought only evaluate and capture data about how patients use the device.

The six HCI methods conduct design and evaluation iteratively. An understanding of how patients interact in their own homes in the long term in real world situations, is required. No development with patients is required in this research; the company that built the device is responsible for the development process related to the device. Only

an understanding of patients' current situation and workflow with the device is required.

3.2.2.3 Consideration 3

The new method must respect clinical trial protocols because that is the most important evaluation. The clinical trial is searching for evidence of medical improvements caused by use of the telemedicine device for T2D, which is life altering. The new method is researching patients' user-experiences with the device. The new method ought not interfere with traditional clinical trial protocols.

3.2.3 The methodology- Clinical User-experience Evaluation (CUE)

HCI methods provide evidence of understanding user-experiences with technologies and users' interactions in the HCI and IT literature. The six prevalent HCI methods (3.2.1) are better suited to the development phase of a technology. In this research, I was involved in a telemedicine clinical trial with an in-home monitoring device in a rollout phase. The telemedicine technology had already been approved by TGA and *Queensland Health*. To evaluate user-experience with a telemedicine device, all the HCI methods are inspiring but do not fit the clinical trial situation.

The six HCI methods are not readily able to comply with the three considerations 3.2.2.1 to 3.2.2.3. At this rollout phase of a telemedicine device, methodologies like PD, co-design, empathic design, and lead user approach were exempt from the possibilities of being used as an evaluation tool. However, ethnography and contextual design still had the functions of understanding the current situation. These are typically used to understand computer-supported work such as CSCW.

To fit the current situation, I adopted an ethnographic approach, instead of a full ethnographic study. A full ethnography did not fit in with the clinical trial regulations and patients' availability. Therefore, I

chose contextual inquiry, an instrument from contextual design methodology, as the first step.

Contextual inquiry involves going to a user's actual work environment and observing and interviewing the user while the user performs regular tasks with the technology. The interviewer adopts an apprentice role, learning from the master who is the user.

To further progress the contextual inquiry I added an open-ended semi-structured interview. This interview was aimed at discussing the user-experience from the patients' perspective. Open-ended interviews assist in gaining an understanding of the domain of patient experience.

To verify findings, I provided the option of an anonymous survey. As this survey was conducted online, anonymity could not be guaranteed, so this survey is called a semi-anonymous survey i.e. I knew who the participants were, but I did not know who gave what answer.

I developed the methodology as a three-stage process with the name of *Clinical User-experience Evaluation* (CUE). Though the HCI community is familiar with contextual inquiry and qualitative interviews, I had to define the precise research actions that would be undertaken to distinguish them from the clinical trial. This facilitated the clinical trial team's comprehension of the nature of this work. The name CUE was inspired by Bardram's *Clinical Proof-of-Concept* (Bardram 2008), which is a prototype evaluation phase with a few patients prior to a full-scale clinical trial.

3.2.4 The three stages in the CUE

CUE consists of three stages, see Figure 3-2. Stage one was a contextual inquiry performed in-situ at a patient's home. During this stage a patient used the device with the think-aloud method as I, the observer, took notes. This contextual inquiry was conducted during a

patient's regularly scheduled time for using the device, in the patient's home.

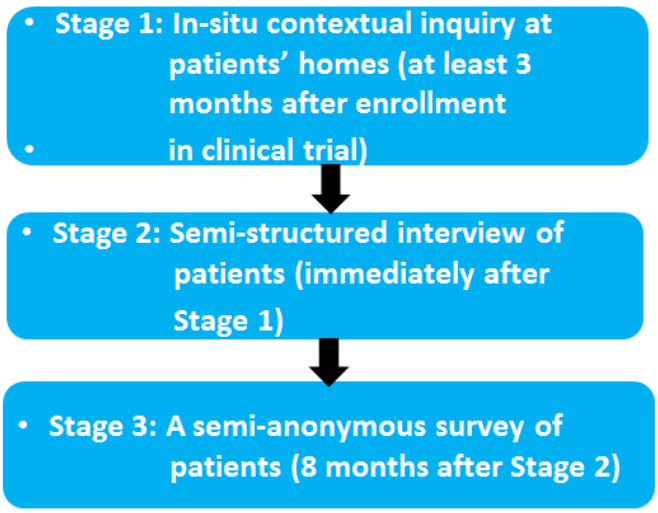

Figure 3-2. The three stages of CUE

Stage two was a semi-structured qualitative inquiry into the patients' experience and expectations; the questions that developed during stage one and anything extra the patient wanted to talk about. The interview took place directly after stage one on the same day, while perceptions were still fresh in the mind of the user. The stage two questions were as follows, but not limited to :

- What do you use the device for?
- Why did you place the device at this location?
- How do you feel using this device?
- What suggestions do you have to make the device better?
- How did you manage your diabetes before you had this device?

However, more questions arose during the interview as the inquiry continued. The additional questions sought details about the following topic:

- Perceived benefits of the device;
- Choices of locations;
- Expectations of the device;
- Impression about the device's current design;
- Suggestions of device design improvements;
- Impressions on the web-based support groups;
- Impressions on health apps in general; and
- Desire to continue using the device after the clinical trial was over.

Paper and pen were provided to patients if they preferred to express some concepts in sketches. The survey in stage three was completed eight months after stage two. The stage 3 semi-anonymous survey was aimed at verifying findings from stages 1 and 2.

3.2.5 Relationship between CUE and clinical trial

The CUE will not interfere with or impede the traditional clinical trial but is an additional activity that is carried out concurrently by non-medical staff. Table 3-1 describes alignment of activities of the CUE to the activities of the full medical clinical trial.

3.2.6 Possible Benefits of CUE

Recruiting participants for HCI research is resource critical. A common concern in HCI research is recruiting users to collect data. Regardless of whether a qualitative or quantitative or a mixed-method study, HCI researchers have to identify the right users who are engaged in the practice of the activity of interest. Resources need to be spent, such as time to follow up users in the right location, and money to attract users during the study.

Recruiting participants for a HCI study in the health field is a harder task than for a regular HCI study with regular technology users. An HCI study for health requires that the users be patients who have been identified as having a certain health condition. This requires the researcher to go through a very strict ethics approval process.

Table 3-1. Comparison between CUE and the Clinical Trial

Activity/Detail	**Clinical User-Experience Evaluation**	**Clinical Trial**
Investigation aims	Investigates how patients use a device and their experiences with it.	Investigates patients' medical condition with an intervention that can be a drug or a technology.
Outcome	To provide user feedback about using the trial device and a guide for future improvement of the device including features that were lacking or non-existent that would benefit the treatment process.	To provide enough evidence for medical practitioners to make sound judgments.
Sample size	A smaller sample population similar to HCI qualitative user-evaluation is appropriate [141].	Requires large sample population to provide substantial and robust evidence.
Time period	Conducted at least three months after the start of the clinical trial. Each participant was contacted twice.	Conducted over an extended period of time depending on the treatment with data collected regularly.
Regulations	CUE does not interfere with medical protocols; there is no physical or psychological stress. CUE is conducted at the regular times a	Rigorous form of testing that must follow HTA guidelines. Clinical trials often include psychosocial analysis questionnaire.

	patient uses the technology as part of the overarching clinical trial.	

However, clinical trials are rich in participants. Clinical trials also have ethical approvals from health departments to conduct healthcare research to gather evidence. The problem of participant recruitment for HCI researchers can be solved if HCI researchers work with a clinical trial. A sample of clinical trial participants is of great assistance for HCI researchers in the healthcare domain.

3.3 Conclusion

The previous chapter presented the background to this research through a review and synthesis of the existing literature. This background indicated that a new methodology is required to understand patients' user-experiences in a clinical trial. This chapter developed the CUE methodology as a possible solution. The next chapter will demonstrate how the CUE was implemented by providing a case study of the CUE in a clinical trial.

Chapter 4. Implementation of the CUE

Chapter 3 described the CUE methodology as a complementary method for a telemedicine clinical trial. This chapter presents the implementation of the CUE. Section 4.1 demonstrates how the CUE was implemented with a clinical trial. The section delves into the clinical trial, how the CUE was implemented, the device of the clinical trial, participant recruitment and schedule. Section 4.2 outlines the human research ethics of this research, involving anonymity and human research guidelines. Section 4.3 provides a brief description of the data analysis methods that were used for the data from CUE.

4.1 Implementation of the CUE with a clinical trial

The CUE was implemented with a clinical trial of a T2D telemedicine device in the Townsville region of Australia.

4.1.1 A telemedicine clinical trial of T2D

The Australian Government rolled out *Medicare Locals*, a national network of primary health care organisations, on July 1 of the year 2011 to provide better primary health care. The *TMML* is one such organisation that covers Townsville and Mackay and surrounds such as Richmond, Cardwell and the Central Queensland communities of Dysart and Clermont [142]. The TMML aims to build a consumer focused integrated primary health care system to provide better and easier access to local health services, for people in these communities [143]. TMML engages with doctors and other health care professionals in service delivery, coordination, education and strategic planning to improve the patient journey across primary health care [142].

TMML commenced a randomised controlled trial to test a model of care for people with T2D in 2012 [143]. This trial was a national

award winner for primary health care in Australia [143]. The trial explored whether telemedicine in-home clinical care, supported over high speed broadband, lead to improved diabetes control that may benefit patients, carers and clinicians [21]. The *National Broadband Network* (NBN) of Australia provided the high speed broadband that was required for the telemedicine technology of this clinical trial. NBN delivers an Australia wide project to upgrade the existing fixed line phone and Internet network infrastructure to provide broadband Internet [144].

The primary aim of TMML's clinical trial was to investigate the effects of the in-home monitoring through telemedicine technology on the health outcomes of T2D patients [21]. The secondary aims of the trial included: to assess improvements in the experience of care for patients, carers and clinicians and to determine the utilisation of the high speed broadband.

TMML's clinical trial was a two-arm prospective randomised controlled trial. 210 adults with T2D were chosen to be randomised either to the '*intervention*' or to the '*usual care*' control arm [21]. Patients in the intervention arm of the trial received online diabetes care from a care coordinator nurse via an in-home broadband monitoring and communication device. This device captured clinical measures, provided regular health assessments and videoconferencing with other health professionals. The patients in the control arm received the usual care from their GP and participated in the clinical measurement and health assessment components of the evaluation.

The clinical trial was open to those people living in certain areas of Townsville where the NBN provided Internet and had T2D with an HbA1c reading ≥ 7.5% prior to commencing the trial [21].

4.1.2 Collaboration with TMML's Clinical Trial

Two formal meetings were conducted with the TMML. The meetings discussed the prospects of the CUE methodology to

complement the existing telemedicine clinical trial of T2D. The topics in chapter 3, sections 3.2.2 to 3.2.5 were presented and discussed in these meetings. My role in the implementation of the CUE was that of a neutral third-party observer in the clinical trial.

4.1.3 The telemedicine device of CUE and the clinical trial

The in-home monitoring device used for TMML's clinical trial consists of a tablet computer with an 11-inch screen, an automatic glucometer and an automatic sphygmomanometer (blood pressure measuring device), shown in Figure 4-1. The device has a touch screen interface and is a single-user system. A regular patient session entails a patient turning on the tablet and waiting to automatically login. The patient then looks at the scheduled blood glucose and blood pressure test that is arranged by the nurse. For blood glucose reading, the patient pricks a finger to get a drop of blood and puts it on a strip. The strip is then placed in the glucometer. For blood pressure measurement, the patient puts an arm in the automatic sphygmomanometer, which automatically takes a reading.

Figure 4-1. The in-home monitoring device of the clinical trial- a tablet pc, sphygmomanometer and a glucometer.

4.1.4 Participant recruitment

Although 210 patients was the overall target of the clinical trial of TMML, the 210 patients did not all enroll at the same time. The

patients enrolled in smaller numbers in different areas. During the CUE implementation with the clinical trial, there were 16 patients enrolled. An information sheet was provided to them about the CUE study (see Appendix B).

Participation in the CUE was voluntary. An information sheet of the CUE study was prepared with simple language. This was presented to those clinical trial patients to introduce the CUE. The information sheet explained what the patients were required to do. The patients were given a week to inform the researcher, if they wanted to participate in the CUE study.

For this CUE study two conditions were used to recruit the patients.

1. Possibly equal number of male and females
2. Possibly equal number of ageing (those who are above 64) and other patients

12 patients initially agreed to participate, however, three of them opted out of the CUE study due to unavailability of time on their part. Nine patients participated in the CUE study. Five of them are considered to be part of the ageing population with an age of at least 64; they are listed in the grey rows of Table 4-1. Four participants are within the age range of 50-63; they are in the white rows of Table 4-1. A participant's diabetes history and computer experience was not part of the selection criteria; however, these details were collected and presented in Table 4-1 after the CUE was conducted.

Two nurses, Nurse1 and Nurse2, were also interviewed individually in the nurses' office. Nurse1 and Nurse2 monitor the data from the back-office to see if a patient's blood glucose and blood pressure parameters are within a safety range. Both Nurse1 and Nurse2 are female and have been in the nursing profession for more than 20 years.

4.1.5 Anonymity of participants

Participants shared their lives, their home environment and their feelings with the telemedicine device. These stories could potentially reveal the identity of the participants. Participants' identity protection is important, as Townsville is a tropical town of 300,000 inhabitants. For anonymity, every participant's identity and real name were protected. Each participant was given a pseudonym as described in Table 4-1. The pseudonyms are extremely different from the participants' original names.

Table 4-1. List of participants and relevant information

Participants (pseudonyms)	**Sex**	**Age**	**Computer use (hrs. /week)**	**Diagnosed with T2D (years)**
Uma	F	74	0	12+
Zach	M	70	70	10+
Yanicka	F	68	20	7
Vince	M	66	20	10+
Bill	M	64	4	20
Heidi	F	60	2	25
Serena	F	55	12	2
Pete	M	53	2	1
Ted	M	52	60	2

The pseudonyms used are *Zach*, *Yanicka*, *Bill*, *Vince*, *Uma*, *Heidi*, *Serena*, *Ted* and *Pete*. The two nurses were given pseudonyms as *Nurse1* and *Nurse2*. Each patients was given an informed consent form to obtain their permission to use his/her recorded data, photograph and audio recording (see Appendix B).

4.1.6 Schedule to conduct CUE

Schedules to visit the participants' homes to conduct stage 1 and 2 of CUE were set up. Every participant was at least 13 weeks into the

clinical trial (Table 4-2) to avoid novelty effects as defined by the CUE methodology (section 3.2.5).

Table 4-2. Schedule of CUE with participants

Pseudonym of Participant	**Date of CUE (Stage 1 & 2)**	**Time enrolled in clinical trial**
Zach	18 Nov, 2013	8th month
Yanicka	27 Nov, 2013	6th month
Vince	3 Mar, 2014	6th month
Bill	4 Mar, 2014	5th month
Uma	7 Mar, 2014	5th month
Heidi	07 Apr, 2014	5th month
Serena	21 Mar, 2014	13th week
Ted	22 Mar, 2014	6th month
Pete	14 Apr, 2014	6th month

4.2 Human Research Ethics

The *Human Research Ethics Committee* of *James Cook University* (JCU) approved (application ID H4900) this low risk study of CUE in October of 2013. This approval complies with the *National Health and Medical Research Council*. The TMML indicated that JCU ethical approval was sufficient for conducting the CUE on the patients of their clinical trial. Written verification of the TMML's acceptance to conduct the CUE with the clinical trial was necessary for JCU ethics protocol.

This research of conducting CUE was deemed a low risk study, as there were no risks to the participants or the researcher beyond normal day-to-day living. However, participants were given the option to withdraw at any point during the CUE, prior to the commencement of the CUE. The researcher's contact details were provided to

participants if they had any further concerns after the CUE had finished.

Despite the aforementioned low risk of distress, all participants verbally expressed that they found the CUE to be an opportunity to discuss the telemedicine device and the clinical trial.

Participant involvement was voluntary and an information sheet was provided prior to commencement of the study. All participants reserved the right to withdraw at any time.

4.2.1 Privacy and anonymity

Privacy and confidentiality were assured during the data transcription and anonymity was maintained through pseudonyms provided to each participant.

All interviews were audio-recorded and then transcribed by the researcher to maintain confidentiality. This also improved the researcher's ability to understand the interviews better. Non-identifiable, soft copy interview transcripts have been stored in a secure online website of the university (https://espaces.edu.au/cuedata/cue-data/view).

All photographs were captured such that the faces of the participants are not revealed. All photographs, audio files, and transcripts were also coded with pseudonyms.

4.2.2 Anonymity of stored data

The audio files of recorded interviews and contextual inquiries, images, and transcribed files are also saved with the pseudonyms. Images of the participants were saved with a naming convention. Two additional digits were added to refer to the serial number of the image. For example, Zach 04 refers to the participant named Zach's fourth photo.

4.3 Data Analysis Methods

The CUE is a qualitative evaluation methodology to understand patients' interaction during a clinical trial. The CUE does not measure or prove findings with statistical significance. The CUE explores knowledge of how patients use and interact with a telemedicine device. The CUE does this through contextual inquiry and interviews.

Entire sessions of the CUE was audio-recorded. Photographs were taken additionally. Sketches were collected from patients in some cases. I transcribed all audio files by myself, to best understand and interpret the patients. The contextual inquiry sessions were analysed using the contextual design method. Interviews were analysed with thematic content analysis of qualitative research methodology.

4.4 Difference between CUE and PD

HCI empirical evaluation such as PD is undertaken throughout the product design, development and evaluation phases. In PD, the evaluation takes place iteratively during the whole research process. A question remains about how many of the existing telemedicine technologies for T2D were developed through PD.

Furthermore, even though telemedicine technology had been developed using PD, the past work of PD had not been involved in the post-rollout phase. In this thesis, the telemedicine technology was in a product-ready state and had received the approval of a regulatory body (e.g. TGA) for safety. Next, it was evaluated in a clinical trial. PD has never worked with a product at this stage. CUE was developed to work at this stage of a clinical trial.

A telemedicine device is approved by the regulatory body, like TGA or FDA, before it is used in a clinical trial. However, should users only be involved in the development phase? The post-rollout phase, when real patients use these devices in the clinical trials for almost a

year, presents prodigious opportunities to obtain patient feedback and test the use of the device, to improve future design decisions.

The CUE is conducted in the post-rollout phase in a clinical trial, unlike the development phase in PD. Logically, the evaluation should continue even after a product's rollout phase so patient feedback can inform future design decisions. The post-rollout phase is the right time to gather the final data that may help to inform future design and predict adoption by the patients. I argue that, for healthcare technology like telemedicine, evaluation of patient interaction should continue in the post-rollout phase such as a clinical trial.

4.5 Conclusion

This chapter described the implementation of the CUE. Chapter 5 presents the findings of the CUE. Chapter 6 and chapter 7 present the analysis of the findings.

Chapter 5. Findings of CUE

This chapter presents the findings from the implementation of CUE, within the TMML's T2D telemedicine clinical trial. The CUE methodology was developed as a means to complement telemedicine clinical trials to answer the research question.

Recall the research question in chapter 1 – "*How to evaluate technology-intervened treatments (such as telemedicine) during a clinical trial, to understand patients' use and experiences with the device*?" This question was broken down into the following sub-questions (section 1.2) as follows:

Q1. How do patients use a telemedicine device?

Q2. How do patients feel while using a telemedicine device?

Q3. Which function, designs of the device satisfies/ dissatisfies the patients?

Q4. How to evaluate traditional clinical trials so they can evaluate questions Q1-Q3?

Q1 to Q3 provide scope to the main research question. Q1 specifies that this research explored how patients use the device. Q2 and Q3 postulate that this research investigates patients' feelings and experience with the device. Q4 restates that, the main research question aims to provide a methodology to understand the patients in the scope of Q1 to Q3.

Stage 1 contextual inquiry and stage 2 interview of CUE was selected to answer the research sub-questions Q1 to Q3. In this chapter, the results of the CUE are presented in sections 5.1, 5.2 and 5.3. Sections 5.1, 5.2 and 5.3 each answer the research sub-questions Q1, Q2 and Q3 consecutively.

5.1 How do patients use a telemedicine device? (Q1)

Each patient was visited individually in their own homes to execute stage 1 of CUE, the contextual inquiry. Each participant had already been enrolled in the trial for 13 weeks or more (Table 4-2), yet some patients showed frustration and discontentment, as presented below.

I noted the positions that the patients selected to locate the device. The patients placed the device in different locations in their homes. Table 5-1 shows the placement of the devices by each participant.

Table 5-1. Placement of the telemedicine device by the patients

Pseudonym of Participant	**Placement of the Device**
Zach	Patio
Yanicka	Study room
Vince	Living room
Bill	Study room
Uma	Living room
Heidi	Bedroom
Serena	Living room
Ted	Living room
Pete	Bedroom

In summary, the nine patients placed the devices in the following manner Table 5-2 -- four in the living room, two in the bedroom, two in the study room and one on the patio.

Table 5-2. Summary of the placement of the device

Placement of the Device	**Number of patients**
Living room	4
Study room	2
Bedroom	2
Patio	1

All of the patients were at least in their third month in the clinical trial. They were at ease to demonstrate how they used the device in a regular session. Uma was the only exception.

5.1.1 An example of frustration –Uma´s case

Uma is a 74-year-old woman who lives alone. She had trouble starting the device and using the glucometer. Uma was in her 5th month in the clinical trial with this device. Uma did not have experience with technologies such as mobile phones, computers, etc. She had never owned a mobile phone or a computer.

Uma was very frustrated during the contextual inquiry. A portion of the transcript of the contextual inquiry (from the 2nd minute until the 5th minute) of Uma is as follows:

Uma: I don't know what's wrong with it, it suddenly slowed down.

She was looking at me, so I encouraged her to continue and added a question

Researcher: Did it slow down today or--?

Uma: No, it has been doing this for a few days. I was talking to the lady (Nurse1) on the phone and-- come on

Uma called "*come on*" to the device after being frustrated with the device for not responding to her touches. Uma got nervous. I tried to make her feel relaxed by asking a question.

Researcher: Is it Nurse1?

Uma: Yeah, not Nurse1, the other one (Nurse2).

Meanwhile Uma was frustrated with the non-responsive screen and continuously tapped on it. She was feeling pressured so I told her not to worry about the device. However, she continued to attempt to show how she used it every day and her frustration continued.

Uma: I have to go through this every morning. It's--aaah

Uma ceaselessly showed frustration, sighed heavily with her hand gestures towards the device, and talked to the device.

I don't know whether it's because it's---Aaaahhhhh (more frustration from Uma)

After the fifth minute, Uma was able to use the device after restarting it and being helped by me.

Due to this situation, I asked Uma, if this kind of situation had occurred in the past. Uma stated that it had happened in the past very frequently. Her response was

Uma: Yes, it can and it happens nearly every day.

Researcher: You are used to it?

Uma: Yeah, I got used to it. (signs of despair)

5.1.2 Difficulty in measurement of blood pressure

All but one patient (Ted) complained about difficulty with the automatic sphygmomanometer. Patients had to use one arm to put the cuff around the other arm and then press a button on the device screen to start the automatic adjustment process (Figure 5-1, 5-2). All patients

used the cuff on their non-dominant hand with the help of their dominant hand.

A major complaint was that the cuff did not fit well on the arm. This resulted in an error during the blood pressure reading by the device. When this error occurred, the blood pressure device continuously readjusted the pressure on their arm. Then it attempted to redo the measurement of the blood pressure from the start, by loosening and then tightening on the patient's arm repeatedly. This could continue for some minutes.

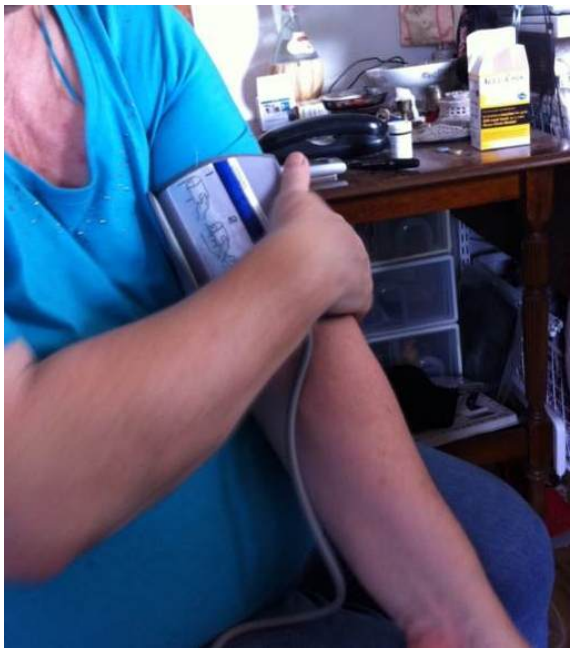

Figure 5-1. Heidi adjusting the cuff with her right hand

The only options available to the patients were to remove the cuff by hand or to switch off the device. This caused great frustration and annoyance to six of the patients.

Heidi said, *"It's not really a one-man job."*

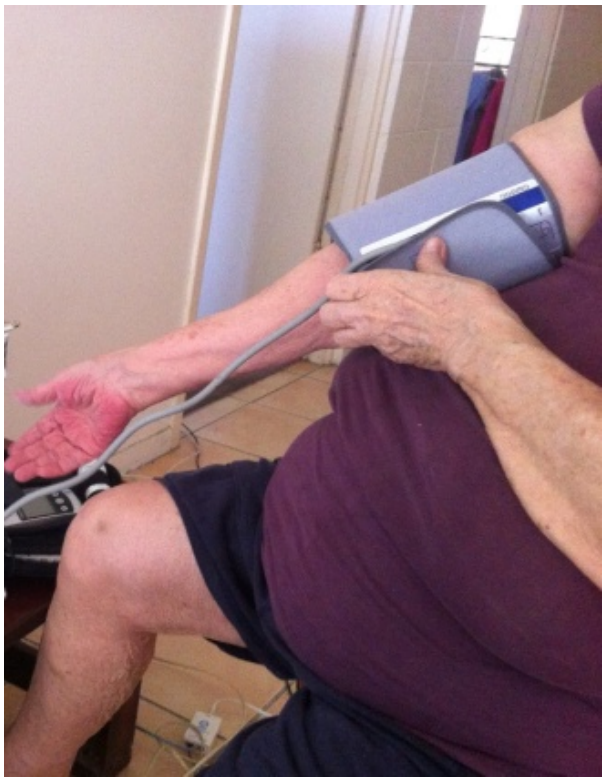

Figure 5-2. Uma adjusting her cuff with her left hand

5.1.3 Frustration due to long response time

Zach mentioned that sometimes the Bluetooth technology stayed unresponsive even though the glucometer was within 18 inches from his tablet PC. In this situation, the data from the glucometer was not transferred to the system and stayed on hold. The glucometer was in a waiting period. A similar issue also happened with the sphygmomanometer.

"Occasionally you got absolutely frustrated when it failed to respond or responded after long period." (Zach)

Yanicka expressed similar frustration with the glucometer. Yanicka said:

"So now it comes up when this appears here and a code of C22, then I turn it off and that comes up to tell me that I can take my blood now, put the blood on there— " (Yanicka)

The reason behind these patients' complaint was that if the data was not transferred immediately it was lost. Even though patients could keep the data written on a piece of paper, they did not have a way to manually enter this data in the system. This meant that even though the glucometer functioned properly and the patients successfully got the result, the glucometer still could fail to transfer the data to the system via Bluetooth.

Heidi stated the slow response time causes frustration to her.

"I find that it is not as quick as it should be. You know you have to wait for this and wait for that and wait for that and then if something doesn't work, you have to do it again. And so you know I try to wash my hands every time because that's part of it and I try to use the same finger every time. And I set up everything fresh each time." (Heidi)

5.1.4 Touch the screen with bloody finger?

All participants praised touch screens. Each of them has had their occasional slow responses from the touch screen but they did not say much about it unless they were asked. However, Zach posed a puzzling thought for designers. He stated that it is not suitable to use a touch screen when the patient had just drawn a drop of blood right beside the device (Figure 5.3) and then touched the device with bloody fingers. He would have to be careful to clean up his finger first and also clean the other hand that he uses to clean. Zach and all patients were instructed to prick a finger, take the blood drop on a strip, and then put the strip in the glucometer. Next, the patient had to touch the screen to make the device read the data loudly. But the patients were strictly instructed to clean the drop of blood first with some cotton, which broke their flow of activity. Zach asked if there would be some other device in future where T2D patients did not need to prick a finger or did not have to touch a screen right after pricking a finger.

Figure 5-3. Pricked index finger with blood next to the touchscreen device.

"I find that touchscreens are touchy things (laughter) you know if you just had a sandwich with butter on your finger (laughter). It suddenly gets greasy marks all over… like this phone of mine. Because telephone ringing you want to answer you can't make an answer because the screen got a bit of hair or grease on it. It's very confusing. One moment you just put a hole through your finger to get blood and then you make the touchscreen bloody (laughter…)?" (Zach).

5.2 How do patients feel during using a telemedicine device? (Q2)

Answers to Q2 were collected during stage 2 of the CUE. The patients answered the open-ended questions during stage 2 of CUE. I chose some of the patients' vocabulary to highlight and present the answers with themes. For example patients used words such as "motivation", "accountability", "safety net", "habit", "awareness", etc.

5.2.1 Motivation

Two participants mentioned that using the device provided them with motivation to manage their diabetes. Heidi found the technology gave an extra push to help her.

"I find it, it just gives you that little extra nudge." (Heidi)

Vince lives with his wife. His wife was actively participating in the interview. They (Vince and his wife) mentioned that Vince found "motivation" from the use of the telemedicine device.

Vince's Wife: *"Motivates— "*

Vince: *"Yea motivates. And it's good that they, that someone else is keeping an eye on you, back at office, nurses."*

5.2.2 To build a habit

Pete lives alone and he stated that he had developed a habit from the use of the device for 6 months. This habit consisted of measuring blood glucose and blood pressure early in the morning before he would engage in his daily life. Pete was in his last week of the 6-month clinical trial, at the time of his participation in the CUE.

"I think it's a great benefit for me, I wish it probably could stay and I would like to keep it. I don´t know how I am gonna go, I am obviously in the habit of doing it every morning now, I am gonna have it. It´s a habit now. So next week it's gonna go and I can still maintain the regime that I am doing it now, you know." (Pete)

5.2.3 Awareness

Enrolment in the clinical trial had made Serena more accountable with the blood pressure measurement and to be aware of her own well-being. The device would make her do things regularly. Serena called this being in a regime where she had to regularly monitor and be aware of her blood glucose and her food.

"Having this does make you more accountable for your health, because before I wouldn't have checked my sugars and those stuff as regularly, but having it here, makes you do that." (Serena)

Serena lived with her son. Serena's son commented that the device had improved Serena's overall awareness.

"It's more like a -- there's a regime for everyday 10 minutes before eating and after eating, she tastes it and morning, afternoon-- it's 10 minutes or 5 minutes—doesn't affect much. But it improved her overall awareness." (Serena's son)

Vince stated that after he had looked at the results he felt more aware and accountable. Looking at the results made him want to use the device more.

"It (the device) makes you, wanna do it (the blood glucose reading)." (Vince)

Heidi compared the use of the telemedicine device with quitting smoking. In 'quit smoking' programs, people are typically encouraged to call a back end or a buddy, each time they have the urge to smoke. Heidi found using the device a similar experience to quitting smoking. This device makes her do the one extra step that she needs to take.

"You know when you haven't done this for a week and oh you should do it. It's like quitting smoking, you know that you have to ring up somebody every time you have to ring up. So it's that extra incentive you know." (Heidi)

Pete lives alone. He thinks the diabetes device has helped him to be more serious about his T2D conditions. One reason for this is that Pete placed it right beside his bed. He saw the device as soon as he woke up. He had several options to place the device in other places of the house. He lives in a two-storey house and the device could also have been placed on the second floor. Yet he chose for the device to be on the ground floor in his bedroom. Pete owns a study room upstairs,

which has his desktop computer. Pete said that logically he would have chosen the device to be there with his computer. However, he chose to place it in his bedroom so the device is the first thing he sees in the morning.

"I have been able to take diabetes more seriously because it´s there in my face every day, and since I have the computers and blood pressure machine, my diabetes is finally under control because I take it seriously now." (Pete)

Ted is an IT professional and is thus a tech-savvy person. Ted had used other gadgets such as a glucometer to measure his blood sugar. Ted said that the telemedicine device forced him to measure his blood glucose, more than a glucometer. Usually when his glucometer strips ran out, he would wait for several months before he bought more. However, enrolment in this trial and use of this device compelled Ted to do his blood glucose measurements everyday unlike the situation when he used other devices. Ted thinks this is an outstanding advantage of this device over only a glucometer at home.

"Look, I have my little blood glucose meter and I used it. I ran out of all these things once expired. So they have expiry date so I never went back to get replacements. And I didn't monitor and waited 2 or 3 months. Again, this tech forces me to think about some results, so that I can deal with rather than me having to force myself." (Ted)

5.2.4 Feel safe

Daily monitoring provided safety and comfort to the patients. In the case of Vince, daily monitoring made his wife feel safe that someone is watching over Vince.

"It´s sort of like a safety net. You know there's someone in the background always watching and they will ring you up." (Vince's Wife)

Uma is a 74 year-old woman who lives by herself. Uma had never used a computer or a smart telephone. For Uma the device was not of

interest for herself, but for the nurses. In Uma's opinion the use of the device provided the nurses with the data that they needed. It was not of any particular interest to Uma.

"Well, it doesn't really. It´s just giving them information, and so they know when it goes up and then they ring me up and find out why that's suddenly from the past week, my readings from blood sugar went 30 while before that it was 6. Yeah, they took me off the medication, because I think it was affecting my kidneys and of course now it's skyrocketed. And that's why I have got back, on Monday, Tuesday till Friday I am going on insulin." (Uma)

Serena's son stated that the device helped him to look after his mother. Serena's son was concerned for Serena's well-being. He stated that his mother's enrolment in the trial and use of the device helped him to look after her. While Serena did regular blood glucose measurements, he would also look at her results. He takes care of Serena's hypoglycemia by preserving additional food items that contain sugar.

"Well, she is doing a lot of exercise and doing well now and it is -- she is looking like she has lost a few kilos already-- it scares me when she says she is having a sugar low or something like that and I check to make sure she is ok-- so it helps me to look after my mum as well. So when her sugar is low I feel like we keep jelly beans and sugar." (Serena's son)

The benefits of being monitored by the nurses are perceived as a great advantage for the patients. Vince thinks that knowing daily readings helps him to stay alert and is lifesaving.

Vince: *"The best thing is you know straight away, if I took my blood pressure today, and the nurse saw it, she can say you better go to the doctor. If I write it in a book, who knows I might have a heart attack tomorrow."*

Serena: *"I think this is absolutely wonderful because you know someone's checking on it because normally I would be like yeah... three months I would go to the doctor-- yah do it a week beforehand."*

Ted mentioned the stored data being of more value than the ordinary glucometer. With stored data he thinks, one may go back and look at the past data.

"I can in theory go back and talk to the nurse and have a look at them all or whatever. If you are just using your standard glucometer then you don't really have a way to go back and look at the historical stuff." (Ted)

Lots of modern glucometers have the function which allows a user to look back at past data by downloading the data onto a tablet or computer. Ted was not aware of this functionality of the new glucometers.

5.2.5 Reduced doctor visits and thorough information

Vince and his wife stated they had less visits to the doctor during the time enrolled in the clinical trial. They indicated that they did not have to see the doctors every three months as the traditional treatment, but saw the nurse every two weeks. Daily monitoring and weekly nurse consultations via the device kept them more informed and aware.

"And less doctor visits now, coz now the doctor says, I don't wanna see you in three months--whereas you are seeing the nurse in every two weeks, because he knows he is being monitored and so that's, she rung me up, nurse rung me up this morning and said you know, you are doing good, your readings are good, your blood pressure is good, if I hadn´t had that, I wouldn't know and I would have to know this four weeks down the road, and that's a long period. And you won't know your blood pressure anyway because you take it at your doctor's but now you got it at home daily, that's also a good thing." (Vince)

5.3 Which function, designs of the device satisfies /dissatisfies the patients? (Q3)

The telemedicine device uses the Internet to send and receive data. The device only functioned with wired Internet that had to be connected through a cable through the telephone port in a patient's house. Therefore, the device was not wireless.

5.3.1 Lack of wireless capability

Heidi, Serena and Uma mentioned that having wires was a problem of the device. Serena complained that the cords were too short and the length was insufficient. She also added that not every room in her house has the Internet socket availability that makes the device difficult to place.

"Ok, so a lot of these cords aren't long enough. And this is plugged in the wall, I have got a socket over there coz it goes through the telephone line. And it's right at its stretch. That's the other thing. The cords were a little bit short. If I had to put it in the lounge room, the phone socket is behind the piano." (Serena)

The device functions only from the patients' homes. Heidi indicated that when she is working outside, she had to arrive home within two hours after eating. This made her stressed and sometimes she could not do all the things that she planned to do outside of her home.

"Apart from when you gotta be home two hours after eating to do it can be a little bit difficult like..Oh my God I have gotta get home so I mean time wise that's it if I am not gonna be at home.." (Heidi)

Uma found alternatives to use the device from home. While she travelled, she used a separate glucometer and would keep her blood glucose readings in a diary. She would later come home and update her nurses about the data. However, the device did not allow users to

manually record data. It only records and sends data to the nurses when a reading is done with the specific glucometer of the device.

"I can take this (her own glucometer that she bought) with me, I can't do the blood pressure, I take this with me and do the blood sugar and then put it down in a book." (Uma)

5.3.2 Unfamiliarity in the beginning

The TMML nurses and technicians provided training to the patients about how to use the device. This training was done at the initial setup of the device in each patient's home. The nurses also provided the patients with a printed user manual for future reference. Each nurse spent 30 minutes in each patient's home. The nurses then asked the patients to practice the whole procedure in the nurse's presence.

Next, patients were asked to practise the procedure the following day while the nurse was on the phone. The nurses instructed while a patient would practise the procedure. The nurse was at the TMML office and looking at her computer to see whether the patient successfully sent the data and whether the data was received at the nurse's end. Each patient had at least two practice sessions via the phone, after the initial in-home training. If the patients still needed additional support, they could call the nurses for additional help. In that case, a member of the IT support team of TMML would be requested to visit the patient at a patient's home. The staff had to be booked and the staff would visit the patient at a later date, usually in a week's time from the date of the request.

However, the patients still reported difficulties using the device. Pete reported that he had some initial difficulties and called the nurses. The difficulty could not be solved via the phone call to the nurses and a technical person was due to come to his home. Pete reported that as yet there was no one to attend to his problem. Finally Pete solved his problem by himself.

"In the beginning there were a few technical difficulties. No I used it, but I --kind of worked out the problem myself you know." (Pete)

Yanicka reported that she had problems with using the touchscreen due to her expertise and familiarity with the mouse. She praised one member of the technical team that visited her home and helped her.

"Lovely young man. And and they didn't leave until I was sure and confident. But it was a bit scary coz I have never worked with that before. Coz I am a mouse skill I can't do that this way." (Yanicka)

5.3.3 Undesirable experience from sphygmomanometer

Every patient criticised the sphygmomanometer. It was difficult to use. It also gave uncomfortable experiences.

Yanicka explained the story in the following excerpt of her interview. The sphygmomanometer was so hard to use that Yanicka questioned, why she needed to measure her blood pressure when she only needed to know her blood glucose reading. She deliberately chose to upload only her blood glucose and made a compromise with the nurses.

"The blood pressure cuff I have more difficulty with. I put it here where my doctor would put it. It re pumps and it takes ages to do it. It marks my arm." (Yanicka)

Yanicka complained of physical pain around her arm from the device. She stated that this pain was more than other sphygmomanometers that she had used in doctor visits.

5.3.4 Lack of visual data

Blood glucose readings are paramount to manage well-being of T2D patients. Based on the data patients generally made decisions regarding diet and physical activities. The nurse, via phone and based on the blood glucose readings, provided medication decisions.

In the current system, each time the patients conducted a test, they were presented with instant data on their blood pressure and blood glucose levels. However, when the patients conducted the next scheduled test, they could not see the previous data. This was stated as a problem with all the patients in this trial.

The initial developers of this telemedicine device focused on the function of providing immediate data (blood glucose and blood pressure readings), but not what data the patients might find important for tracking their progress. For example, if a patient did a test in the morning and one in the evening, they were unable to compare the readings, as the earlier test was not available. These comparisons could be helpful to the patient to track progress on a daily, weekly and monthly level. In reality, patients expressed their desires and the importance to see the previous data to help them know if they were doing better or worse in terms of their blood glucose. Patients stated they manually record the data instead because the system did not have this function. The only historic view they received was a three-monthly hard copy report from their nurse.

The patients were content to see the data and the three-monthly reports. However, they sought to see more. Bill wanted to view more visual data. Bill compared this device with his personal glucometer that he had bought and used in the past. Generally he could see a lot of data on his glucometer.

"I know it does it here (glucometer) but it would be good to see every day's. But it doesn´t show you. Like last week I might have been 5.5 and this week I am 7.5 why? Why am I? Then I would do exactly the same things that I did last week." (Bill)

Heidi mentioned that if visual data was compared and shown on a graph daily that would help her to compare and understand the reasons for the changes. For example, she stated that she wanted to identify if her improvements were caused by her own diet and exercise

or it was caused by her insulin dosage. She commented that seeing a daily feedback and visual data to compare her blood glucose was of immense benefit to any patient.

"I would like to see my results displayed rather than wait for them to email. So like my graphs. Because she (Nurse) said I am doing really well, and it's definitely going down. We have to decide how much of that is changes that I made and how much of that is the drug change. Because you know it's one of those, it does progress and never and eventually you can become insulin dependent which makes life that more difficult, I take one in the morning and medication in the night and if I am out through the day it's impossible to slowly take the medication so I am on slow." (Heidi)

Vince and his wife also mentioned the adjustment of insulin, similar to Heidi. They said that while Vince took insulin and was adjusting the dosage of the insulin, they would prefer to see a day-by-day comparison of Vince's blood sugar in a graph.

Vince and his wife commented about the current method of TMML. In the current practice one of the nurse sends each patient a summary of his/her past blood sugar data by mail or email once every three months. Vince thinks this should be done in an instant on the device. He said a one click button could have been the best way to show the comparison on a graph.

Vince's Wife: *"It would be much better if he could just push a button and see the last three weeks of his readings."*

"Coz he is adjusting his insulin and he needs to know---all the time."

Vince: *"Yeah, I got a graph on my computer the other day, I have a two weeks and it chose me a graph of mine and in between certain numbers, I understand that's a good idea, that would be great if you can get it that way."*

Notably, the patients had the option to speak to a nurse. They could either call the nurse directly, or they could schedule an

appointment on the device. Alternatively, nurses could also call the patients. Generally they would call a patient to warn if a patient's blood glucose readings were indicative of concerns related to T2D. Nurses sent a paper based report every 90 days that was mailed to the patients. This report contained the summarised data of the patient.

Pete complained of never receiving any summarised data in his entire 5 months (at the time of his interview). Pete is not a supporter of paper based summarised data. He preferred it on the screen of his device and its summary and comparison from the previous day and the previous week in the form of a graph. Pete stated that the blood glucose reading was a number and with a graph it can be more meaningful. The number was all right to know, however, he wanted to know the changes in this number through the graph.

"Probably I would like to see a graph of my results, more often. Like even once a month would be good to show it on a graph. How my results are going, because you just see number everyday, but you want to know your ups and downs, and you want to know using that computer why my diabetes goes higher, I know the reason now why it goes higher, before I didn´t know the reasons. But now I do. And it's just the difference the food that I have eaten and the foods prepared and I have found that because I am monitoring my blood glucose carefully." (Pete)

Zach stated that graphs are a great tool to compare trends. Zach was very particular about using a progressive graph. He also commented that much research is required on how to show the blood pressure and the blood glucose level in the graph.

"There is nothing like graphs to see trends. They have to display in a sensible way, if that makes sense. I will be thinking that a progressive graph will do it." (Zach)

5.3.5 Lack of medication name

The device has a feature that opens information sheets. There are two types of information sheet. The first type consists of information on how to take care of the body. For example, foot care, nail care, skin care, food selection, etc. for diabetes patients. The second type consists of information on the medication.

Yanicka stated that the medication that she was taking was not included in the information sheet listed on the device. This meant that the database did not contain a full list of all possible diabetes medications that the patients in this clinical trial were using. This necessitated Yanicka using another computer to locate information about the medication that was prescribed for her. This caused Yanicka a lot of dissatisfaction with the device.

"To see my change of insulin and I couldn't find on here so I went back through here with my computer and Internet. My medicine is also here… and insulin is not there but I looked that up at the computer. Not everyone has that. When I want to see what that thing do I check it up here. I don't ever touch the unit because it automatically shuts down. It's simple as that, quite easy to use. Bit challenging at the beginning." (Yanicka)

Zach reported the same problem - his medication was missing from the available information sheet on the device.

5.3.6 Mismatch with life due to immobility of the device

The device currently works only with Internet cables that are available at home. The device cannot be moved far away from the Internet socket due to the short length of cables, let alone when a patient is out of home. Some of the patients work full time and had to adjust to the schedule of their regular test. Other patients who were not working still had to leave home for outdoor activities. All of the patients stated that a mobile device, which could be used from outdoors, would have been much more suitable than the current device.

"Apart from when you gotta be home two hours after eating to do it can be a little bit difficult like.. Oh my God I have gotta get home so I mean time wise that's it if I am not gonna be at home..It's an issue but it's not taxing." (Heidi)

Ted, who works full time in an IT job, stated that his job hours were the reason for the device being a mismatch with his lifestyle.

"I have an issue being consistent. In other words, I am not home until late at night and as a consequence me being on a schedule that demands I do it on a certain time of the day is not gonna happen for me. I don't find it taxing in that way. I do it when I have time to do. Whether that has a value clinically is another story." (Ted)

Zach, who is a retired engineer, still spends a lot of time out of home. Zach said the use of the telemedicine device, forces him to be at home and he cannot be at home always.

"That's a fundamental problem. If I was at home this will be in the specific place where I know it works." (Zach)

Uma stated that she cannot carry the device. So she carries a different glucometer to keep the data for her records.

"I can take this with me, I can't do the blood pressure, I take this with me and do the blood sugar and then put it down in a book." (Uma)

5.3.7 Glucometer Discomfort and Pain

When a patient uses a glucometer, a small drop of blood is obtained by pricking the skin with a lancet. The drop of blood is placed on a disposable test strip that the meter reads and uses to calculate the blood glucose level. Slight discomfort is experienced when the lancet pricks the skin of the finger. However, T2D patients use a glucometer frequently, often more than once a day. Some of the patients in this clinical trial mentioned the discomfort and pain from the glucometer.

Ted stated that after frequent use over a long period, his finger feels bruised.

"Problem I see with this is you have to prick your finger every time you use it. It's not that bad but after a while you are bruising your fingertips sore so in that respect I guess it's not really something that one looks forwards to going and doing." (Ted)

Every other patient also felt the pain and complained of being hurt. As a remedy, Zach is interested to see what the scientists come up with in the future. Ted also mentioned that he wants science to advance in such a way that a chip can be inserted and left in a human body so it will transmit continuous readings to the machine. In this way, Ted thinks, bruising and pain may be avoided.

5.4 Conclusion

This chapter presented the results from stages 1 and 2 of the CUE. The results answer the research sub-questions. Section 5.1 showed the patients' decision about where to place the device in their homes and how they use the device. Section 5.2 showed patients' experiences with the device. The experiences include all the positive and negative outcomes that were perceived by the patients during the interviews and observations by the researcher. Some of the positive experiences perceived by the patients were motivation, awareness and habit development, etc. Other positive experiences were the perceived impacts of the device on their daily lives such as, less frequent visits to the doctor and their feeling of safety from being monitored. Section 5.3 presented the shortcomings of the current device from the patients' perspective. The patients made comments about the hardware, especially the lack of wireless capability. Additionally, they mentioned the unfamiliar feelings at the initial stages of the trial. Other shortcomings they mentioned were the lack of visual data and discomfort using the sphygmomanometer and glucometer. The

interview transcripts (transcribed by myself) were uploaded on an espace (https://espaces.edu.au/cuedata/cue-data/view).

Chapter 6 provides an analysis of these results. Results of stage 3 of CUE and analysis of the results are presented and discussed in chapter 7.

Chapter 6. Analyses and Discussions

The previous chapter presented the findings from the contextual inquiry and interviews. This chapter begins with an analysis of the contextual inquiry of stage 1 of CUE in section 6.1. The analysis was conducted using the contextual design methodology. This analysis serves as a validation of section 5.3 where the patients subjectively provided a critique of the current version of the device through interviews. The analysis shows how the current device should be designed to fulfil the workflow of the patients.

Next, this chapter continues with the findings, analysis and discussion of placement of the device in the patients' homes in section 6.2. These findings were observed during the contextual inquiry and interview session in Stages 1 and 2 of CUE.

Section 6.3 discusses the behavioural effects on the patients from using the telemedicine device. Finally, section 6.4 presents a categorisation of the patients based on observations.

6.1 A User-Centred System Design for in-home monitoring of Type 2 Diabetes Patients

This section proposes a UCD for the T2D patients of this research. This design is created using *CD* methodology [107]. The CD process generally consists of eight steps: (1) Contextual Inquiry, (2) Interpretation Session, (3) Work Models and Affinity Diagramming, (4) Visioning, (5) Storyboarding, (6) User Environment Design, (7) Paper Mock-up, and (8) Interaction and Visual Design. This section conducts the first three steps of the CD to create a UCD for T2D patients. A comparison of the current design of the device used in this research with the UCD created through the first three steps of the CD is presented. The focus is predominantly on how the "*system should have*

been" in contrast to "*how the system is now*". Therefore, only steps 1 to 3 were sufficient and had been completed. Steps 4 to 8 were not completed with the CD process because the full creation of the system is not required to show the comparison. Steps 4 to 8 are suitable for creating a new system that does not yet exist. In addition, creation of a new system is not in the scope of this research due to strict ethics regulations with health care technologies.

Eight participants' contextual inquiry field notes were used to create the UCD of this chapter (Table 6-1). The ninth participant (Ben) was uncontactable during the CD process in this section. However, the ninth participant's work process was matched afterwards with the work process of the other eight participants. No significant differences were found in the ninth patient's activity. The details are discussed in the discussion section at the end of the chapter.

Table 6-1. Participant code name during the UCD

Participant Code Name	**Pseudonym**
P1	Zach
P2	Ted
P3	Yanicka
P4	Vince
P5	Bill
P6	Serena
P7	Uma
P8	Heidi

The *contextual inquiry* of each participant was done in-situ in his or her own home. This study explored how the participants worked with the device on a day-to-day basis. According to Beyer and Holtzblatt [107], users often cannot articulate *what* activity they do and *why* they do it, as work becomes so habitual. Hence, this research uses contextual inquiry to understand the exact work process of the patients during a regular blood pressure and blood sugar upload session. Interpretation was conducted after returning from the fieldwork.

"Work modelling" captures the way users work. Each user's work modelling is created based on the contextual inquiry and field notes that the researcher keeps. These individual work models are then consolidated. Consolidation brings data from individual users together in one place so common patterns and structure could be seen without losing individual variation. During the work modelling, individual models are consolidated to portray the full system since a system is never designed for a single-user. The work modelling of this research is done using a flow model, a sequence model and affinity diagramming.

6.1.1 Flow Model

A flow model in CD captures communication and coordination between people to accomplish work. The flow model shows formal and informal workgroups. Ideally, nurses, doctors/GP or any other professionals from whom the participants seek help should be part of the formal workgroup while family members are part of the informal workgroup. However, the telemedicine clinical trial is still between the nurses and the patients. Therefore, the doctor and family members are not considered as a formal work group of this research. Any other communication between the participants and any other human that is not part of the clinical trial is considered here as informal workgroup. The flow models of each of the participants were created and are presented in the Appendix C. In this chapter, only the consolidated flow model is presented in Figure 6-1.

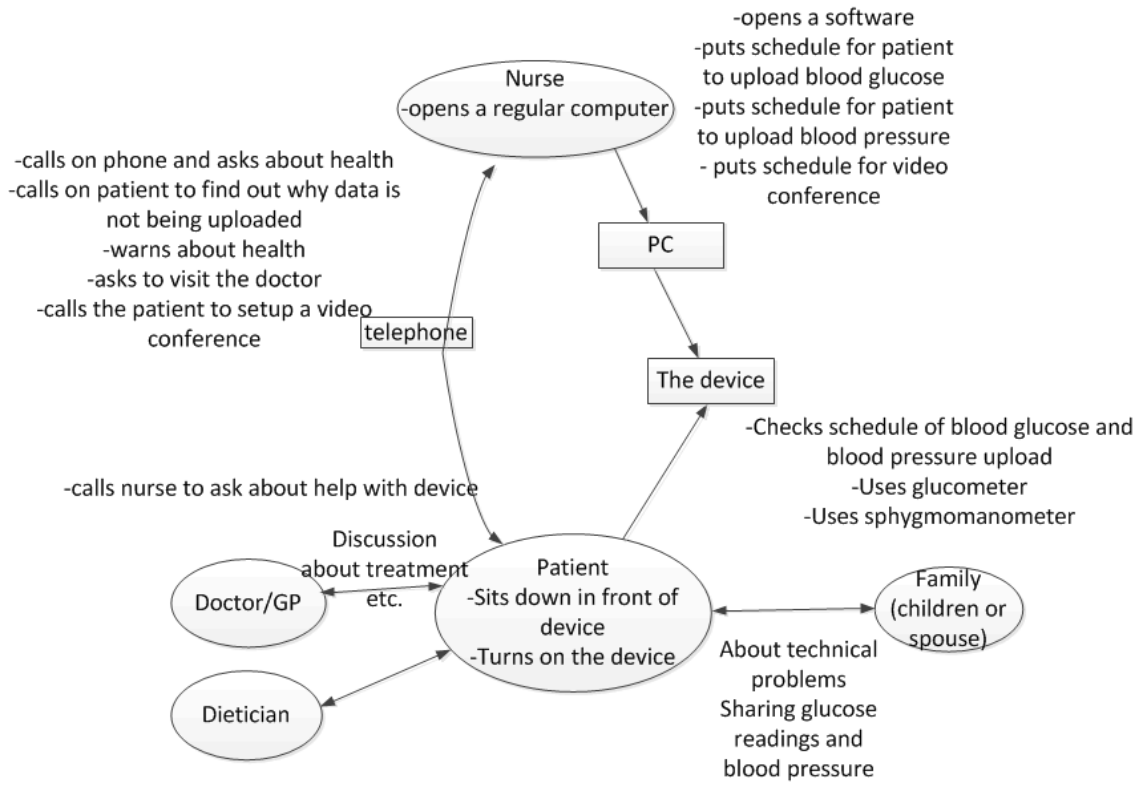

Figure 6-1.Consolidated flow model.

6.1.1.1 The Consolidated Flow Model

The consolidated flow model is shown in Figure 6-1. The ovals represent the humans, the rectangles represent the technologies and the arrows represent the flow of communication. Every participant has a doctor that they visit, generally every 3 months. However, for health reasons they may also meet their doctors more frequently.

The common workflow in the flow model of every participant was very similar. The flow model generally captures (i) every person that a user communicates with, and (ii) every device (or artefact) a user uses, in the process of communication.

A regular session entailed four steps where the patient would:

1. Sit down in front of the device;
2. Turn on the device;
3. Check the schedule of blood glucose and blood pressure;

4. Upload the blood glucose; and blood pressure data using the glucometer and the sphygmomanometer.

In addition, a patient could do the following activities

- Watch videos on the device;
- Accept videoconference requests and video conference (sent by nurses); read diabetes awareness information; and
- Take a quiz to test one's diabetes awareness.

Only two patients (P1 Zach and P3 Yanicka) were seen to do the additional activities.

A nurse accesses the other end of this system from her office. A nurse opens a regular computer in her office. Then, she opens the software that has patient information. She can view patient data once she is inside this software. She could put a schedule for the patient to upload blood glucose and blood pressure. She could put a schedule for videoconference if needed. The PC of the nurse sends all the requests to the device of the patient via the Internet. The participants and the nurses often engaged in verbal communication via telephone.

All participants also communicate with their doctors by doctor visits. The device in the clinical trial is not a mediator of doctor visits. Four participants (P4, P5, P6 and P7) make communication with some family members. Two participants (P8 and P5), additionally consult dieticians for better guidance on their choice of food intake. The family member is a spouse in some participants' cases while in other participants' cases the family members are children.

6.1.2 Sequence Model

Sequence diagrams are presented to show the sequence of tasks carried out by a participant during the contextual inquiry. All participants' sequence models are attached in the Appendix D.

An *intent* in a sequence model shows the intention of the user, which leads to numerous steps that the user carries out holding that intent. A *trigger* shows the cause that leads a user to do the intent. In a general case, in a life of a person a phone ring is a trigger, which prompts a person to answer or not answer a phone. A break in a sequence is shown with the mark "~". A break interrupts the natural workflow; for example, when a user has to move away physically from the working device or has to move out from the working application to a different application inside a system.

A full sequence model of P1 Zach is presented here. Most of the other participants' sequence models are similar to Zach, with less intents and triggers. Therefore, Zach's sequence model is a good representative sequence model to be presented in this chapter. Zach is a tech-savvy person who likes to analyse his results further by keeping a record of his own in a Microsoft Excel spreadsheet. Zach also likes to use the Internet to read about medicine or certain conditions of T2D. P1's (Zach) sequence of activity is as follows (Table 6-2).

Table 6-2. Sequence diagram of Zach

Sequence 1:
(Regular task-Uploading blood glucose and blood pressure)
Intent: Doing the regular task as advised by the nurse.
Trigger: Time of the day
Sits in front of the device
Turns it on with the switch
Waiting for auto log in [Feels impatient due to the long logging time]
Taps on the icon to see scheduled tasks
Trigger: Device tells with voice message to measure blood glucose
Opens the strip box

Takes a strip
Inserts strip in the glucometer
Pricks finger with needle
Puts blood drop on the strip
Waits for the reply from the device
The voice from device reads it aloud
Puts the glucometer away
Rubs his pricked finger with tissue paper
Trigger: Device tells with voice message to measure blood pressure
Wraps the cuff of the blood sphygmomanometer around the biceps of left arm
Turns the button on sphygmomanometer
Waits while the cuff tightens around the bicep
Waits for the reply from the device
The voice from device reads it aloud
Takes off the hand out of the cuff and puts the sphygmomanometer aside
Intent: Keeping blood glucose reading in a record
Trigger: After work with device, self –motivated
reads from glucometer
goes to laptop
inputs the data in an excel sheet [self-created]
Intent: Comparing blood glucose reading in a record

Trigger: After keeping blood glucose in a record self – motivated
reads from excel
clicks on graph view [with X and Y axis line plot]
Intent: Looking at the awareness information
Trigger: Just finished regular task
Cleans fingertips to free from any blood drops
Taps on the touchscreen button for information sheet
Intent: Searching for the medicine
Cannot find
Goes to laptop
Opens Internet browser
Searches for medicine
Intent: Watching informational videos
Cleans fingertips to free from any blood drops
Taps on the touchscreen button for informational video
Sequence 2:
(Troubleshoot)
Intent: To inform the nurse
Trigger: The device not responding
Get up
Get the mobile phone
Calls the nurse
If nurse answers then continues to fix the problem with nurse
Else tries to restart

6.1.2.1 Breaks in sequence model

P1 (Zach) had three breaks in the sequence model shown with the mark "~". The first break was caused right after Zach pricked his finger to get a blood drop. Immediately he had to put a cotton bud on his fingertip with the other hand. Then he had to clean the other hand before he could tap on the touchscreen. Zach also mentioned this matter in the interview session.

Zach being one of the tech-savvy personalities performs extra tasks of keeping a record of his blood sugar and blood pressure on Microsoft Excel and searching for diabetes related information on the Internet. He has two breaks for doing these two extra tasks. When he tries to record his blood glucose and blood pressure he has to use his personal computer and move away from the current device. This results in the second break. The main reason for this break is also found in the interview sessions of this research, where every participant (except Uma) said the device did not show past readings - the device only shows the latest reading. Therefore, there was no way for a participant to know what was going on with their health.

When Zach wanted to find information about his medication, he had to go back to his laptop computer for two reasons (i) the name of the medicine was not listed in the device and (ii) the device does not have Internet browsing capability. This results in a third break in Zach's sequence model.

All of the other seven participants experienced the first break, similar to Zach. Everyone had to slow down to stop the bleeding followed by cleaning of the fingers on the other hand before they could tap on the touch screen. Not all participants kept records of their blood glucose and blood pressure data like Zach did. P7 (Uma), P4 (Bill), P5 (Serena) and P8 (Heidi) record their data in a diary. All of them also had a break similar to Zach's second break in their tasks. Patients who

searched the Internet for additional data also had the same third break in the sequence as Zach. These patients were P7 (Uma) and P8 (Heidi).

Participants who only use the current device for blood sugar uploading do not experience much interruption in their work flow. However, several participants who do multiple tasks with the device were seen to have breaks in their sequence of tasks. For example in the sequence model presented earlier, one participant has a break in the sequence when he cleans his fingertip just after pricking it for taking a blood drop. The same participant has another break when he looks for a medication name that cannot be found in the existing medicine list on the device. This causes the patient to open his laptop and search for the medication name. The red mark represents the breaks in the task. All participants' sequence models have been consolidated and presented in Figures 6-3 to 6-7. The consolidation process was performed in an office. Every participant's sequence diagrams were placed and compared side by side. The consolidation was then immediately transferred to a laptop computer.

These sequence models were created based on the audio of the contextual inquiry session and field notes. These were later typed into Microsoft Word and printed out. At first the printed sequence diagrams were laid on a wide surface (Figure 6-2) (1). Next all field notes were put on the printed copies of the eight participants and breaks were marked with red coloured pens. All participants' sequence models were compared side by side (Figure 6-2) (2). Some participants did more activities, which resulted in their sequence models being longer. All of the sequence models were compared and an A3 sheet was brought to write notes (Figure 6-2) (3). Finally the consolidated sequence diagram was created in the laptop computer with Microsoft Excel (Figure 6-2) (4).

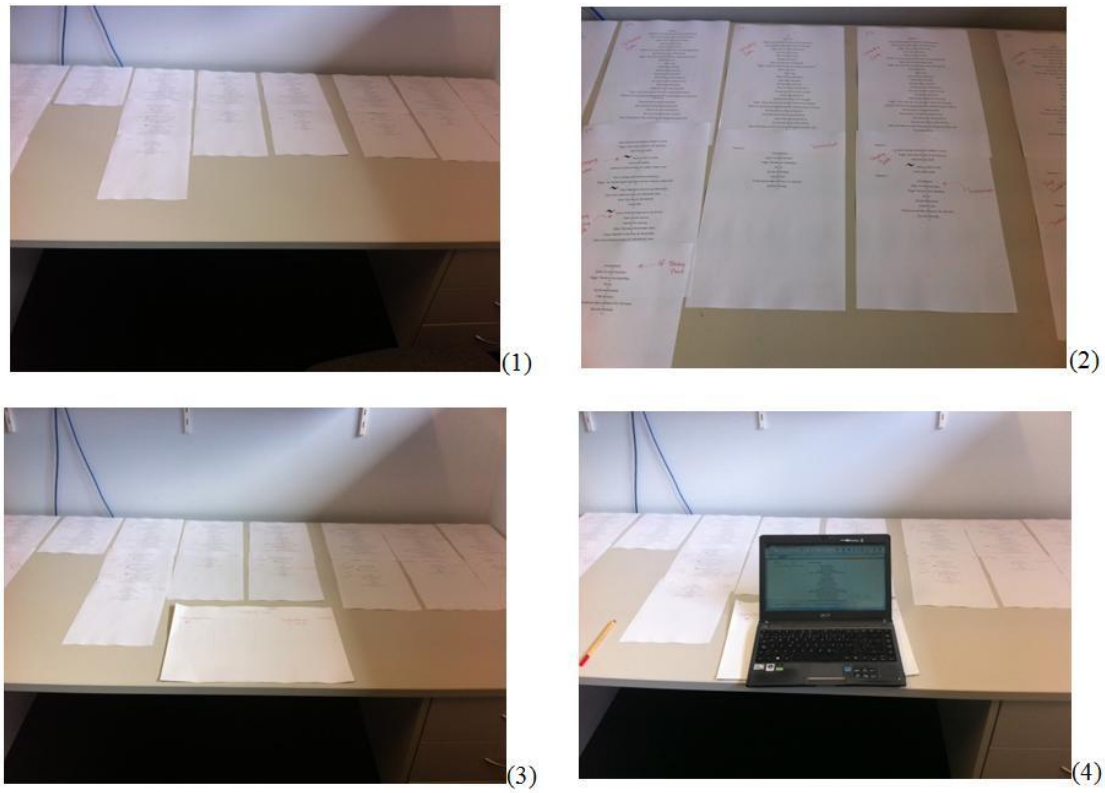

Figure 6-2. Sequence consolidation process (1) all eight participants sequence models laid out (2) marked and field notes added (3) a blank A3 page was added to take notes (4) the consolidation process done with a laptop.

6.1.2.2 Consolidated Sequence Model

The consolidated sequence model of the eight patients is presented here. In CD a consolidated sequence model shows three columns. The leftmost shows the activity of the users, the middle shows the intent behind the activity and the rightmost shows the abstract step strategy taken by users. In this chapter, the users are the patients. The eight patients of this research were shown to be performing seven different activities. They are presented below. The order of presentation is not based on importance.

The most common activity performed is uploading blood glucose and blood pressure data using the device. This activity (Figure 6-3) was performed by every patient and there were no individual variations among the patients. All patients performed the steps in a similar way although two patients P2 (Ted) performed some steps in a different

order. Only two patients P1 (Zach) and P3 (Yanicka) stated that they watch the awareness videos.

	Activity	Intent	Abstract Step Strategy
1	Uploading Data using the device	To send data for nurse	Sits in front of the device Turns it on with the switch Waiting for auto log in Taps on the icon to see scheduled tasks Trigger: Device tells with voice message to measure blood glucose Opens the strip box Takes a strip Inserts strip in the glucometer Pricks finger with needle Puts blood drop on the strip Waits for the reply from the device The voice from device reads it out loud Puts the glucometer away Rubs his pricked finger with tissue paper Trigger: Device tells with voice message to measure blood pressure Wraps the cuff of the blood sphygmomanometer around the biceps of left arm Turns the button on sphygmomanometer Waits while the cuff tightens around the bicep Waits for the reply from the device The voice from device reads it out loud Takes off the hand out of the cuff and puts the sphygmomanometer aside

Figure 6-3. Consolidated sequence model- most used activity.

The second and third activities (Figure 6-4) were to watch videos and read the information sheet, respectively. The step taken to watch the video is simply by tapping on the touch screen. The third activity is also a simple step to read information for diabetes awareness. This step can be performed by patients by tapping on the information they want.

	Activity	Intent	Abstract Step Strategy
2	Watching Videos	Diabetes awareness	Taps on touchscreen button for informational videos

	Activity	Intent	Abstract Step Strategy
3	Reading diabetes education information	To be aware	Taps on touchscreen button for datasheet

Figure 6-4. Consolidated sequence model - second and third activities.

The fourth activity is to keep notes of the blood glucose and blood pressure data. The fifth activity is looking through the notes (self-created records) of the data and comparison. Both these activities are interrelated as one leads to doing the other. These activities (Figure 6-5) surfaced as very important according to the users. Patients performed

this activity using their own artefacts because the current system does not have this function yet. Variations were seen among the three patients who did this activity. P1 (Zach) performed this activity with his own individual strategy by inputting the data in a Microsoft Excel spreadsheet on his laptop. P3 (Yanicka) performed this step by noting the data first on a piece of paper near the device, which later she noted down in another diary. P4 (Vince) performed this step by putting the data directly in his diary.

	Activity	Intent	Abstract Step Strategy
4	Noting the data	To preserve record	P1 : Opens laptop and stores data in an excel sheet P3: Opens diary and writes down there P4: Writes down in diary

	Activity	Intent	Abstract Step Strategy
5	Looking at record	To compare today's data with another day's data	P1: Opens laptop and looks at excel sheet P3: Opens her diary and turns pages to look P4: Opens his diary and reads

Figure 6-5. Consolidated sequence model- fourth and fifth activities.

The sixth activity (Figure 6-6) is a rare activity that was performed by only two participants - P1 and P3. Both of them wanted to search for the information on their medication in the current system that the device uses. In the current system they were unable to find the name of their particular medication so they opted to search via the Internet. However, the device does not yet have browsing capability. Therefore, both P1 and P3 had to use their personal computers to search for the medication information. P1 and P3 also mentioned that they would like to search for other diabetes related information as well on the Internet, which could not be done on the current device.

	Activity	Intent	Abstract Step Strategy
6	Searching Information	Want to find out about some drug or situation not in the system	P1: Opens browser in laptop and searches P3: Opens brower in mac book and searches

Figure 6-6. Consolidated sequence model- sixth activity

The seventh activity is calling the nurse during troubleshooting of the device. This was generally done by phone (Figure 6-7). Initially the

nurse guided the patients through some basic instructions. If a patient still had problems, the nurse would schedule a physical meeting where a nurse or a technician would visit later.

	Activity	Intent	Abstract Step Strategy
7	Troubleshoot	Trying to fix why someth is going wrong	Turn on off Call Nurse via telephone P6, P8 asks help from children

Figure 6-7. Consolidated sequence model- seventh activity

The consolidated flow model showed all possible activities performed by eight T2D patients through the in-home monitoring device. The first three activities are within the capability of the current device. Activities of noting the data to keep a record (fourth activity) and looking at the record (fifth activity) are essential for T2D patients. As a result a few patients found their own way of performing the fourth and fifth activities. Searching for information was deemed to be important for some patients and they browsed the Internet through their personal laptop computers. During troubleshooting, patients could call the nurse for help. The discussion chapter expands further on the sequence model.

6.1.3 Affinity Diagramming

An affinity diagram brings together issues and insights about all users into a wall-sized hierarchical diagram [1]. Ideally it is done with sticky notes to stick on a wall, however in this research it was done with sticky-note sized papers on a huge table top. Figure 6-8 shows a portion of the affinity diagram for the eight participants of this study.

Figure 6-8. A portion of the affinity diagramming process

The completed affinity diagram is digitally drawn and presented in

Figure 6-9. According to Bayer and Holtzblatt (1997) [107] the colour codes represent the different themes and levels of abstraction. Yellow represents the notes from individual patients of doing an activity. The activities in yellow are grouped together and the blue colour code describes the general theme of the activities of the yellow notes under them. Pink represents another level above the blue level and abstracts the data further. Yellow, blue and pink are written in first person as if the user is directly speaking. The green labels of the affinity diagram (Figure 6-9) are the highest level of affinity. These represent activities of the patients' story.

Figure 6-9 depicts that there are three types of main activities being performed with the current in-home monitoring device. These are represented with the green labels. They are

1. Current function of the device,
2. Supporting functions that users need, and
3. Communications that are done by telephone.

The leftmost green theme shows that the current function, which consists of users uploading their blood glucose, watching videos and accessing information sheet for awareness, are satisfying the users. The users are performing these activities. However, the users need more

things as part of their activities. These are joined under the green label. These are supporting functions that users need. The device does not meet all of these supporting functions. The supporting functions (Figure 6-9) show the needs of the users. The users (patients) need the following features as part of the activity.

1. need for Internet browser,
2. ability to store, view and compare blood glucose of different days, and
3. Internet connectivity to find information.

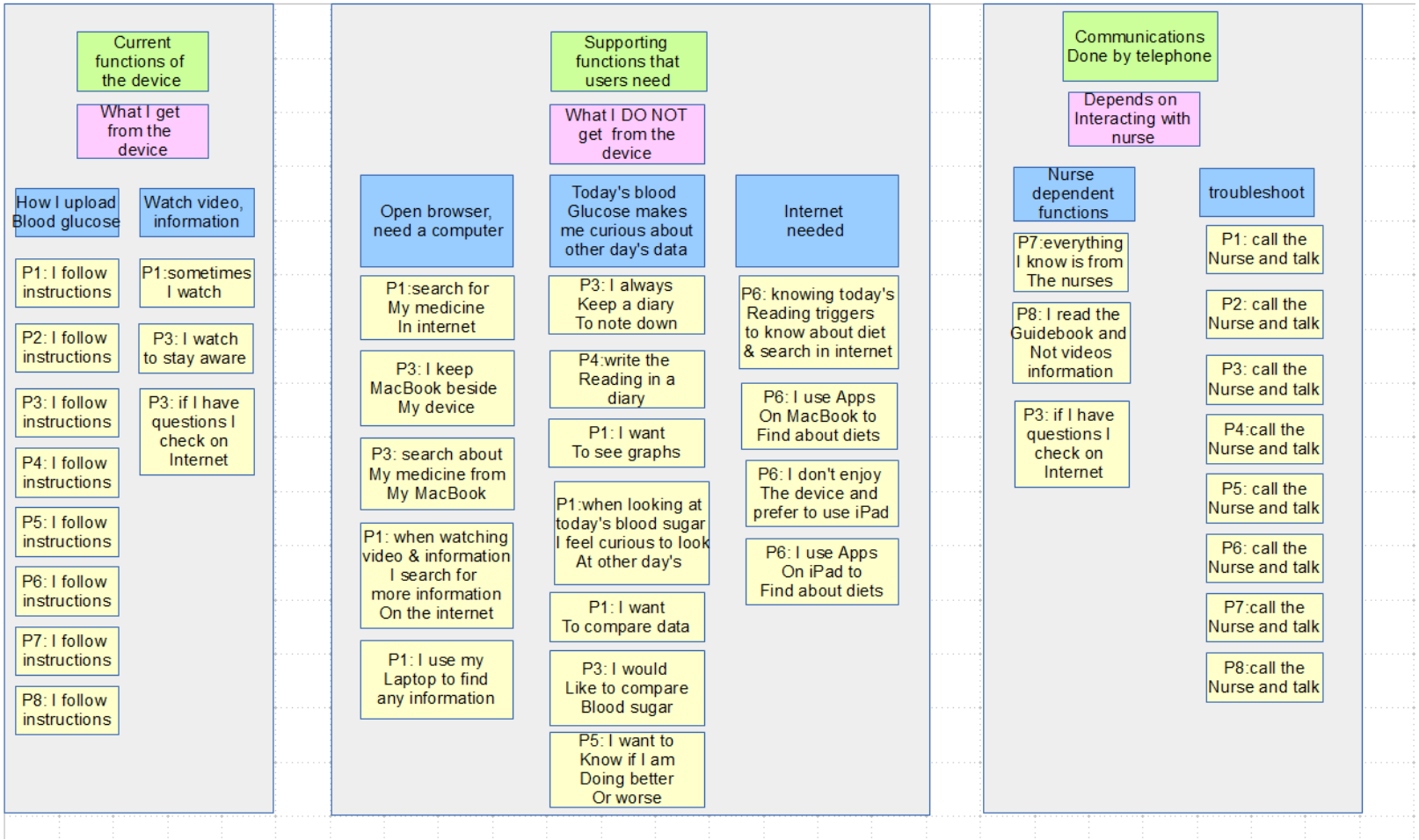

Figure 6-9. The complete affinity diagram.

6.1.4 Discussions on the UCD

The UCD shows that the current system design of the telemedicine device does not satisfy the requirements of the workflow of the patients. Patients have mentioned the shortcomings of the current device in the interviews documented in chapter 4. From a system design perspective with UCD, section 6.1 demonstrates that the current system design of the device is not designed in a user (patient) centred way. The following paragraphs discuss these issues.

The communication with the current device is one-directional as section 6.1.1 showed through the flow model. The patients can only use the device and do tasks as scheduled by the nurses. The nurses can use their PC to send a schedule of tasks. However, the patients cannot ask or prompt the machine to do anything if they wish to do so. The only way to do this is by making a phone call to the nurses because the system has not considered a patient's needs in this device.

The system assumes that nurses have power over patients. The patients and the nurses communicate via phone to have a bidirectional conversation due to the lack of a bidirectional communication facility of the current device. Consequently, as seen in section 6.1.3 and Figure 6-9 the patients require a communication function to call the nurses. Due to the lack of this, the patients are currently using the telephone to call the nurses, as shown in Figure 6-9.

There are several breaks in the sequence of tasks with the current design of the system. Section 6.1.2 showed that the sequence of tasks with the current device is not optimally designed. For example, when a patient looks for a medication name or information that is missing in the system, the patient has to use a different device that breaks the workflow. The break also happens with all patients when they do the blood glucose test and have to wash the fingertips before returning to the device to continue.

Patients with the current device can perform the most important tasks, such as uploading their blood glucose data and accessing information about diabetes management. These are marked on the left group of functions in the affinity diagram (Figure 6-9). The centre of the affinity diagram shows the activities and functions that patients do which they do not receive from the system. The centre of the diagram shows that the patients may need an Internet browser, Internet connectivity and data from the past. This affinity diagram validates the findings from chapter 4 by triangulating the shortcomings of the current version of the device. For example the lack of visual data 5.2.4 prompts a patient to use his or her own diary or laptop. The lack of medication name, as mentioned in section 5.2.5 in chapter 5, prompts a patient to need Internet services and a web browser.

The patients communicate with the nurses over the phone, as this is the only way the patients can contact the nurses. The current system is designed for unidirectional communication from the nurses to the patients but not for a two-way communication. The rightmost part of Figure 6-9 shows details of all the communication by telephone.

6.2 Domestication of the device by patients

This section continues with the findings, analysis and discussion about placement of the device in the patients' homes in section 5.1. These findings were observed during the contextual inquiry and interview session in stage 1 and 2 of CUE.

The efficient use of in-home monitoring devices for T2D management depends not only on the functionality of the device. How individual patients adopt these devices in their private homes is an important step towards reaching the overall goals for successful T2D management. T2D requires day-to-day management. For a successful device that patients use on a daily basis, understanding the domestication of the device unlocks ways to keep patients motivated in

using the device. Therefore, of primary interest in the observation of the device was capturing where the patients chose to place the device.

From the observations in stages 1 and 2 of the CUE, the patients chose to place the in-home monitoring device in four locations: living room, bedroom, study room and patio. Internet/phone socket availability, convenience, comfort and self motivation were the four main reasons the participants identified for device placement. The device runs via ADSL Internet that is delivered through the phone line. The device does not have wireless Internet capability.

Figure 6-10. Vince's device (left) is located in his living room. Yanicka's device (right) in her study room.

6.2.1 Convenience

Vince and his wife mentioned convenience as the reason for their choice of position for the device. The device was placed in the living room. There was already an existing table beside the television shown in Figure 6-10 (left). Both Vince and his wife were involved in the decision making process. As mentioned in chapter 4, Vince's wife actively answered questions during the interview. At the time of the contextual inquiry, Vince's wife was watching TV. Vince brought a chair to upload his post-breakfast blood glucose and blood pressure. "*Just leave it there* (living room) *and come around and get a chair to sit down. There's a table there, it's easy access*". (Vince, 66 yrs.)

Yanicka mentioned convenience as the reason for her choice of placement. She put her device in her study room, see Figure 6-10 (right), because she found her study room to be the most convenient place in her home. She shares this room with her husband. In this study room Yanicka owns a MacBook while her husband has a desktop PC. They have an approximately 10-foot long shared study table. She mentioned that this study room was the only place where her grandchildren would not be able to interfere with the device.

"This (study room) is the most convenient place for me. I don't think this is something we can transport easily. I think you pick the spot and it's less intrusive, too, especially with the grandchildren around." (Yanicka, 68 yrs.)

Heidi and Zach also identified convenience as the main reason for choosing the location of their devices. Heidi placed her device in her bedroom because that was the most convenient place for her and her children (Figure 6-11). Her children were partly involved in the decision making for the placement.

Figure 6-11. Heidi's convenient location in her bedroom

Zach placed it on his patio in the back of the house. Zach's home could not be photographed due to the identifiable features of his patio and home. Therefore, a photo of his patio was not taken. However,

Zach agreed to be photographed with his device in a manner that did not capture any identifying parts of his home.

6.2.2 Comfort

Comfort was the reason that determined Ted's choice of placement of his device. Ted chose his living room due to comfort. Ted works full time and often more than 40 hours a week. He spends his evenings watching TV in his living room. Ted has a comfortable reclining lounge chair and keeps the device on a side table to his right. Ted did not consent, for his living room to be photographed, so he provided his own hand-drawn sketch (Figure 6-12) to be shown.

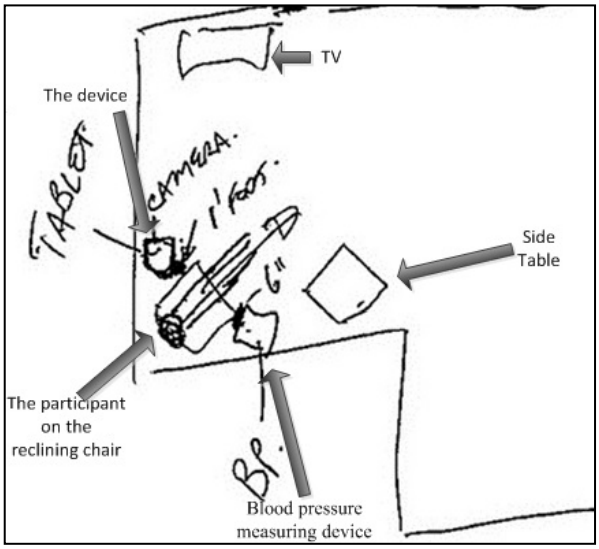

Figure 6-12. Ted's hand-sketch of his device in his living room

6.2.3 Internet/phone socket availability

Uma is a 74-year-old woman who lives alone. Uma does not use any computers, nor has she ever owned one. Uma does not own a mobile telephone. Uma wanted the device to be in her bedroom; unfortunately, her bedroom had no Internet/phone socket. Compromised by this circumstance she had to place the device in her living room. She was not content with the placement, yet had no other options.

"I chose this coz I've only got one phone inlet and that over here and that's the only reason, otherwise if I had one inlet in the bedroom, I would put it over there." (Uma, 74 yrs.)

Uma's table containing the device (Figure 6-13) was very low and her work posture during using the device is prone to tension-neck syndrome, according to ergonomic recommendations [145].

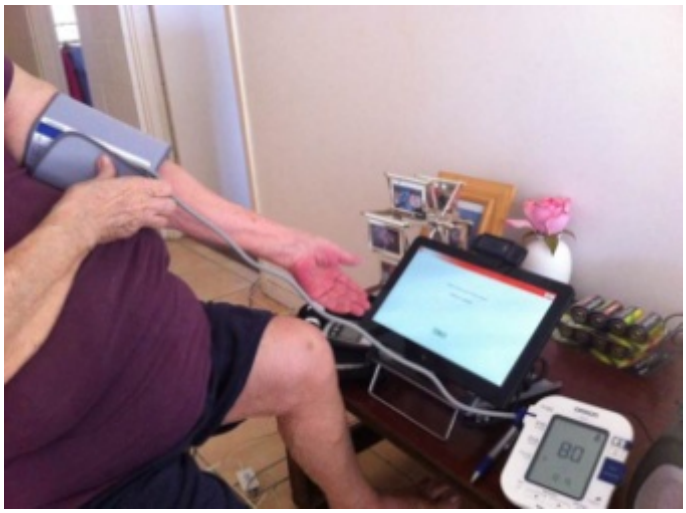

Figure 6-13. Uma's placement in her living room

Serena was obliged to place her device in the living room due to the availability of the Internet socket there (Figure 6-14). "*It was around the corner there* (pointing to her bedroom) *but they have only had the NBN put in and I have got a connection here so it had to be here*" (Serena, 55 yrs). NBN is the national broadband network in Australia that provides high speed Internet. Serena was displeased about this location.

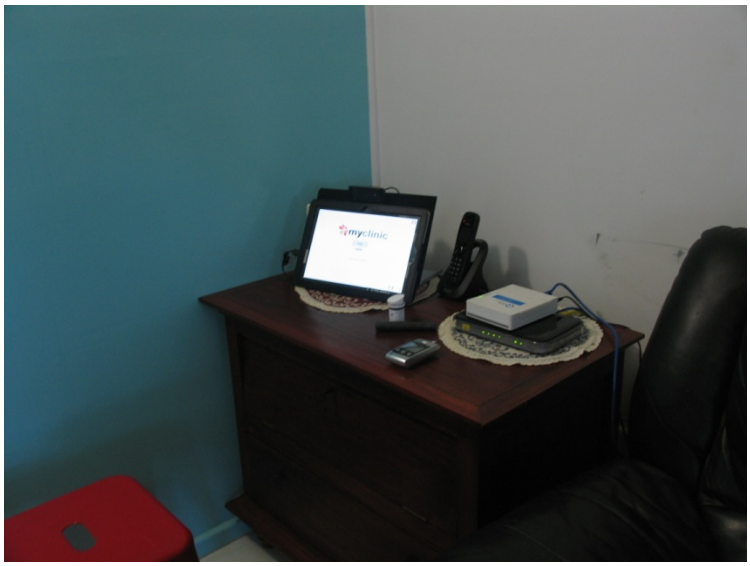

Figure 6-14. Serena's device in the corner of her living room

Bill placed his device in the study room. His study room had Internet socket availability while other preferred locations of his house were lacking Internet socket availability (Figure 6-15). "*The only reason why is because I had a computer in here* (study room) *as well. And I had an outlet there* (on the wall behind his computer) *for the Internet*". (Bill)

Figure 6-15. Bill's device in study room

Like the other three patients, Bill was discontented about this situation.

6.2.4 Adherence/building a habit

Pete had been diagnosed just 13 months ago with T2D. Pete is very determined to get better. Throughout his interview, his determination was evidenced from his responses to questions. Pete mentioned he was over-weight and needed to lose weight. He had learned the importance of weight loss through this clinical trial program. Pete chose to put his device in the bedroom, to develop a habit (Figure 6-16). He intended that the device is the first thing he would see when he woke up each morning. "*Every morning I do it as the first thing in the morning. I wake up and I do it the first thing. Before I have a drink of water or --*" (Pete)

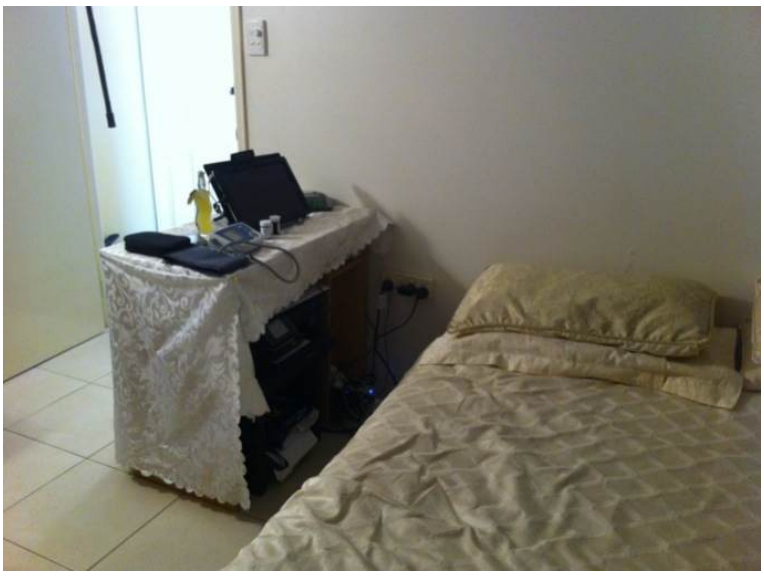

Figure 6-16. Pete's device beside his bed

Pete lives in a two-storey house where his study room is on the upper floor. He owns an iPad that he keeps in his study room. He deliberately chose to place the device in his bedroom. *"If I left it upstairs, I won't have gone upstairs that much you know. So probably won't have get out of the habit of doing it. Get up I do my blood sugar and my blood*

pressure and then I take insulin and my medication. That's all my routine" (Pete, 53 yrs.).

6.2.5 Family Involvement

Involvement of family members with the device was found during observations and interviews. Each of the participants lives with their families, except Uma and Pete. During the contextual inquiry, some family members participated to add ideas to those of the interviewees (patients). This research took an ethnographic approach as described in chapter 3. I (the researcher) did not invite the family members. I interviewed the family members only if they stepped forwards to talk about the patient. Two observations were evident as presented below.

6.2.5.1 For men, wives are care givers

Bill lives with his wife. He enjoys his independence to use the device. His wife generally asks him his readings each day. His wife was present during the contextual inquiry and she left after reading Bill's blood glucose data. Bill said that his wife is involved with the device in terms of knowing his results. Quote from Bill: "*Well, my wife is my carer and ah sometimes she-- she doesn't have to do anything, she might give me a needle*". At that moment, his wife left the study room, nodding to approve what he said. With a sense of independence and pride, Bill stated, "*I do it alone.*"

Vince's wife is strongly involved in his well-being. Her involvement in Vince's well-being became apparent during his contextual inquiry session. Often she would reword Vince's answers, during Vince's interview with me (the researcher). She was watching TV with the volume muted during Vince's interview session. She had a watchful eye on how he was doing. Vince's wife described the situation: "*It's sort of like a safety net. You know there's someone* (nurse) *in the background always watching and they will ring you up."*

6.2.5.2 Children watch over mothers

Heidi lives with her three children, all of whom are university students. Two of them are studying medicine. Heidi does her regular tests in her bedroom, but occasionally her children come to have a look at her readings. "*But sometimes my children, because they are doing both MED* (medical science)*, they would look at me and see the blood pressure and they will take the mmmm-- use their stethoscope to see how that's going."* (Heidi, 60 yrs.) One of Heidi's daughters arrived during the contextual inquiry. Her daughter had a look at her blood glucose by looking at the monitor and left without any engagement with Heidi or the researcher.

Serena's 19-year-old son is her "tech guy". Serena often asks her son for help with technical issues.

"I am not good technically and he is the one that I call come and help me. It doesn't work! Help me! Help me! So having a younger person around is a big help too." (Serena, 55 yrs.)

Serena broke into laughter while making this comment, showing signs of happiness as she talked about her son.

Serena's son initiated a conversation with the researcher during Serena's interview. When her son heard her talking about him, he peeped through the door and added: "*It's more like a -- there's a regime for every day. 10 minutes before eating and after eating she* (Serena) *tests it and morning afternoon—it's 10 minutes or 5 minutes-- doesn't affect much. But it improved her overall awareness"* (Serena's son).

6.2.6 Discussions on Domestication

The domestic environment as a research area for IT has received considerable attention since the late 90's. The methodological and technical challenges involved in realising, for instance, 'living laboratories' was one early project to develop IT for the home and

enabled researchers to explore ways in which inhabitants might experience IT at home [146, 147].

The findings and analysis in section 6.2 shows the domestication of the telemedicine device for T2D patients for in-home monitoring. Table 6-3 presents a summary of the placement of the device and reasons behind the placement.

Table 6-3. Summary of placement of the device

Reasons / Locations	Living room	Study room	Bed room	Patio
Internet Socket	2	1	-	-
Comfort	1	-	-	-
Convenience	1	1	1	1
Self Motivation	-	-	1	-

Nurse1 confirmed in her interview the reasons behind the patients' choices of placement of the device.

Researcher: *What was the reason they (patients) decided to put in those locations?*

Nurse1: *Connections, convenience and also that is out of their way like little children would not interfere -- yea--*

6.2.7 Telemedicine device as a Domestic Technology

Nurses called the telemedicine device potentially "lifesaving"; however, the patients treated the device just as a regular domestic technology. Patients wanted it to be mobile as compared to other mobile current gadgets available, which also showed that patients consider the device as a regular technology, unlike the nurses.

Crabtree [148] suggests that designs might be usefully informed by attending to stable and compelling routines at home. The findings of this research resemble Crabtree's findings[148]. This research found

that in domestic settings, the patients might have multiple other gadgets; the telemedicine device became one of those devices. This influenced the patients' decisions on where to place the device. The patients did not treat the device as a priority because it is "lifesaving." The case of Ted, who placed his device in his living room beside his reclining chair, shows comfort as a reason. Other participants, like Vince and Yanicka, chose the device locations based on convenience.

The findings from CUE, extend the domestication of technology research into the domain of telemedicine technology. Though domestication research had been undertaken with technology and users, the results of the CUE present telemedicine and patients. Domestication of an in-home monitoring device, for example this T2D device, has not been researched in the past.

6.2.8 Patients considered the device as a regular consumer device

This research show that even though telemedicine is an intervention that can provide help to T2D patients, patients still consider the device to be similar to an iPad or tablet. The nurses know that the device is a great life improvement device, but the patients, regardless of knowing the value of the device in their lives, still consider the device as any other device they have at home. Many patients complained about the lack of wireless capability of the device (section 5.2.3) because they consider it another technology, while nurses may think that the benefits to health should be enough reason for patients to adopt this technology. Serena stated that she will not use this device after she completes her clinical trial. She preferred an app that she could use in her existing tablet.

Researcher: *If the trial is over how long will you use this technology?*

Serena: *I wouldn't. Because I wouldn't have the thing unless I got something that I can download onto my tablet then yes I would continue.*

6.2.9 Relation between age groups and computer skills

Five participants were elderly (above 64) and four were in the younger group (50-63). The results are expected and are in accordance with older people's ICT work present in the HCI literature [149-151]. The younger group was more at ease with the device compared to the elderly. The only elderly person, who was totally at ease with the device was Zach, who uses computers 70 hours per week, an equivalent of 10 hours per day. Zach's high amount of computer use could be the possible reason for his fluency with the device. Zach defined his activities per day in an email to us as:

"In the 14 hours from 10 am to midnight, 10 hours use allows 4 hours for general activity.

There is space for electronic newspapers, (Age, Australian, Guardian, cricket, NW Star and Financial times at midnight [p.m. Zulu])

Emails for general and Youth Exchange Program administration, excel spreadsheets for commodities analysis, superannuation/ banking etc.

Editing a website content" (Personal email from Zach)

Four other elderly participants were slower and less engaged with the device, compared to the younger group. In the younger group, regardless of Ted's high experience of using the computer for 60 hours per week in comparison to Serena (12 hours/week), Heidi (2/week) and Pete (2/week), all of them were equally at ease and speedy during their contextual inquiry sessions.

6.3 Influence on patients from the use of the technology

Motivation is defined by the Oxford Dictionary of Psychology, as the mental processes that arouse, sustain, and direct human behaviour [152]. The study of how to design technology to motivate behavioural

change has been of increased interest to researchers and industrial practitioners due to the widespread uses of technology such as computers, mobile phones, iPad, etc. Fogg lead the way to *Persuasive Technology* as "a computing system, device, or application designed to change a person's attitude or behaviour in a certain way" without using coercion or deception [153]. Oinas-Kukkonen concluded that technology is never neutral; it influences users in one way or another [154]. However, the influences occur as side effects of technology use, rather than the planned effect of the technology design [153]. On the contrary, persuasive technology is designed to intentionally target a specific behavioural change of the users.

Persuasive Technologies in e-commerce are designed to motivate customers to purchase products and services by automating a variety of strategies such as tracking and monitoring: Persuasive Technology are designed to track consumers' online activities and their preferences across multiple stores and recommend products and services to customers based on their interest [155, 156].

PTs in environmental sustainability aim to motivate people to preserve or maintain the natural ecosystem. "UbiGreen" [157] is a technology that motivates users to ride a bicycle instead of drive a car by depicting the carbon emission from the car and its effect on the ecosystem. Substantial PT research has been conducted to motivate better energy consumption behaviour for users, for example one study examined the use of mobile media to encourage the pro-environmental behaviours of employees with feedback on their computer-based energy usage [158].

PTs have a great potential in the health domain as arguably most health challenges can be mitigated with a change in lifestyle[159]. Designing persuasive systems that could resolve even some small parts of health problems and aid in true long term sustainable change would be very valuable[159]. Health problems such as obesity, alcoholism, smoking, and drug addiction can be controlled with lifestyle choices. A

few examples are: serious video games for health[160], mobile games to help adults choose healthy meals [161], LunchTime--a goal-based slow-casual game that educates players on how to make healthier meal choices [162] and Squire's Quest targeted at fourth grade students to influence fruit and vegetable consumption[163]. The design of effective PT interventions for motivating healthy behaviour in the health domain have been thoroughly researched to motivate people with healthy eating habits [162, 164, 177].

From the results of CUE in the previous chapter, effects of the use of the telemedicine device by the patients were significantly evident, as stated in [162], [165], [167], [177], [153], [154] and [159]. Three such results are presented below.

Section 5.2.1 showed that two patients, Heidi and Vince mentioned motivation as a side effect of using this telemedicine device. Heidi said she received that extra motivation from this device to do her regular blood glucose check. Vince felt motivated to manage his blood glucose because the device motivated him to check his blood glucose.

Section 5.2.2 mentioned that Pete lived alone and had benefitted from using the device. Pete used the device to develop a habit of checking his blood glucose (section 5.2.2). Pete achieved it by placing the device beside his bed. Pete was in his last week of the clinical trial study, when he participated in the CUE. He expressed the desire to keep the device longer. He expressed a concern on how he would continue without the device.

Section 5.2.3 showed improvement of awareness among various patients due to the use of the device. For example, Serena and her son mentioned during the interview that Serena was more accountable to look after her blood glucose while using the telemedicine device. Serena’s son stated that Serena was more aware of her blood glucose and food intake after using the device.

Other examples of improved awareness (section 5.2.3) include Vince, Heidi, Pete and Ted. Vince mentioned that knowing his results increased his desire to do the blood glucose readings. He also felt aware of the situation. Heidi thought the device gave her one extra initiative by being aware of her results, similar to 'quit smoking' patients. Pete used the device to build his habit of blood glucose measurement, which raised his awareness about his health. Ted stated that the telemedicine device had an outstanding advantage over a glucometer, which he had used in the past. The telemedicine device compelled him to do regular blood glucose tests.

Additional interviews with the two nurses who monitored these nine patients were also conducted. Both nurses also mentioned that the patients were more aware after using the telemedicine device.

Nurse1: *"When someone can see what happens to their blood glucose after a meal, they can reflect on their reading and a lot of people have made their changes simply because of that reading -- you know one gentleman was having five "weet-bix" with sugar on for breakfast and you know so he has managed to change his breakfast and the difference is in before and after it has dropped and those sort of things have changed for him-- but another gentleman with weet-bix and toast-- he cut out the toast and he-- that difference came down -- but he only cut it out because he could see that it was higher. So I believe that monitoring gives people an awareness-- so they are much more engaged in self-management really".*

This telemedicine device was not designed to motivate, build habits or create awareness among patients. This device was an automated way to send and receive data from T2D patients regularly to the nurses for better T2D monitoring from home. Yet remarkably, this device showed significant promise to change patients' behaviour. This telemedicine device has the potential to be improved by persuasive technology research and could be targeted at specific behaviours of T2D patients to help manage their conditions better.

Nurse2 remarked that the device is interesting for patients, which she stated as the reason for an improvement in the patients' health.

Researcher: *"Do you see any changes in their behaviour after they started using this?"*

Nurse 2: *"Yes actually. They find it interesting, to see that they are monitoring they have to make a bit of an effort which makes the improvement. So the outcome is better".*

PT research in health and games to motivate healthy eating has shown that one design does not fit all gamers [165]. Similarly, a telemedicine device should take into consideration the different types of patients and their expectations from the device, as one design may not be suitable for all kinds of patients. Research also showed how to effectively design technology interventions to persuade healthy eating habits to improve health [166, 167,177]. Telemedicine can benefit from this research in the future to target T2D patients to control and monitor their blood glucose and choice of food. Unfortunately, a direct correlation between these patients' behavioural improvements and medical improvements could not be investigated in this research because the medical data of the patients are out of the scope of this research. The TMML owns all medical data of the patients.

6.4 Categorisation of the patients as users

In the absolutely different domain of sustainable energy consumption behaviour, Lockton *et al.* [168] categorised users' behaviour into three categories; pinball, shortcut and thoughtful. These models were developed from 368 statements about users from approximately 130 user-experience designers.

The pinball category represents those users who do not think about their decisions, because they cannot or simply do not want to. The shortcut category represents users who want to minimise

consumption, but are 'lazy' in the sense that they do not want to spend time thinking deeply about problems and solutions. These users need simple and concise choices presented in front of them. The final category of thoughtful users, are those who spend time thinking about what they are currently doing and why. They are open to changing their behaviour if they are given a good reason.

In the CUE, the patients did not all use the device with the same degree of interest. I found different levels of interest in the patients based on the observations and their explanations to me during stages 1 and 2 of the CUE. Lockton's model provides substantial evidence to model the energy consumption behaviour of users using some PT. In this section I provide a categorisation of the nine patients of the CUE, based on my observations. This categorisation is not unlike Lockton's model which involved 130 user-experience designers. However, this categorisation provides a basis for understanding the nine patients in the CUE.

I categorised the nine patients into four types: enthusiastic, accepting, indifferent and resistant patients. These categories need to be validated with a higher population of patients.

An *enthusiastic patient* (Zach), not only used the technology to upload his daily blood glucose and blood pressure with regularity, but also used the diabetes awareness information eagerly. This information was available on the tablet PC. Zach explored all the features of the device. The device contained information sheets and educational videos, which Zach was aware of. He also watched those to educate himself. He checked frequently about his foot care and colour changes of his toenails. He was also familiar with the mini videos in the device that were given for patient education. Regarding the information sheet Zach said:

"Well, they were useful. It's not something you looked at everyday. But from time to time you look em up. Sometimes you go to the food, the food

people, she (the narrator´s voice in the device) tells you about portion of the food."

Zach was very thoughtful about the device and he seemed to be using the device proactively during his clinical trial. He provided extended comments on how the graphs of the monthly reports should look.

Accepting patients are those who welcomed the use of the technology but did not spend extra time to explore the features for diabetes awareness. Ted, Heidi, Serena and Pete fall into this category.

Ted said he never had any interest in looking at the information sheets on the device. He mainly uses the device to upload the blood glucose and blood pressure and receive feedback from the nurses.

"I have never used them (the information sheets)". (Ted)

Heidi never mentioned using the sheets. She used her own diet guidelines because she has been living with T2D for 25 years. Serena also did not mention the information sheets. Similarly, Pete had never used the information sheets on the device.

"I believe there is (information about diabetes). They have a few things that you can do. I haven't looked at them, but they are there." (Serena)

Indifferent patients use the technology because they are told they have to. They do not resist and do not seem to care either way. Yanicka, Bill and Vince fall into this category. These patients understand the value of the technology for their health, but they did not seem to care to use it.

A *resistant patient* is opposed to using any technology. For example, one patient, Uma, was resistant to using the telemedicine device due to her lack of experience in technology use and lack of ownership of a computer or mobile phone. Uma was in the clinical trial intervention group due to the random participation for recruitment (i.e., a lottery).

6.5 Nurses' Interviews validate the patients' needs

Patients clearly stated the data they need to see such as graphs (section 5.3.4). As mentioned earlier, patients mentioned the need for visual data or graphs to compare the blood glucose readings of different periods. If a patient did a test in the morning and one in the evening, the readings of the earlier test (morning) were unavailable to make a comparison. Both Nurse1 and Nurse2 recognised that the patients wanted to see graphs. Nurse1 commented that the graph was a motivational tool for the patients, especially when the blood sugar level was going down, the decrease would indicate better health for a patient.

"They (patients) like to see their progressions. Some of them like to see how they are going in, and often that's a very good motivational tool to send them a graph or be able to have access to their readings so that they can see that graph physically -- you know going down-- that's very exciting." (Nurse 1)

Nurse2 also recommended that data be provided to the patients as graphs or tables. She speculated that although not every patient may be interested in the data, patients should be given the choice to see the data on their screens.

"They need to have a choice to access what they are reading so like there's a graph or a table on their monitor, because not everybody wants to see what they are doing rather discuss it." (Nurse2)

Nurse2 also confirmed that the software of the current telemedicine system is unable to meet the current visual data needs mentioned in section (5.3.4). She remarked—

"They (patients) need to have the option to have a look at it but as I said the software wasn't constructed that way."

6.6 Conclusion

This chapter has presented analysis of the results from different perspectives. Section 6.1 presented an analysis of the contextual inquiry of stage 1 of CUE. This analysis also validated the findings of section 5.3 that contained the patients' subjective critique of the telemedicine device.

Section 6.2 presented the analysis and discussion of placement of the device in the patients' homes. Section 6.3 discussed the behavioural effects on the patients from using the telemedicine device in the light of PT. Section 6.4 presents a categorisation of the patients based on my observations. The categorisation requires further validation with a larger sample of patients. Section 6.5 presented the validations of the two nurses about the requirements of visual data for the patients.

Chapters 5 and 6 presented the results and analysis of stages 1 and 2 of the CUE. Chapter 7 will present the findings and discussions of stage 3 of the CUE.

Chapter 7. Hidden Hypotheses in the Clinical Trial

This chapter presents stage 3 of the CUE, which consisted of a semi-anonymous online survey. The researcher knew *who* the participants were, but did not know *which* participant gave *what* answer. This chapter is based on the researcher's observations and further exploration of these observations. The personal pronoun "I" is frequently used in this chapter to express the researcher's observations and explorations.

I recorded observations about the patients during stages 1 and 2 of the CUE. I noted that patients made some assumptions about the telemedicine clinical trial. For example, the patients did not know if they could talk about the telemedicine device with the nurses, since this trial is about their diabetes only. In this thesis, the assumptions that the patients or the nurses made about the clinical trial are called "hidden hypotheses". The hidden hypotheses were verified with eight participants of the CUE, in stage 3.

7.1 What are the Hidden Hypotheses?

The concept of the "hidden hypotheses" occurred while some observations were made in the CUE. After formal completion of stages 1 and 2, while I prepared to leave the homes of the patients, patients made further remarks. These remarks were very interesting because they indicated that a patient had some assumptions about the clinical trial. A few of the patients (not all of the patients) made these remarks when their interview was formally over. Most of the time, the remarks occurred while I put on my shoes, at the doorsteps of a patient's home. (NB. as a courtesy, I took off my shoes in each patient's house prior to entry). All of these remarks were made while the recording device was

off. For example, participants like Yanicka, Zach, Ted and Serena had mentioned that the nurses were very nice to them. These patients seemed to be concerned that I would discuss the results of the observations with the nurses. I observed that each of the above patients seemed to feel uncomfortable after criticising the device, because the nurses were very nice to them.

Interestingly, these remarks raise the matter that perhaps the patients did not comment about the telemedicine device to the nurses because the nurses were nice. If a patient had the impression that a nurse was very nice and adequate to his/her aid, perhaps the patient did not want to mention the shortcomings of the device to the nurses. Further investigation is required to find out the extent to which the nurses' impressions had influenced the patients to refrain from talking about the device. For example, had the patients known that they could talk about the device in this clinical trial, other than only about their diabetes and physical well-being? Some remarks that the patients made while the recording was off were intriguing to explore the nature of what the patients had assumed about the clinical trial.

A patient might not have provided the interesting remarks if I recorded the conversation during the farewell period after conducting the CUE. For example, I asked Yanicka to repeat the comments she made while I was putting my shoes at her door so I could record them. She was reserved to repeat that the nurses were too nice so she does not bother them with too many questions. Yanicka was one of the out-spoken participants yet she had reservations when I wanted to record her comments that were made to me outside of the formal interview. Consequently, I did not attempt to record any remarks made by the rest of the eight patients during the farewell time from a patient's home, after conducting the CUE.

My interview with the nurses also showed that the nurses adopted some assumptions about the patients. For example, the nurses did not know that the patients wanted to see more data than what was

presented to them. The nurses thought that they were looking after the patients, so the patients may have not needed that extra data.

I gathered these remarks from both patients and nurses through observations after the CUE. Whether these remarks really influenced the behaviours of the patients in this clinical trial needed to be verified. This verification was conducted in stage 3 of the CUE. This verification step was vital to clarify whether I, as a researcher, had solely recognised these assumptions, or if the patients had really been influenced by these assumptions that I observed. Similarly, the two nurses also made assumptions that were verified with them through interview.

I considered that the reasons behind these interesting remarks by the patients and the nurses were due to some assumptions they held. I call these assumptions the "hidden hypotheses" of the clinical trial.

7.2 The designation of "hidden hypotheses"

According to the Merriam-Webster dictionary, the word "hypothesis" in science and social science experiment means, "a tentative assumption made to draw out and test its logical or empirical consequences" [169]. However, the word "hypothesis" originally refers to "an interpretation of a practical situation or condition taken as the ground for action". The second and original meaning of the word "hypothesis" applies, when not used in the context of an experiment in science or social science. I call the assumptions of the patients and the nurses collectively "hypotheses" based on the second definition of the word "hypothesis".

The patients and nurses in this particular clinical trial formed some hypotheses unknowingly and the patients and the nurses were unaware of each other's hypotheses. The ethnographic research methodology enabled me to observe these hypotheses which otherwise

may not have been noticeable. As a third-party researcher, not being involved in the clinical trial, I had observed these assumptions of the patients and the nurses. These assumptions were "hidden" in the plain sight of both the patients and the nurses, due to their roles in the clinical trial. For this reason, I define them in this research as "hidden hypotheses."

7.2.1 Past uses of "hidden hypotheses"

The term "hidden hypotheses" had been used in an entirely different context in the scientific literature in the past. In 1980 it was used by Davis in a letter to the editor of the British Medical Journal [170]. In that letter, Davis recounted how two medical doctors had conducted pejorative discussions about psychoanalysis. Davis suggested that there could be "hidden hypotheses" or assumptions for the pejorative criticisms that were common among medical doctors about the psychology discipline in that period. This was reflected in Davis's letter and he went on to state that the two doctors might have hypothesised certain ideas about the psychology discipline.

Alternatively, the term "hidden hypotheses" had a different connotation in the context of an economic evaluation of a European Union (EU) project in Switzerland [171]. This EU project measured cross-border cooperation in Switzerland. The project mentioned "hidden hypothesis" as an evaluation approach to measure the success of political projects. This particular evaluation method differed from traditional methods of economic evaluation. The evaluation used the short-term invisible goals of an evaluated program or instrument and learning and motivation with the actors involved. As a result, small hidden hypotheses were placed in different milestones. The hidden hypotheses measured the success of the milestones without the participants' awareness of them.

7.3 Hidden Hypotheses in this clinical trial

I collected seven assumptions that patients made, which I call the patients' hidden hypotheses. In Table 7-1, they are labelled as HH1 to HH7. These hypotheses were gathered through observations and patients' remarks which were off the record and outside the formal interview.

Table 7-1. The list of Hidden Hypotheses of the patients

HH1: *I want to bother the nurses the least, when I have some problems with the device.*
HH2: *The nurses are really helpful, so I don't want to bother them when I have problems with the device.*
HH3: *I was given training to use this device, so I feel shy to call the nurses when there is a problem.*
HH4: *I do not suggest about the device to the nurses because this trial is about my diabetes.*
HH5: *No one wanted my suggestions about the device so I did not have a chance to say how to improve it.*
HH6: *I don't change the location of the device in my home, because I don't want to have some problems with it and call the nurses or IT people.*
HH7: *Talking with a Human-Computer Interaction researcher (like XXXXX) was additionally helpful to give our feedback on the device.*

The following paragraphs describe the reasons for including these observations.

7.3.1 Patients' Hidden Hypotheses

This section provides brief descriptions on why I elected to investigate these *hidden hypotheses*, HH1 to HH7. Each of them is presented below, followed by the rationale for which I considered them as a patient's hidden hypotheses.

7.3.1.1 HH1 and HH2

Yanicka, Zach, Ted and Serena remarked that the nurses were very nice to them. They stated this at the end of the session and mentioned that they tried to fix problems by themselves. Yanicka

particularly said that only if she could not fix a problem with the device at all, would she then talk to the nurses by calling them on the phone. HH1 and HH2 reflect that the patients refrained from communicating with the nurses about problems for this reason.

7.3.1.2 HH3

Serena mentioned that -

"But you know, they trained me and showed me how to use so if something is wrong I try to not bother Nurse1" (off the record conversation).

Yanicka and Heidi made similar remarks during our informal conversation. As an observer, I deduced that because Serena (and the other patients) were given training, they seem not to have asked the nurses about any problems with the device. HH3 was to check this issue.

7.3.1.3 HH4 and HH5

Yanicka remarked that she did not know that she could talk about the device to the nurses. She particularly thought that the clinical trial was about diabetes management. Bill, Ben and Vince also remarked off the record that they thought the clinical trial is only about their health so they did not suggest anything about the device. HH4 was raised for this reason. Zach remarked that no one of the clinical trial team had inquired about the device, so he did not get to comment about the device. Yanicka, Ben and Heidi made similar remarks. HH5 was added as a hidden hypothesis for these remarks.

7.3.1.4 HH6

Interview results (chapter 5.3) show that one shortcoming of the telemedicine device mentioned by the patients was its limited mobility. The telemedicine device did not have wireless Internet capability. Patients also could not place their devices in the exact locations they

would have wanted to (section 5.1). An additional off the record remark from Heidi indicated that she did not want to change the location of her device because she was afraid to have problems with it and to tell the nurses. Yanicka similarly mentioned that since the nurses and the technicians set the device in her study room, she did not want to change it. The examples of Heidi and Yanicka raised the question of whether the patients would have liked to change the placement of the device but did not do it to avoid having any trouble with it.

7.3.1.5 HH7

Yanicka, Serena and Zach especially remarked that they were very happy to have a conversation with the researcher. They exclaimed that they were unaware that they could talk about the HCI. Yanicka and Zach mentioned that they did not know if these interactions and the way that they use the device were of any importance.

7.3.2 Hidden Hypotheses with Semi-anonymous Survey Results

An online survey was designed for the patients using "surveymonkey.com". The online survey was anonymous, as it did not collect any names of the participants (https://www.surveymonkey.com/r/MF8MLWX). Screenshots of the web version of this survey is presented in Appendix E. This survey was anonymous to provide patients with a greater degree of freedom. However, the survey may be called semi-anonymous because I know the identity of the participants, but I do not know *who* answered *what*.

Eight participants were emailed and given the link to complete the online survey. Participants were given the seven hidden hypotheses. They had four choices to rate each statement "*Strongly Disagree*", "*Disagree*", "*Agree*" and "*Strongly Agree*". There was no neutral choice to force the participants to pick one side, which was important to prove or disprove if these observations are acceptable to them. The response rate was 75% (n=6, N=8). N= 8 since Uma does not use computers.

Table 7-2 presents the results of the survey. The first column presents the hidden hypotheses and the choices that the eight participants made. HH4 was not answered by one participant and resulted in a total number of five responses for HH4, while there were six total responses for the rest of the hidden hypotheses.

Table 7-2. Results of semi-anonymous survey of stage 3 of CUE

	Strongly Disagree	**Disagree**	**Agree**	**Strongly Agree**
HH1: *I want to bother the nurses the least, when I have some problems with the device.*	1	2	3	0
HH2: *The nurses are really helpful, so I don't want to bother them when I have problems with the device.*	1	3	2	0
HH3: *I was given training to use this device, so I feel shy to call the nurses when there is a problem.*	1	5	0	0
HH4: *I do not suggest about the device to the nurses because this trial is about my diabetes.*	0	3	2	0
HH5: *No one wanted my suggestions about the device so I did not have a chance to say how to improve it.*	1	2	1	2
HH6: *I don't change the location of the device in my home, because I don't want to have some problems with it and call the nurses or IT people.*	0	2	2	2
HH7: *Talking with a Human-Computer Interaction researcher (like XXXXX) was additionally helpful to give our feedback on the device.*	0	0	2	4

7.4 Discussions on the results

HH1: *I want to bother the nurses the least, when I have some problems with the device.*

Earlier some patients mentioned that they did not want to call nurses to ask for help if they had problems. However, the result of the survey proved different. The participants were equally divided on HH1. 3 participants chose “Agree”, which means they did not want to call the

nurses if they had problems. However, another 3 participants chose to disagree with this observation; of them 2 participants chose “Disagree”, and 1 participant chose “Strongly Disagree”. The responses show that while some of the participants did not want to bother the nurses when they had problems, other participants did not think the same way. Clinical trials of telemedicine should be aware that patients not talk about problems with a technology with the nurses. Normally, a nurse gives them impressions about the focus on their health, not on technology. Future research should investigate how many of the patients feel hesitant to call the nurses when they have a problem with a technology. Had the patients been given an option to directly contact a technician instead of the nurses, would they have felt no reservations to make contact when they had problems with the device?

HH2: *The nurses are really helpful, so I don't want to bother them when I have problems with the device.*

4 patients disagreed with this hidden hypothesis and 2 of them agreed. Though the number of disagree is higher than number of agree, this refers to those 2 patients who may not have talked about the technical difficulties with the device because the nurses were very nice to them. Telemedicine clinical trials should consider that patients might have a relationship with the nurses based on their health needs. This relationship may prevent disclosure of the truth about the problems the patients have with the technology.

HH3: *I was given training to use this device, so I feel shy to call the nurses when there is a problem.*

From off the record conversations, several participants seemed to be shy to call the nurses. They expressed that because they had been given training, they tried to figure out any problems with the device before calling the nurses for any help. However, in the survey the results were different. The hidden hypothesis that I noted is thus incorrect. According to the patients’ responses, all of them disagreed with this. 5 participants chose “Disagree”, and 1 participant chose

"Strongly Disagree". The responses show that none of the participants was shy to ask for help.

HH4: *I do not suggest about the device to the nurses because this trial is about my diabetes.*

Until the HCI researcher met with the participants, many of the participants did not know that they could talk about the telemedicine device, such as how the device could be better, what their expectations were, etc. The participants mainly thought the clinical trial was only about their diabetes and physical well-being. The results of the survey showed mixed opinions. Of the 6 participants, there were 5 responses, which means that one of the participants declined to answer this. Among the responses, 3 participants chose "Disagree" while 2 participants chose "Agree".

Patients' experience with technology is not a formal protocol of clinical trials as discussed in the literature review. Many clinical trials carry out additional qualitative research, which is not a standard of practice, and the questions of the qualitative research in the clinical trials normally depend on the researchers.

HH5: *No one wanted my suggestions about the device so I did not have a chance to say how to improve it.*

This hidden hypothesis question was asked to elaborate on HH4. This investigates if anyone from this clinical trial team had actually asked the patients to express comments about the device and interactions.

The results showed that 2 participants responded "*Strongly Agree*" and 1 participant respondent "*Agree*" to this hidden hypothesis. On the contrary, 1 participant responded "Strongly *Disagree*" and 2 participants responded "Disagree". The results showed that the participants were divided in their opinions. Half of them think no one from the clinical trial team wanted their suggestions on the device.

I observed that the nurses in this clinical trial did not want suggestions about the device from the patients. However, the nurses had been available to help and support the patients to manage their diabetes. The choice to disagree by the three participants with this hidden hypothesis is contradictory to what happened in the clinical trial.

HH6: *I don't change the location of the device in my home, because I don't want to have some problems with it and call the nurses or IT people.*

This hidden hypothesis was accepted as true for all of the 6 patients who responded. 4 of the participants chose "*Strongly agree*" and 2 chose "*Agree*" responses. This point raises the question that the device might have been moved had not the patients been worried about the consequences. Several reasons exist for the patients not moving the telemedicine device from its original placement. Some of these are described in section 6.2.

HH7: *Talking with a Human-Computer Interaction researcher (like XXXXX) was additionally helpful to give our feedback on the device.*

All 6 responses from participants in the survey, agreed with this observation (with 5 "Strongly agree" and 1 "Agree" responses). Interestingly, they perceived the HCI researcher's role as helpful, even though they made contact with the researcher only twice. A comment was left by one participant that said-- *"It was really nice to meet XXXXX and know all about HCI and design."*

7.5 Hidden Hypothesis of the Nurses

The nine patients that participated in the CUE frequently mentioned the two nurses who were involved with the patients. The two nurses went with technicians to set up the telemedicine device and trained the patients to use the device. These nurses had regular weekly communication with the patients after the initial setup and training. The two nurses were interviewed to investigate and triangulate parts of

the results of CUE. The interview with the two nurses was not part of the CUE.

The two nurses, like the patients, had made some assumptions about the patients in the clinical trial. The interview with the nurses indicates that the nurses assumed some beliefs and took them as a ground for further action. For example, when Nurse1 was asked if the patients ever have any problems with using the telemedicine device, she expressed that

"Usually when you do the original setup you make sure that you know they (patients) are fairly proficient in using the equipment."

Nurse1 also added further comments such as how they handle any issue, without mentioning any problems that the patients might have had. After the interview, Nurse1 also remarked that because training was provided to the patients, the patients should not have any problems with the device. Nurse1 was very defensive when the question was asked if the patients had any problems using the device.

Nurse2 was also asked during her one-to-one interview whether the patients mentioned any trouble using the device. Nurse2 was also defensive and did not mention any problems at all. She added that the main problem was that patients were inured to forget the process, which is the only reason for the patients to have any problems with the device, if they have any.

"They don't have the problem with using it in as much as sometimes they forget the process."

Following the two nurses' personal interviews, I concluded that the nurses had the following hidden hypothesis about the patients.

Nurse Hidden Hypothesis: *Technical support is provided to patients with training with the technology hence, patients should not have any problem.*

7.5.1 Results and Discussion

There were only two nurses so an online survey was not necessary, unlike the patients. Each of the nurses was interviewed individually. At the end of the interviews, the nurses were provided with a paper that had the above hidden hypothesis printed. Below the four choices (as with the patients' online survey) were provided: "*Strongly Disagree*", "*Disagree*", "*Agree*" and "*Strongly Agree*". There was no neutral choice to force them to pick one side.

Both nurses chose "*Strongly Agree*" with this hidden hypothesis. This shows that due to this hidden hypothesis the nurses did not ask questions about the interaction of patients with the device. The nurses also expected the patients not to have any problems with the device because training was provided to the patients initially.

7.6 Discussion

The hidden hypotheses of the patients and nurses provide evidence that simple beliefs may exist in a clinical trial that may be spotted by a third-person observer. The hidden hypotheses that I introduced and verified, are one person's observations. A different researcher may not have noticed them or may have interpreted these observations in a different way.

I found the hidden hypotheses to be the invisible bias that explains the way in which the clinical trial team representatives, such as the two nurses in this case, and the patients acted during this research. The hidden hypotheses are a prospective way to show the "the clinical researcher team's world" and "the patients' world", through my ethnographic observations. The hidden hypotheses provided a way to compare between these two different worlds.

The concept of hidden hypotheses proves a step forwards for the HCI researcher about the clinical trial. Earlier in section 3.2.1.7 of this thesis I described the gap mentioned by [133] in HCI, between the

"researcher's/designer's world" and the "user's world". [133] recommended that in HCI practice, researchers/designers have to make a choice whether to move to the "user's world" or move the users to the "researcher's/designer's world". The observation of these hidden hypotheses provides a way for HCI observers to notice how clinical trials are conducted and what assumptions the patients and the research team may have adopted.

The hidden hypotheses showed that patients performed differently while they were interviewed, and that they might provide very important information while they are not being interviewed. A recent study in participatory design in hospital settings in Denmark [172] showed that researchers should be very aware to notice the subtle changes in participants' behaviours, similar to my experience, when patients talked at the doorway during a goodbye.

Two important points surfaced from the hidden hypotheses HH6 and HH7 of this trial. HH6 found that participants did not change the location of the device once it was placed. HH7 found that all participants in this clinical trial found my role as a HCI researcher helpful.

Participants were split in their opinions towards and against hidden hypotheses 1, 3 and 4. Split results indicate that even though my initial observations were correct, some patients may behave differently. Split results provide information that in a clinical trial, researchers cannot treat all patients in the same manner. For example in hidden hypothesis 4, three participants thought that they could not talk about the device because no one asked them. They assumed they could only talk about their diabetes. I urge that every clinical trial needs to provide information explicitly so that not even one patient thinks that they cannot opine about the device in use.

Hidden hypothesis 2 was disproved by all of the patients. This showed that I had an incorrect observation about the patients.

However, to become aware of the disagreement from the patients through the semi-anonymous survey provides important validation. This validates that none of the patients were shy to contact the nurses, even though they seemed to suggest that they were shy during the interviews.

Results of hidden hypothesis 6 further ensure that HCI may add value to a clinical trial. All the participants expressed that they experienced the interviews with me as beneficial. A comment was left by one participant who expressed that information was learned through communication with me.

The findings from this study align with previous research of domestication and persuasive technology. In the result of hidden hypothesis 6 of the patients, the participants mentioned that they never changed the location of the device. Kluckner *et al.* [173, 174] demonstrated in a seven months in-situ study of a kitchen clock, which suggests energy efficiency, that only 16% of participants changed the position of the clock during the seven months. Crabtree found that users decide on the placement of a technology in the beginning and rarely makes changes [175, 176]. The finding from hidden hypothesis 4 is similar to those of Kluckner *et al.* and Crabtree *et al.*

Notably, where the patients would have placed their telemedicine in-home monitoring device, if the device had mobility remains a question of high interest for future researchers. As suggested by the findings from chapter 4, the dynamics of placement of the device and interaction with the device could have been very different, had the device not needed an Internet cable and socket. Patients encountered some limitations that changed their decision on where to place their devices. For example, not all patients could place the device in a location where they would have liked, thus they were limited by the device not having wireless capabilities. A wired device that uses the Internet is limited by Internet sockets available in the walls.

7.7 Conclusion

This chapter provided an analysis and interpretation of a concept called “Hidden Hypotheses”. This section used the hidden hypotheses to interpret and discuss some important findings in this research.

HCI possesses the promise to complement medical clinical trials such as this research project. The hidden hypotheses results from the nurses show that from their perspective they are unaware of many things that the patient wants. Probable reasons for this could be their involvement in the medical profession. The nurses may have put strong emphasis on the patient’s medical condition. Therefore, they are unaware of the expectations and dissatisfactions of the patients with the device.

Chapter 8. Conclusion

In-home monitoring technology such as telemedicine can be an effective tool for T2D patients to manage healthy behaviours. Recent years have witnessed an increasing number of telemedicine movements where health care providers monitor T2D patients. However, during a traditional clinical trial of a telemedicine device, the technology remains a 'black box'. How patients use the technology and what happens during this use, remain obscure. Researchers in a telemedicine clinical trial for T2D adopt the traditional approach and compare only the medical benefits of patients at baseline and the end to determine the effectiveness of a telemedicine device.

This thesis examined and conducted a meta-synthesis of past telemedicine clinical trials of T2D. The meta-synthesis uncovered two major findings–

1. Lack of data on patient dropouts; and
2. Positive behavioural outcomes in patients from using a telemedicine technology

Therefore, a new methodology was required to evaluate areas that are not in the scope of clinical trials, such as understanding patients' use of the device and experiences with the device. This thesis proposes the *CUE*, which is a patient focused qualitative evaluation approach to understand how the patients use a telemedicine device during a clinical trial.

The CUE was developed as a part of this project using evaluation methods from the discipline of HCI. The CUE consisted of three stages. Stage 1 is an in-situ contextual inquiry, stage 2 is an individual interview and stage 3 is an online survey. It was necessary that the CUE function effectively within a clinical trial without impeding the clinical trial. Roles of a CUE researcher and a clinical trial researcher

are vastly distinct. Next, the CUE was implemented with a sample of the clinical trial patients documented in chapter 4.

To understand and interpret the patients the best possible way, I transcribed every audio recording of the stages 1 and 2 for each patient. The results from the CUE brought out 1) how the patients used the telemedicine device, 2) how the patients felt using the device and 3) what recommendations patients provided to improve the device. The findings show that all patients benefitted from using the in-home monitoring device to manage their T2D. Patients and their family members found the device provided them with a safety net. Many patients benefitted from using the device because their awareness, motivation and engagement about T2D increased from using the device.

The CUE also exposed the negative experiences of the patients. Slow response time, frustration with measurement of blood pressure, lack of a graph or visual data and, significantly, the lack of wireless Internet capability were the main shortcomings mentioned by the patients. The patients could not place the device in their preferred location in their homes due to the limitation of the lack of wireless Internet capability of the device.

Stage 1 of CUE was analysed using the contextual design method to provide a design of "how the telemedicine device should have been designed to fulfil the T2D patients' needs." This analysis in chapter 6 triangulated the findings in chapter 5 where patients mentioned the shortcomings of the current device.

An analysis on domestication of the telemedicine device was also conducted in chapter 6. This analysis discovered that the nine patients of the CUE placed their devices in four main locations. The choices of the locations were determined by Internet power point availability, convenience, comfort and adherence/to build a habit of use.

Surprisingly, even though the nurses described the telemedicine device as lifesaving and thus expected the patients to welcome the

device; the patients treated the device just like an ordinary consumer device, such as an iPad or tablet. The patients did not treat the device with added fascination because it was lifesaving. The patients criticised the device for its limitations, for example, lack of mobility, visual data, wireless Internet, etc.

Analysis in-depth showed that the patients found the device to influence them positively towards management of T2D. This influence confirms that the emerging research domain of persuasive technology is essential for behaviour improvements. PT intentionally uses the power of technology to guide users to a targeted behaviour change. This telemedicine device was not built with persuasive design considerations, yet it showed significant improvements in the clinical trial patients. Patients felt motivation, adherence and improved awareness towards management of their blood glucose due to the use of the telemedicine device. Nurses also additionally reported change in the awareness and engagement of patients for their own well-being from the use of the device.

Unsurprisingly from a HCI perspective, not all of the patients engaged with the telemedicine device equally. I divided the patients, based on their description during stage 1, into four categories: enthusiastic patients, accepting patients, indifferent patients and resistant patients.

Unpredictably, a concept arose from this research, which I defined as the hidden hypotheses of this clinical trial. I possessed a neutral observer's role in this research because I was not involved with the developers of the technology or with the clinical trial team. I found that the patients had some assumptions or beliefs. These beliefs made them act in a certain way. For example, they did not know that they could talk about the telemedicine device because the clinical trial was conducted by nurses. Likewise, the nurses also had assumed one belief of this sort. Both the patients and the nurses were unaware of these hidden beliefs. From my observer's role I could notice these. In stage 3,

I validated these hidden hypotheses through an online anonymous survey of the same patients. The hidden hypotheses provide readers with an insight into the world of a patient and the world of the nurses during the period in which a clinical trial is conducted.

8.1 Contributions

A new methodology was required (chapter 1, chapter 2) to evaluate areas that are not in the scope of clinical trials. This thesis was guided by the research question

"***How to evaluate technology-intervened treatments (such as telemedicine) during a clinical trial, to understand patients' use and experiences with the device?***"

The research carried out in this thesis provided the following outcomes.

8.1.1 A New Methodology the CUE

This research provided a new qualitative methodology, the CUE, to be used within a clinical trial. The CUE specified the roles of the CUE researcher and the clinical trial researchers. The CUE defined the protocol of the CUE researcher in order to avoid hindrance to the main clinical trial. Clinical trials are costly evaluation measures and very resource intensive. Nevertheless, clinical trials only extract medical data. For a technology like telemedicine, these data can be inadequate. A technology may improve the medical conditions of a patient, but whether a patient will adopt the technology still remains debatable.

CUE can provide evaluation from the technology use and the patients' perspective during a clinical trial. Within the same facility of a clinical trial, a huge amount of data can be collected, such as the case study of this thesis. One or two HCI researchers can collect valuable data, which are important for policy makers, in addition to the medical evidence from a clinical trial.

8.1.2 Evidence that CUE works with clinical trial

The case study of this research showed that the CUE functions without hindering a medical clinical trial. In this research, the clinical trial was solely about T2D. This provides evidence for future researchers to delve deeper into specific ways of working within a clinical trial.

8.1.3 Bridges the gap between IT and Medical Science through HCI

This research is a novel approach where a clinical trial and HCI researcher worked in tandem. Currently several works with the Commonwealth Scientific and Industrial Research Organisation (CSIRO) and Sydney University are in progress, where the telemedicine device is developed through HCI expertise. However, in those works the development is occurring hand in hand between medical and HCI researchers and the evaluation of the device is not neutral. Unfortunately, most of the telemedicine device are not designed that way and telemedicine devices are increasing due to their convenience. Those devices may go through clinical trial and completely ignore the patients' use of the devices. The CUE provides new method to evaluate telemedicine devices not only for T2D patients but for other patients too. The CUE can complement any clinical trial and thus bring HCI and medical researchers to work closely.

In this research, I am not involved with the clinical trial research and their interests. The TMML who conducted this T2D telemedicine clinical trial was receptive to the idea of allowing me to perform a human-centred evaluation of the telemedicine device. The non-involvement of TMML in this research helped to show how new ways of evaluation may be performed.

The findings of the CUE showed that CUE has significant potential to provide additional data about the telemedicine technology; this kind of investigation had never been conducted in a clinical trial before. Generally, HCI evaluation is often done during the development phase but in this work, an HCI evaluation was conducted in the rollout phase. This research provides an exemplary case study, which should provide the basis for future HCI researchers to work with clinical trials.

Due to the demography shift, the problems of the world are changing. This research shows that to face the problems of health care such as T2D management, HCI can join medical science for a complete evaluation. Telemedicine and other technology-intervened treatments lie at the intersection of IT and medical science. HCI can bridge a gap between the two disciplines.

8.1.4 Domestication of telemedicine

This research provided knowledge on how a telemedicine device for T2D is domesticated by patients. Previous domestication research had focused on smart homes, digital artefacts, etc. This research is the first example to provide evidence of domestication of a telemedicine device.

8.1.5 Design Implications for a telemedicine device for T2D

Through the CUE, this research discovered data to provide future design implications and considerations to develop a telemedicine device for T2D patients. How the patients feel and how they use the telemedicine device in their own homes was detailed in this research. Patients are the most important users of an in-home monitoring device for a chronic disease like T2D. However, in clinical practice, patients' technology needs are not raised, since most of the attention goes to the medical needs. Unfortunately, if a telemedicine device does not provide the comfort, the data and the features that the patients need, patients will not adopt the device even though medical practitioners may expect

them to. The findings of this research can inform future telemedicine T2D development that thoroughly meets patients' requirements and expectations.

8.1.6 Promises of Persuasive Technology

Persuasive Technology is a popular discipline and extension of the IT discipline. PT provides guidelines and techniques to use IT for desirable behaviour changes among the users. The telemedicine device for T2D patients in this research was not developed with persuasive design considerations. Surprisingly it showed significant behavioural improvements in the clinical trial patients. This research indicates that telemedicine will immensely benefit if telemedicine collaborates with PT researchers. PT has already been successful in healthy eating, health awareness, environmental awareness, sustainability, etc. This research provides evidence that PT and telemedicine can work together to provide better benefits to the patients.

8.2 Limitations and Future Work

The CUE was conducted with a small sample size of patients. Nine patients were part of the research in this case study. However, due to the qualitative nature of the CUE the small sample size provides a strong evidence base. To generalise these findings across the T2D population, future work of CUE should include a higher number of patients and expand the work quantitavely to prove the findings of this research.

The hidden hypotheses that the patients held, were verified in stage 3 with the same sample of patients. Intriguingly, these hidden hypotheses could have been verified with a larger sample of the patients, who were not participating in the CUE. However, due to the lack of permission and strict and time-consuming ethics approval that is required to do so, I could not perform that step. The initial ethics approval of the CUE took 13 months.

The hidden hypotheses were based on one person's observations. Another researcher in the same situation might have found more or less hidden hypotheses in this clinical trial.

This research showed that the CUE discovered detailed knowledge about the patients' use of a telemedicine device in a clinical trial. Future work should inspire more HCI work in medical science practices of this sort. A bigger HCI team rather than one individual researcher in this research may cover a huge number of patients and results can be generalised for a bigger population.

The concept of hidden hypotheses should be investigated in other telemedicine clinical trials of different health problems than T2D. The hidden hypotheses of this research should be checked in other telemedicine clinical trials of T2D through anonymous surveys. Whether the same hidden hypotheses exist among other patients should be confirmed.

PT provides guidelines to keep users targeting healthy behaviour. PT researchers should be working in future to develop engaging telemedicine devices. Telemedicine technologies possess a power to influence T2D patients' behaviours. T2D is a chronic disease that requires daily management. This power should be utilised by including PT researchers to develop or enhance existing telemedicine devices for T2D.

8.3 Concluding Remarks

This thesis does not indicate that clinical trials are inadequate. Clinical trials have contributed for over three centuries in medical science to provide evidence of the effectiveness of drugs/treatments.

This thesis cautions that the demographic shift and the advancements in IT have initiated a paradigm shift in traditional healthcare models with an increase in the use of technology-intervened treatments. Since there is a paradigm shift in the healthcare model, a

paradigm shift in evaluation methods of these technology interventions is required. Hence, we need additional methods to evaluate the patients' experience besides their medical improvements.

The CUE is one approach to complement a clinical trial of telemedicine. The CUE was implemented with T2D patients in a real clinical trial. CUE provided sufficient knowledge that traditional telemedicine clinical trials overlook. CUE provides the potential to be used in future for clinical trials of T2D or other forms of telemedicine in-home monitoring.

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Appendix A : Emails of two authors

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Appendix B : Information for participants

INFORMATION SHEET

PROJECT TITLE: Identifying User (patient) Interaction with Healthcare Technology

An IT (Information Technology) PhD student is doing research to understand you as a user of the unit to manage diabetes from home.

He will come to talk to you to learn about how you use the unit. He is trying to understand the interaction that you have with the unit. Please note, this is not evaluating you but learning from you. So you are the master an he is the apprentice. He is trying to find out how people use it at home naturally.

This kind of research is in the area of Human-Computer Interaction. You are participating as a lead user to learn from for better design for other users.

He will ask you questions about the unit and the interface etc. He will meet you at your normal time that you use it to upload the data of your blood pressure and blood glucose.

He will take some notes, some non-identifiable photos (hands and the Tablet PC). He will record the interview to find out your opinions and your suggestions for future design.

The results from these interviews will be used in publications and his PhD Thesis.

There is a consent form which you may sign if you agree to participate in this study.

. If you have any questions about the study, please contact **– Prof. Ian Atkinson** or **Mr. Sakib Jalil.**

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Name: Dr. Trina Myers

School: School of Business (Information Tehcnology)

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If you have any concerns regarding the ethical conduct of the study, please contact:
Human Ethics, Research Office
James Cook University, Townsville, Qld, 4811
Phone: (07) 4781 5011 (ethics@jcu.edu.au)

INFORMED CONSENT FORM

PRINCIPAL INVESTIGATOR	**Sakib Jalil**
PROJECT TITLE: Identifying User(patient) Interaction with Healthcare Technology	
SCHOOL IT, School of Business	

I understand the aim of this research study is **"to investigate users' interaction with the diabetes monitoring technology".** I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written information sheet describing this project. The information sheet is for me to keep.

I understand that my participation will involve **interview in form of conversation and I will be observed by the researcher and notes will be taken,** and I agree that the researcher may use the results as described in the information sheet.

I acknowledge that:

- taking part in this study is voluntary and I am aware that I can stop taking part in it at any time without explanation or prejudice and to withdraw any unprocessed data I have provided;

- that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval;

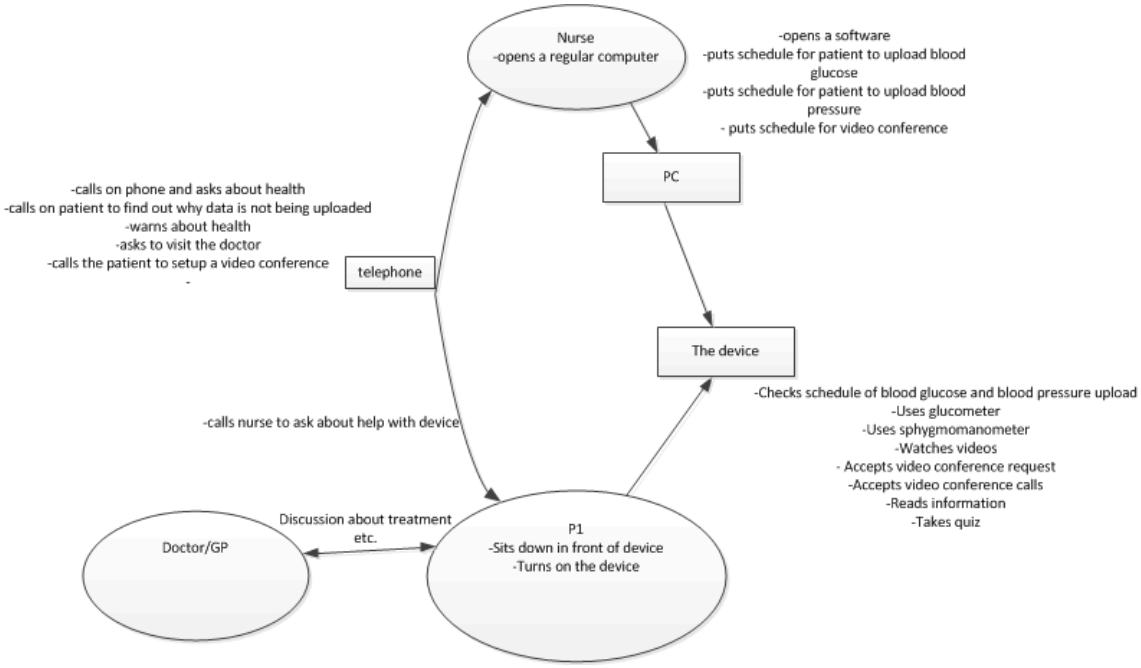
(Please tick to indicate consent)

I consent to be interviewed		**Yes**		**No**
I consent to be observed and the investigator will take notes anytime during my participation		**Yes**		**No**
I consent for the interview to be audio taped		**Yes**		**No**

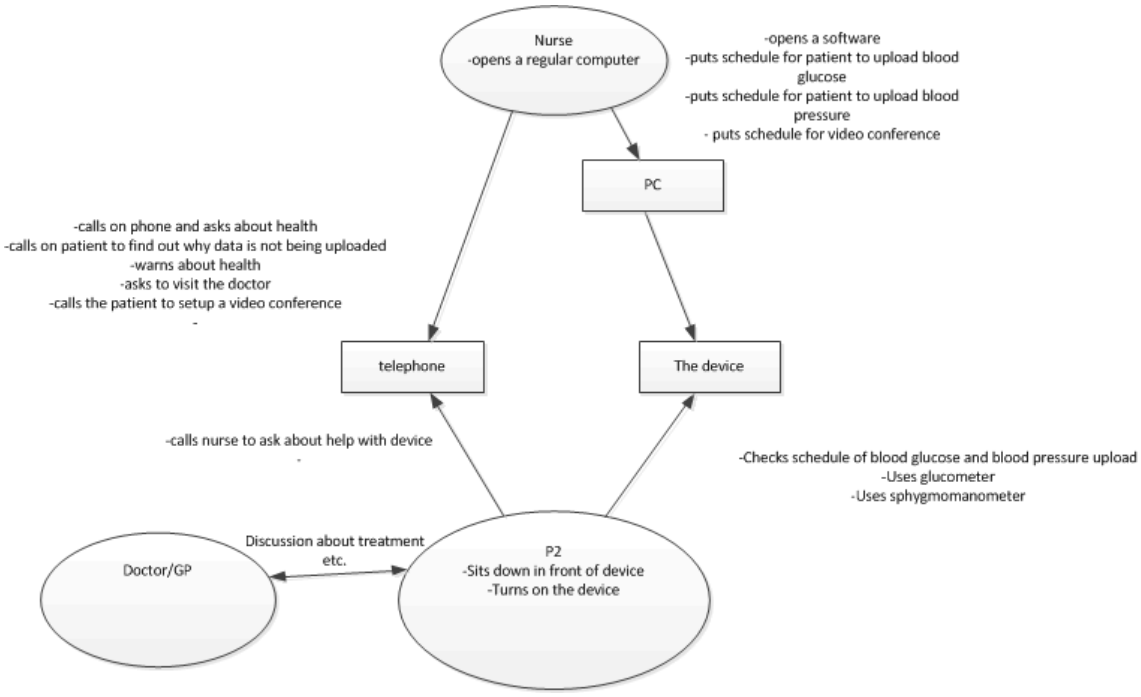
I consent to be photographed and the photographs are non-identifiable as mentioned in the information sheet		**Yes**		**No**

Name: *(printed)*	
Signature:	**Date:**

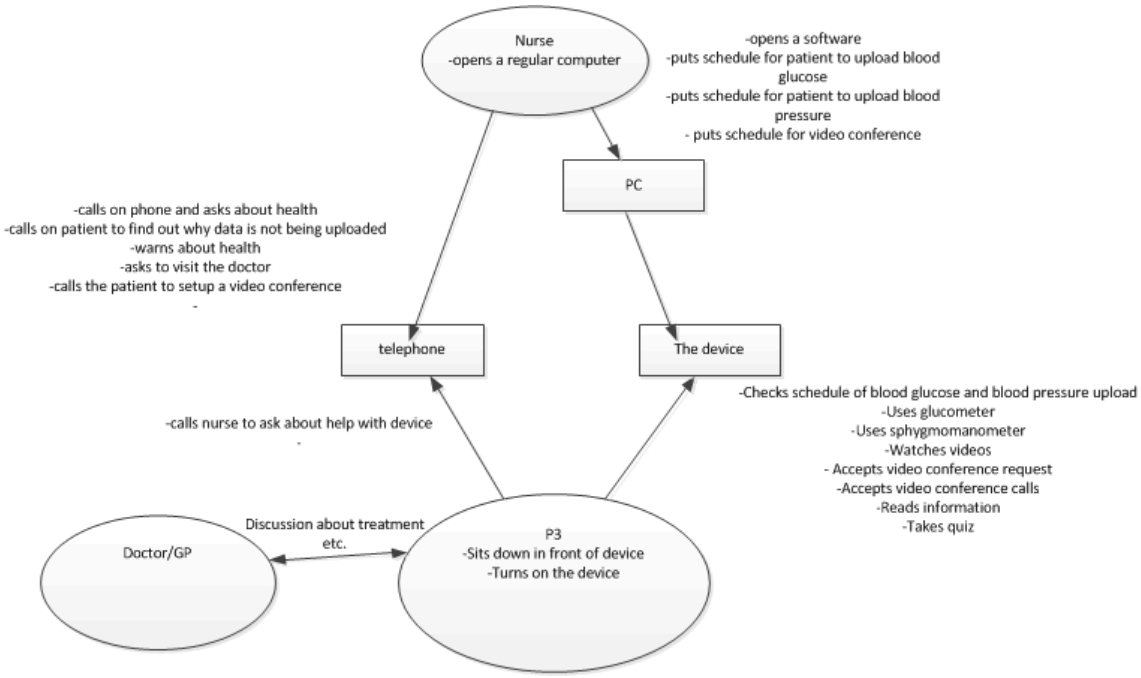
Appendix C: Flow Models



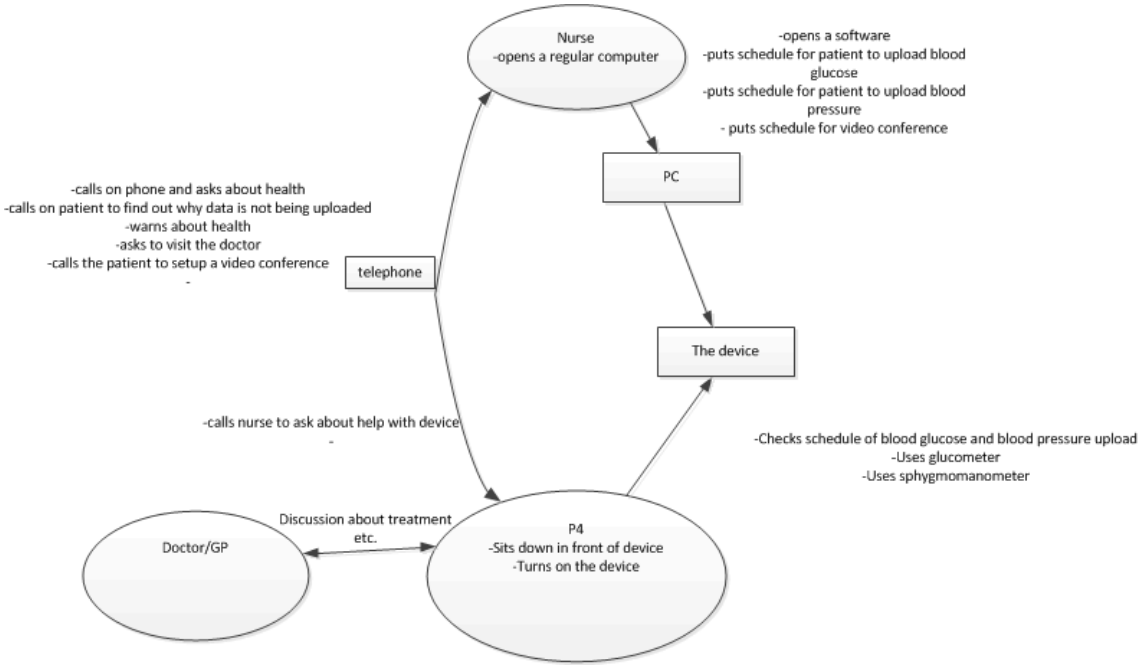
Zach´s flow model



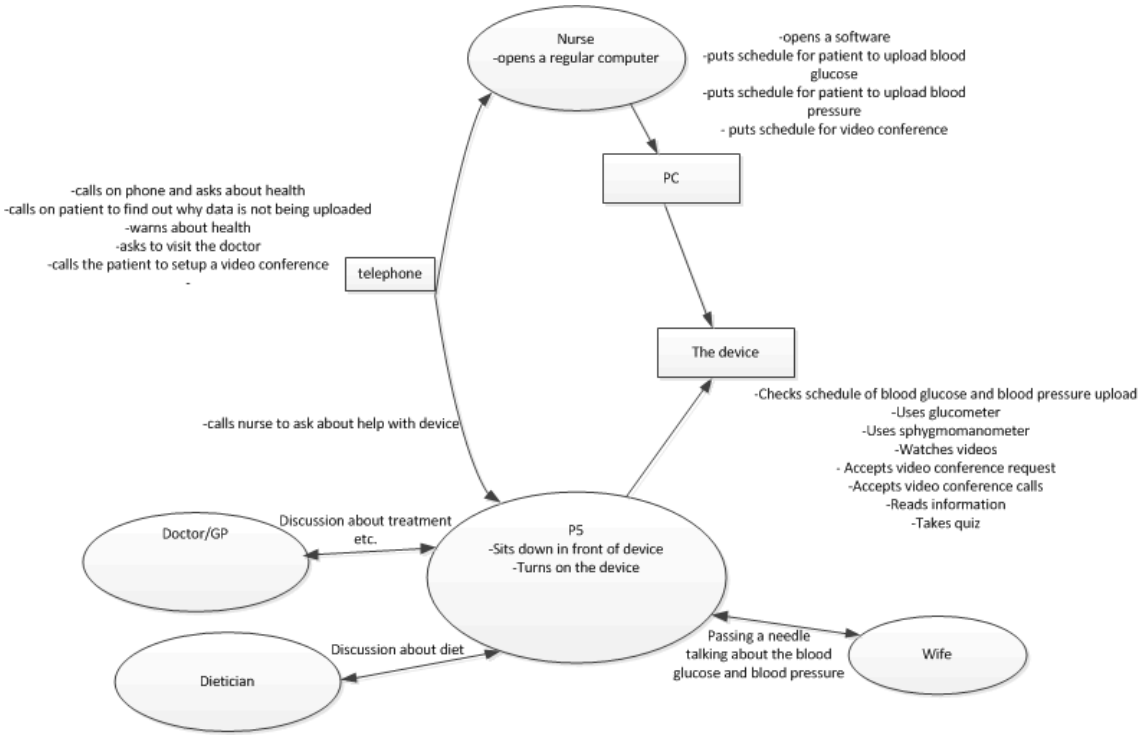
Ted’s flow model



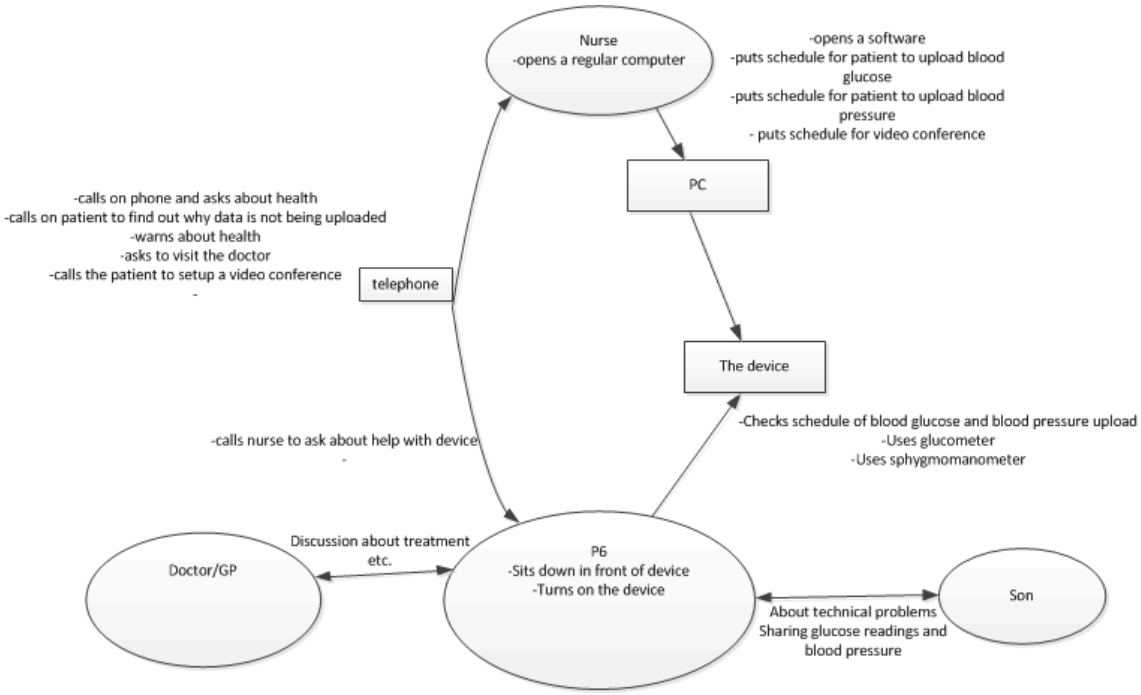
Yanicka´s flow model



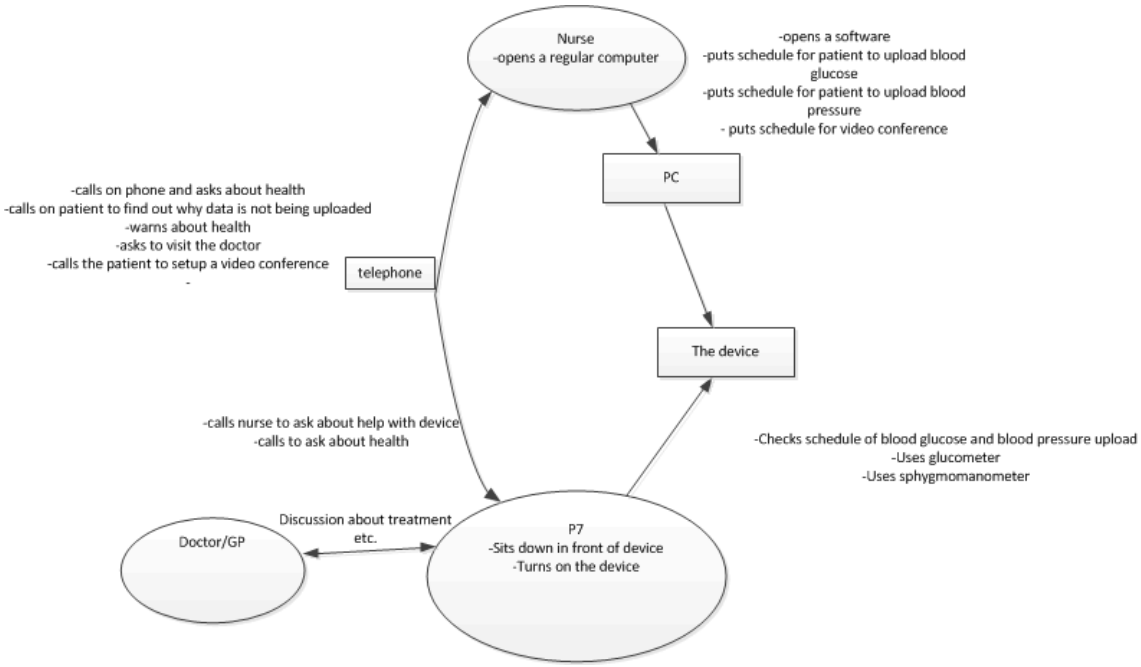
Vince´s flow model



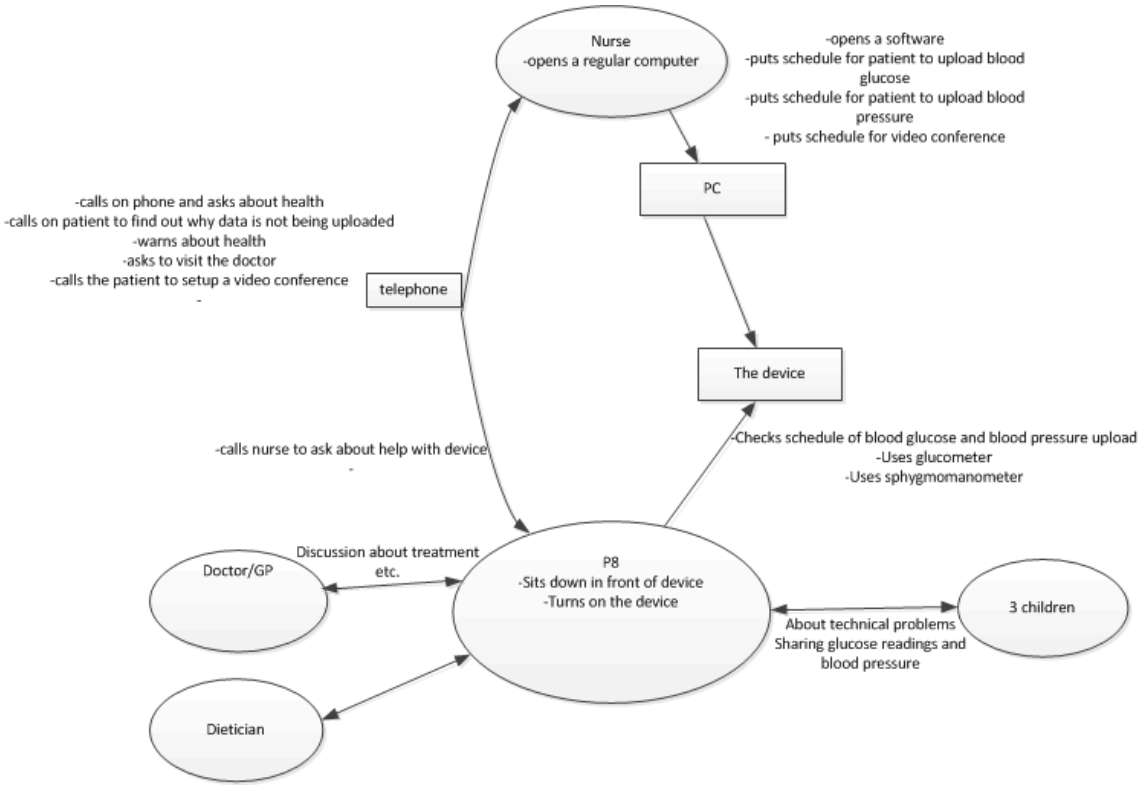
Bill's flow model



Serena's flow model



Uma's flow model



Heidi's flow model

Appendix D: Sequence Models

Zach

Sequence 1:

(Regular task-Uploading blood glucose and blood pressure)

Intent: Doing the regular task as advised by the nurse.

Trigger: Time of the day

Sits in front of the device

Turns it on with the switch

Waiting for auto log in [Feels impatient due to the long logging time]

Taps on the icon to see scheduled tasks

Trigger: Device tells with voice message to measure blood glucose

Opens the strip box

Takes a strip

Inserts strip in the glucometer

Pricks finger with needle

Puts blood drop on the strip

Waits for the reply from the device

The voice from device reads it out loud

Puts the glucometer away

Rubs his pricked finger with tissue paper

Trigger: Device tells with voice message to measure blood pressure

Wraps the cuff of the blood sphygmomanometer around the biceps of left arm

Turns the button on sphygmomanometer

Waits while the cuff tightens around the bicep

Waits for the reply from the device

The voice from device reads it out loud

Takes off the hand out of the cuff and puts the sphygmomanometer aside

Intent: Keeping blood glucose reading in a record

Trigger: After work with device, self -motivated

reads from glucometer

goes to laptop

inputs the data in an excel sheet [self-created]

Intent: Comparing blood glucose reading in a record

Trigger: After keeping blood glucose in a record self -motivated

reads from excel

clicks on graph view [with X and Y axis line plot]

Intent: Looking at the awareness information

Trigger: Just finished regular task [Due to the fact of doing a regular task]

Cleans fingertips to free from any blood drops

Taps on the touchscreen button for information sheet

Intent: Searching for the medicine

Cannot find

Goes to laptop

Opens Internet browser

Searches for medicine

Intent: Watching informational videos

Cleans fingertips to free from any blood drops

Taps on the touchscreen button for informational video

Sequence 2:

(Troubleshoot)

Intent: To inform the nurse

Trigger: The device not responding

Get up

Get the mobile phone

Calls the nurse

If nurse answers then continues to fix with nurse

Else tries restarting

Ted’s Sequence Model

Sequence 1:

(Regular task-Uploading blood glucose and blood pressure)

Intent: Doing the regular task as advised by the nurse/self motivation

Trigger: Being at home

Sits in front of the device

Turns it on with the switch

Waiting for auto log in

Taps on the icon to see scheduled tasks

Trigger: Device tells with voice message to measure blood glucose

Opens the strip box

Takes a strip

Pricks finger with needle

Puts blood drop on the strip

Inserts strip in the glucometer

Waits for the reply from the device

The voice from device reads it out loud

Puts the glucometer away

Rubs his pricked finger with tissue paper

Trigger: Device tells with voice message to measure blood pressure

Wraps the cuff of the blood sphygmomanometer around the biceps of left arm

Turns the button on sphygmomanometer

Waits while the cuff tightens around the bicep

Waits for the reply from the device

The voice from device reads it out loud

Takes off the hand out of the cuff and puts the sphygmomanometer aside

Turns off the device

*Never had any trouble shoot

Yanicka's Sequence Model

Sequence 1:

(Regular task-Uploading blood glucose and blood pressure)

Intent: Doing the regular task as advised by the nurse.

Trigger: Time of the day and if at home

Sits in front of the device

Turns it on with the switch

Waiting for auto log in [Feels impatient due to the long logging time]

Taps on the icon to see scheduled tasks

Trigger: Device tells with voice message to measure blood glucose

Opens the strip box

Takes a strip

Pricks finger with needle

Puts blood drop on the strip

Inserts strip in the glucometer

Waits for the reply from the device

The voice from device reads it out loud

Puts the glucometer away

presses her pricked finger with cotton

Trigger: Device tells with voice message to measure blood pressure

Wraps the cuff of the blood sphygmomanometer around the biceps of left arm [Feels discomfort]

Turns the button on sphygmomanometer

Waits while the cuff tightens around the bicep

Waits for the reply from the device

The voice from device reads it out loud

Takes off the hand out of the cuff and puts the sphygmomanometer aside

Intent: Keeping blood glucose reading in a record

Trigger: After work with device, self -motivated

reads from glucometer

writes by hand on a diary

Looks at past reading and

compares by number [cannot see a graph, wishes to see]

Intent: Looking at the awareness information

Trigger: Just finished regular task [Due to the fact of doing a regular task]

Cleans fingertips to free from any blood drops

Taps on the touchscreen button for information sheet

Intent: Searching for the medicine

Cannot find

Goes to MacBook [keeps next to the device]

Opens Internet browser

Searches for medicine

Intent: Watching informational videos

Cleans fingertips to free from any blood drops

Taps on the touchscreen button for informational video

Sequence 2:

(Troubleshoot)

Intent: To inform the nurse

Trigger: The device not responding

Get up

Get the mobile phone

Calls the nurse

If nurse answers then continues to fix with nurse

Else tries restarting

Vince's Sequence Model

P4

Sequence 1:

(Regular task-Uploading blood glucose and blood pressure)

Intent: Doing the regular task as advised by the nurse.

Trigger: Time of the day and if at home

Sits in front of the device

Turns it on with the switch

↓

Waiting for auto log in

Taps on the icon to see scheduled tasks

↓

Trigger: Device tells with voice message to measure blood glucose

↓

Opens the strip box

↓

Takes a strip

↓

Inserts strip in the glucometer

↓

Pricks finger with needle

↓

Puts blood drop on the strip

↓

Waits for the reply from the device

↓

The voice from device reads it out loud

↓

Puts the glucometer away

↓

Rubs his pricked finger with tissue paper

↓

Trigger: Device tells with voice message to measure blood pressure

↓

Wraps the cuff of the blood sphygmomanometer around the biceps of left arm

Turns the button on sphygmomanometer

↓

Waits while the cuff tightens around the bicep

↓

Waits for the reply from the device

↓

The voice from device reads it out loud

↓

Takes off the hand out of the cuff and puts the sphygmomanometer aside

↓

Turns off the device

Sequence 2:

(Troubleshoot)

↓

Intent: To inform the nurse

↓

Trigger: The device not responding

↓

Gets up

↓

Gets the mobile phone

↓

Calls the nurse

↓

If nurse answers then continues to fix with nurse

↓

Else tries restarting

↓

Bill's Sequence Model

Sequence 1:

(Regular task-Uploading blood glucose and blood pressure)

↓

Intent: Doing the regular task as advised by the nurse.

↓

Trigger: Time of the day and if at home

↓

Sits in front of the device

↓

Turns it on with the switch

↓

Waiting for auto log in [Feels impatient due to the long logging time]

Taps on the icon to see scheduled tasks

↓

Trigger: Device tells with voice message to measure blood glucose

↓

Opens the strip box

↓

Takes a strip

↓

Inserts strip in the glucometer

↓

Pricks finger with needle

↓

Puts blood drop on the strip

↓

Waits for the reply from the device

↓

The voice from device reads it out loud

↓

Puts the glucometer away

↓

Rubs his pricked finger with tissue paper

↓

Trigger: Device tells with voice message to measure blood pressure

↓

Wraps the cuff of the blood sphygmomanometer around the biceps of left arm

Turns the button on sphygmomanometer

↓

Waits while the cuff tightens around the bicep

↓

Waits for the reply from the device

↓

The voice from device reads it out loud

↓

Takes off the hand out of the cuff and puts the sphygmomanometer aside

↓

Looking at the information sheet for the medicine

↓

Looking at the videos

↓

Turns off the device

Sequence 2:

Intent: Keeping blood glucose reading in a record

↓

Trigger: After work with device, self -motivated

↓

reads from glucometer

↓

writes by hand on a diary

↓

Looks at past reading

Sequence 3:

(Troubleshoot)

↓

Intent: To inform the nurse

↓

Trigger: The device not responding

↓

Get up

↓

Get the mobile phone

↓

Calls the nurse

↓

If nurse answers then continues to fix with nurse

↓

Else tries restarting

↓

Serena's Sequence Model

P6

Sequence 1:

(Regular task-Uploading blood glucose and blood pressure)

↓

Intent: Doing the regular task as advised by the nurse.

↓

Trigger: Time of the day and if at home

Sits in front of the device

Turns it on with the switch

Waiting for auto log in [Feels impatient due to the long logging time]

Taps on the icon to see scheduled tasks

Trigger: Device tells with voice message to measure blood glucose

Opens the strip box

Takes a strip

Inserts strip in the glucometer

Pricks finger with needle

Puts blood drop on the strip

Waits for the reply from the device

The voice from device reads it out loud

Puts the glucometer away

Rubs his pricked finger with tissue paper

Trigger: Device tells with voice message to measure blood pressure

Wraps the cuff of the blood sphygmomanometer around the biceps of left arm

Turns the button on sphygmomanometer

Waits while the cuff tightens around the bicep

Waits for the reply from the device

The voice from device reads it out loud

Takes off the hand out of the cuff and puts the sphygmomanometer aside

Turns off the device

Sequence 2:

Intent: Finding guides for diet

Trigger: Blood glucose reading

Opens ipad

Uses different apps at different times

Sequence 3:

(Troubleshoot)

Call son to help [If doesn´t solve then continues]

Intent: To inform the nurse

Trigger: The device not responding

Get up

Get the mobile phone

Calls the nurse

If nurse answers then continues to fix with nurse

Else tries restarting

Uma’s Sequence Model

P7

Sequence 1:

(Regular task-Uploading blood glucose and blood pressure)

Intent: Doing the regular task as advised by the nurse.

Trigger: Time of the day and if at home

Trigger: If forgets called by nurse

Sits in front of the device

Turns it on with the switch

Waiting for auto log in [Feels impatient due to the long logging time]

Taps on the icon to see scheduled tasks

Trigger: Device tells with voice message to measure blood glucose

Opens the strip box

Takes a strip

↓

Inserts strip in the glucometer

↓

Pricks finger with needle

↓

Puts blood drop on the strip

↓

Waits for the reply from the device

↓

The voice from device reads it out loud

↓

Puts the glucometer away

↓

Rubs the pricked finger with tissue paper

↓

Trigger: Device tells with voice message to measure blood pressure

↓

Wraps the cuff of the blood sphygmomanometer around the biceps of left arm

Turns the button on sphygmomanometer

↓

Waits while the cuff tightens around the bicep

↓

Waits for the reply from the device

↓

The voice from device reads it out loud

↓

Takes off the hand out of the cuff and puts the sphygmomanometer aside

Sequence 2:

(Troubleshoot)

↓

Intent: To inform the nurse

↓

Trigger: The device not responding

↓

Get up

↓

Go to phone

↓

Calls the nurse

↓

If nurse answers then continues to fix with nurse

Heidi's Sequence Model

P8

Sequence 1:

(Regular task-Uploading blood glucose and blood pressure)

Intent: Doing the regular task as advised by the nurse.

Trigger: Time of the day and if at home

Sits in front of the device

Turns it on with the switch

Waiting for auto log in [Feels impatient due to the long logging time]

Taps on the icon to see scheduled tasks

Trigger: Device tells with voice message to measure blood glucose

Opens the strip box

Takes a strip

Inserts strip in the glucometer

Pricks finger with needle

Puts blood drop on the strip

Waits for the reply from the device

The voice from device reads it out loud

Puts the glucometer away

Rubs his pricked finger with tissue paper

Trigger: Device tells with voice message to measure blood pressure

Wraps the cuff of the blood sphygmomanometer around the biceps of left arm

Turns the button on sphygmomanometer

Waits while the cuff tightens around the bicep

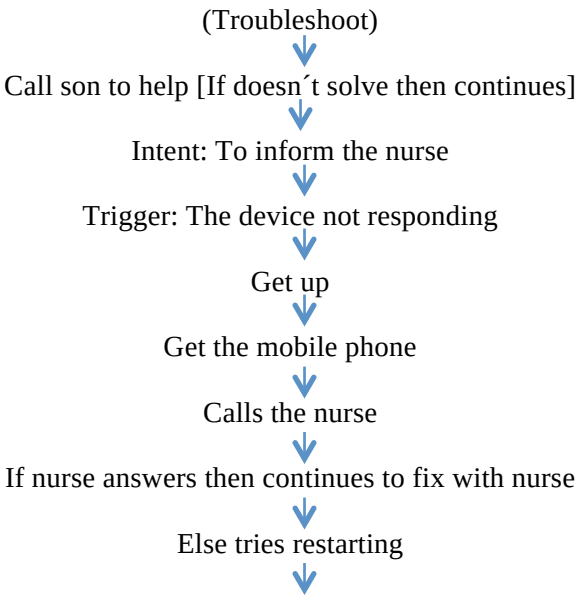
Waits for the reply from the device

The voice from device reads it out loud

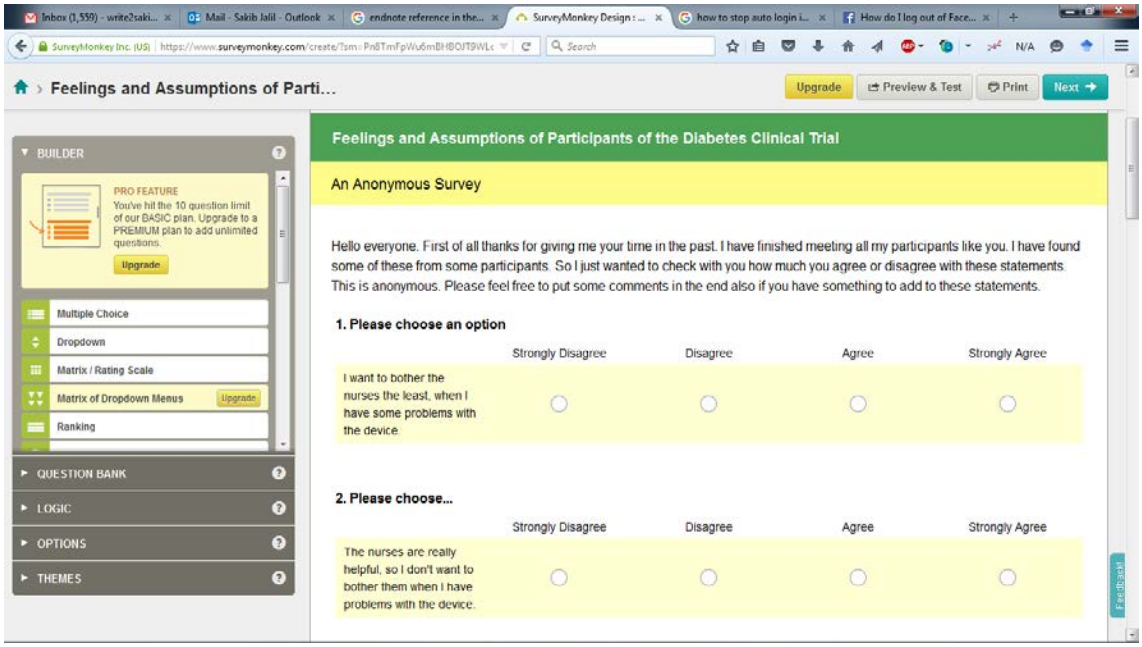
Takes off the hand out of the cuff and puts the sphygmomanometer aside

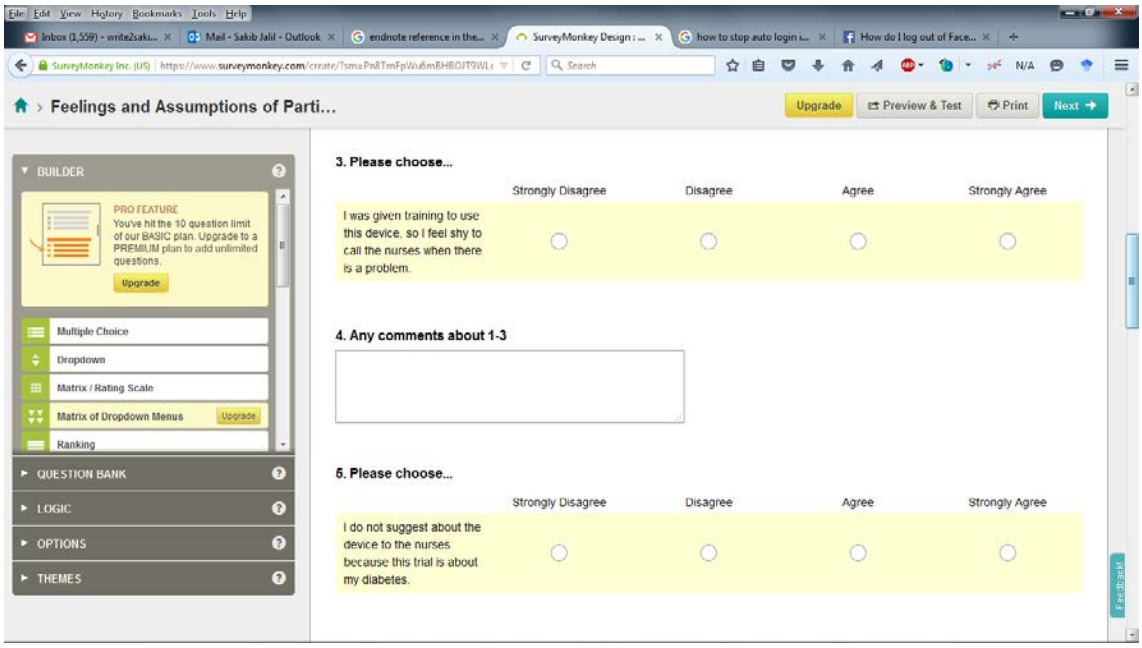
Turns off the device

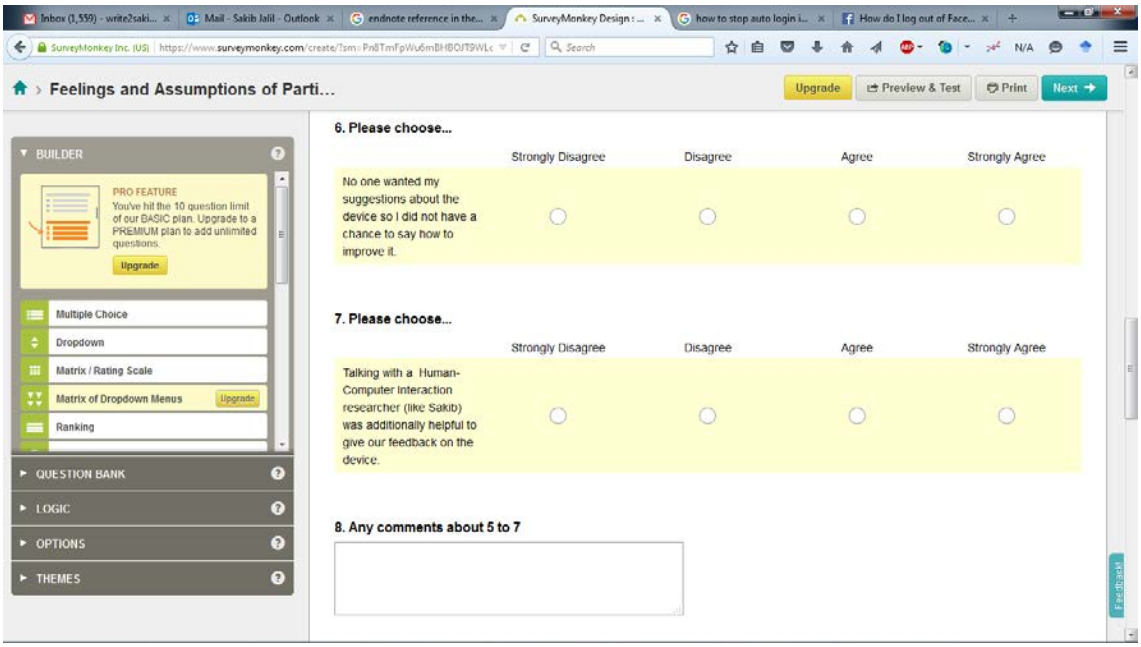
Sequence 2:

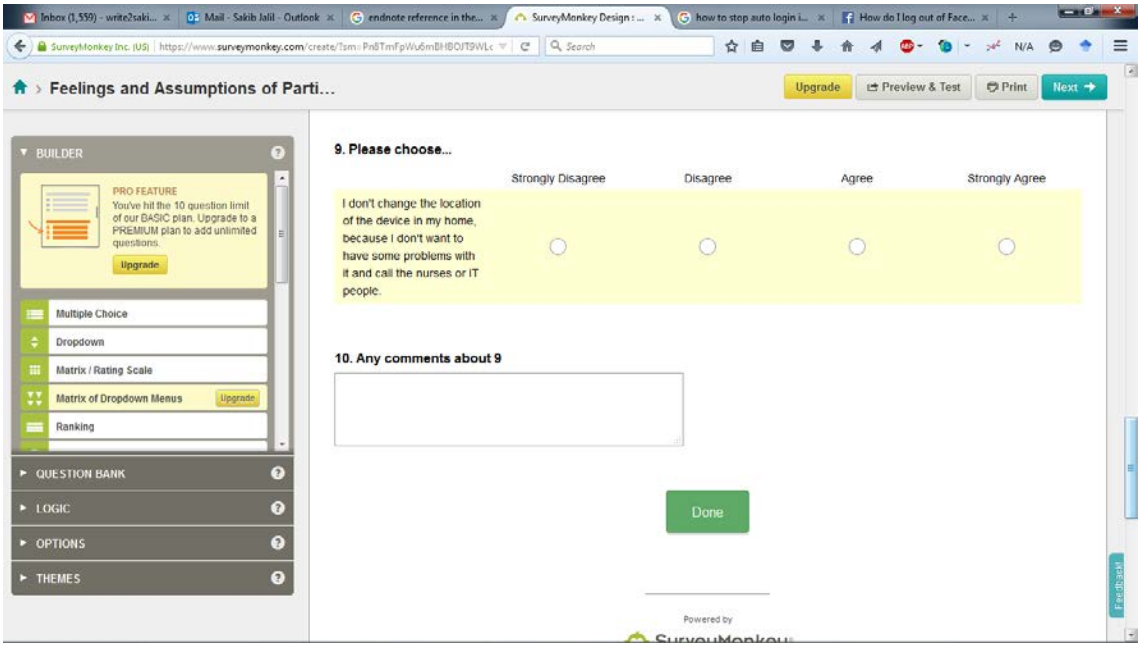

(Troubleshoot)
Call son to help [If doesn´t solve then continues]
Intent: To inform the nurse
Trigger: The device not responding
Get up
Get the mobile phone
Calls the nurse
If nurse answers then continues to fix with nurse
Else tries restarting

Appendix E: Screen shots of survey






Feelings and Assumptions of Parti...
Upgrade
Preview & Test
Print
Next
BUILDER
PRO FEATURE
You've hit the 10 question limit of our BASIC plan. Upgrade to a PREMIUM plan to add unlimited questions.
Upgrade
Multiple Choice
Dropdown
Matrix / Rating Scale
Matrix of Dropdown Menus
Upgrade
Ranking
QUESTION BANK
LOGIC
OPTIONS
THEMES
6. Please choose...
Strongly Disagree
Disagree
Agree
Strongly Agree
No one wanted my suggestions about the device so I did not have a chance to say how to improve it.
7. Please choose...
Strongly Disagree
Disagree
Agree
Strongly Agree
Talking with a Human-Computer Interaction researcher (like Sakib) was additionally helpful to give our feedback on the device.
8. Any comments about 5 to 7
Feedback


Feelings and Assumptions of Parti...
Upgrade
Preview & Test
Print
Next
BUILDER
PRO FEATURE
You've hit the 10 question limit of our BASIC plan. Upgrade to a PREMIUM plan to add unlimited questions.
Upgrade
Multiple Choice
Dropdown
Matrix / Rating Scale
Matrix of Dropdown Menus
Upgrade
Ranking
QUESTION BANK
LOGIC
OPTIONS
THEMES
9. Please choose...
Strongly Disagree
Disagree
Agree
Strongly Agree
I don't change the location of the device in my home, because I don't want to have some problems with it and call the nurses or IT people.
10. Any comments about 9
Done
Powered by
Feedback