

Interactive Symptom Assessment And Collection (ISAAC):  
A qualitative usability study of an electronic tool at the British Columbia Cancer Agency

by

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B.A., University of Victoria, 2001

A Thesis Submitted in Partial Fulfilment of the  
Requirement for the Degree of

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School of Health Information Science

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University of Victoria

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Patient Experience and Usability Testing of an Electronic Tool:  
A Study of the Interactive Symptom Assessment And Collection (ISAAC) tool at  
the British Columbia Cancer Agency

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## **Abstract**

Information technologies are making their way into health care. While they have been primarily in the domain of the health care providers, applications are being created for use by patients. This qualitative study looks at the usability of an electronic tool with a broader view of patient-as-user; the research question asks how this tool stands up to an assessment of the tool's usability. Usability seeks to find out how easy a system is to use, whether the system is acceptable, and whether the system is enjoyable to use. Qualitative description techniques were employed for a broader perspective on the usability results. Key findings indicate that *patients need to be in control of the process of using self-reporting tools; patients want to be able to use these applications at home; computer technologies do not replace the need for human contact in the health care setting; self-reporting assessment tools can give a voice to patients who are otherwise silent; privacy concerns must be handled*. Few studies have attempted to look at patients as they use electronic applications, but if we want patients to use them, tools need to be designed with the patient-as-user in mind, considering diverse levels of functioning among patients.

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And to P05 who passed away shortly after the data collection period. Our interaction moved me in a way I could not have anticipated.

## 1 Background and Context

Studying a technology from the patient perspective can offer insights into how developers can build applications that will not only be easy to use but will be enjoyable enough that the patient will use them on a regular basis. The use of information technologies in health care is increasing as the sophistication of applications improve. Thus, as patients and their family members will likely play a greater role in caring for the patient at home, technologies that keep the patient connected to health care providers will demand excellence in the development of those applications. The British Columbia Cancer Agency recently started a pilot study for an application called ISAAC: Interactive Symptom Assessment And Collection to see if this kind of application would be of benefit in the cancer clinic. With ISAAC, patients can enter their own symptom information into a web-based tool, either at the clinic or from the patient's home. Since this new application required evaluative testing, the research question was as follows:

*How does this tool (ISAAC) measure up to usability requirements, including ease of use, acceptability and enjoyability?*

To study usability with a broader view of patient-as-user, qualitative descriptive methods and usability methods were used. These included observations, interviews, audio recordings of the patient using the tool, screen capture of the software, and later chart audits to compare clinical observations with the data collected from the patient.

### 1.1 Cancer Care Ontario and ISAAC

Cancer Care Ontario has created and implemented the electronic Interactive Symptom Assessment And Collection (ISAAC) for patients to add self-assessment information about their symptoms to their record system. Patients can enter their responses to an assessment scale, either through an on-site computer touch screen or through the web-based application, and the data is sent to the electronic health record (EHR). Since the patient has already provided information about their current symptoms for screening purposes, this provides a computer generated ‘trigger’ if a threshold is reached for the health care professional to more closely assess and address symptom distress. Ideally, this can save time in the consultation between the patient and health care professional by clinicians viewing the patient-entered data just before seeing the patient. Having the symptom scores in front of the clinician can also help to address any concerns about the symptoms the patient may be experiencing, which may otherwise not get addressed.

### 1.2 BC Cancer Agency and ISAAC

The BC Cancer Agency (BCCA), an outpatient cancer centre with five locations in British Columbia, is seeking to implement this technology as a part of routine patient care as well. One of the assessment tools in ISAAC, called the Edmonton Symptom Assessment Scale, (ESAS) is of particular interest to stakeholders at the BCCA. A 2007 audit at the BCCA demonstrated that patients can use the ESAS and that “unearthing individual symptom distress could be achieved by asking patients to fill out an ESAS form on each clinic visit (Syme, 2007, p.8).

The method of data collection in the 2007 audit was paper-based, and implementing a touch-screen application may improve patient care by pre-screening for symptoms and maximizing the interactions between the patient and health care professionals.

Stakeholders at the BCCA sought an evaluation of ISAAC and of patients' view of using the tool to determine whether this type of technology would enhance the quality of care they provide. Prior to the introduction of this tool, patients would only be treated for symptoms if they remembered to discuss it with the health care professional, primarily the oncologist who would refer the patient to the Pain and Symptom Management (PSM) Clinic, or if the patient presented themselves to PSM. This often included filling out the paper version of the ESAS. By providing an accessible screening tool, at home or in the clinic, patients who previously would have had untreated symptoms could now highlight problematic symptoms for their health providers that might lead to better symptom control.

While no formal studies have been done on ISAAC in Cancer Care Ontario, informal surveys suggest patients and the health care providers are extremely happy with the tool (Syme, 2008). Upon finding success with the ISAAC platform, Cancer Care Ontario agreed to extend ISAAC to the BCCA. ISAAC needed considerable modifications to fit within the Provincial Health Services Authority (the health authority that governs the BCCA) and the Cancer Agency itself. Stakeholders at the BCCA then sought funding to acquire the equipment and staff needed to get this project off the ground. While they conducted their own survey assessment, I was invited to conduct my master's research on the ISAAC tool.

### 1.3 Assessment Tools and the Edmonton Symptom Assessment Scale

Busy clinicians are getting busier and there is a trend in healthcare toward practicing Evidence-Based Medicine (EBM). To this end, the number of assessment tools used in the health care setting is on the rise with the assumption that these will help streamline the information needs of clinicians. While it is difficult to track precisely the use of assessment tools, one way to measure is to note how many studies have been published in recent years. A quick search of the literature in five databases (CINAHL, Cochrane Systematic Reviews, Medline, Consumer Health Complete, and PsychINFO) yielded 41,500 hits when “assessment tools” was entered. In the first 300 results, 182 of them were from only the first half of 2009, 114 in 2008, two in 2007 and two in 2006. Certainly there were more studies reporting on assessment tools, but this search demonstrates that such studies are increasing. There are assessment tools for a patient’s functional status, how their bowels are moving, to what degree the patient has bedsores, symptoms, and so on.

In 1991, Bruera and colleagues developed the Edmonton Symptom Assessment System (Bruera, Kuehn, Miller, Selmsler, & Macmillan, 1991), which later came to be known as the Edmonton Symptom Assessment Scale (ESAS). The format was originally a paper-based scale where (ideally) the patient would rate eight symptoms on a visual analog scale (VAS) by placing a mark on a line from 0 millimetres to 100 millimetres. The tool was later expanded to include nine symptoms plus ‘other’, and has been adapted and translated for use in several countries worldwide. If patients are to have a larger role in the management of their

care as well as access to their records, self-assessment tools like the ESAS can provide valuable information to clinicians. This tool in particular is important because of its widespread use in Canada as well as internationally, (Chang, Hwang, & Feuerman, 2000; International Association for Hospice & Palliative Care, 2009; Moro et al., 2006; Rees, Hardy, Ling, Broadley, & A'Hern, 1998; Syme, 2007; University of Montana, 2004; Yesilbalkan, 2008) which will benefit a mobile population that may require these kinds of assessments. Pai and Lau studied a population of men with prostate cancer with web access to their electronic health records and found that “most men prefer to use an electronic [health records and information] system at home” (Pai & Lau, 2005, p.2707). With aging patients either moving to retire or traveling in their retirement, electronic access is possible from any number of settings. As Nekolaichuk et. al. observe, the “increasing frequency of studies published over the past nine years... serve as an indirect marker for the uptake of the ESAS across countries and cultures” ( Nekolaichuk, Watanabe, & Beaumont, 2008, p. 116). In their review of ESAS validation studies over 15 years, Nekolaichuk et. al. point out that none of the studies they looked at “involved the patient’s perspective as a source of validity evidence” ( Nekolaichuk et al., 2008, p.117).

#### 1.4 Usability testing

Usability can be defined as ease of use, how enjoyable a system is to use, and whether or not the system is acceptable<sup>1</sup>. Usability testing is one of the two main branches of usability engineering, which looks at a system’s usability in the context

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<sup>1</sup> The definition I use here is a modification of conventional definitions of usability.

of its use and involves a systematic analysis of that system (Kushniruk, Triola, Borycki, Stein, & Kannry, 2005, p.520). Assessing the usability of health information systems includes determining:

- (a) how easy the task can be carried out using the system
- (b) how easily mastery of the system is attained
- (c) how the system impacts work practices
- (d) identifying what problems users have (Kushniruk & Patel, 2004, p.57)

Because this study only entails a one-time look at the patient users of the ISAAC system, only the ease of use (a) and problems encountered by users (d) will be addressed below. Due to the nature of this study, the analysis will simply be referred to as ‘usability’ rather than ‘usability testing’ since (b) and (c) are not addressed.

### 1.5 Summary

This chapter introduced the subject of studying patient-as-user within the context of a clinical setting. The ISAAC tool was created by Cancer Care Ontario and then shared with the BC Cancer Agency. The assessment tool used in this application is the Edmonton Symptom Assessment Scale, a commonly used clinical tool in multiple health care settings worldwide and one that is familiar to clinicians at the BCCA. An exploratory evaluation was carried out using the methods of usability and qualitative description as a qualitative study. Next is the research problem and rationale for this study.

## 2 Research Problem and Rationale

### 2.1 Research Problem

One of the problems with symptom management is that health care professionals need to *know* that a patient is experiencing symptoms that are moderate or severe in order for those symptoms to be managed. In some inpatient settings, routine evaluation at regular intervals can be completed. Challenges of continuity and communication can characterize the difficulty in managing a patient's symptoms in the outpatient setting. Patients registered at the BC Cancer Agency may not need to come to the clinic regularly for care, but may need help with managing symptom distress between appointments. Particularly for patients who must travel from another community to the cancer clinic, symptom management at home would be preferable to traveling to see the oncologist. Tools like ISAAC by using the ESAS can keep patients connected with their care team and allow the health care professional to monitor the patient's symptoms from a distance. At the moment however, ISAAC is only available in the clinic setting, and in order to fully understand patients' needs in terms of usability of the tool, an evaluation was required.

### 2.2 Rationale

In order for patients to use ISAAC at home, stakeholders needed to know how patients would respond to ISAAC in the clinical setting. They especially needed to know what changes need to happen to the tool before launching the web-

based version. Furthermore, this study looked at patient-as-user with usability testing methods but with a larger qualitative descriptive lens. Stakeholders at the BCCA felt that it would be better for a non-clinical researcher who was not involved in the patients' care to conduct this research, in order that patients would be able to respond candidly about the tool and their experience.

### 2.3 Researcher Bias and Assumptions

Having a familiarity with the workings of the clinic at the BC Cancer Agency proved to be very beneficial. Since I do not have a clinical background, my perspective of what happens in the clinic is probably somewhat different from a clinician's perspective. As a non-clinician but as a person who has spent considerable time as a patient in a number of health care settings while looking through the lens of health informatics, I had an observant and critical eye to the needs of the patient. From my background of working in customer service in the food and public service industries prior to my academic pursuits, I developed people skills and can communicate with many different people on different levels. This helped me to build rapport with and earn the trust of the patients. Because of my own experiences of being a patient, that was my primary focus in this study. As a user of technology and wanting to take part in improving the way health care is delivered with information and communication technologies, I have a vested interest in wanting technologies to perform their intended tasks seamlessly. In addition, with qualitative inquiry the researcher tries to be aware of her/his assumptions in doing any research. My assumptions shaping this study include:

1. I assume older patients who are sick would only be interested in participating in this pilot if the tool was easy, fast, and provided them with some benefit.
2. Because this was a group of patients with a lung cancer diagnosis, I assumed they would be fairly ill and therefore vulnerable. I did not want to overburden the patients who agreed to participate in a cumbersome study when patients and their families were managing a lot already, especially for those patients who had to travel for their clinic appointment.

### **3 Research Approach**

#### 3.1 Methodology

##### 3.1.1 Introduction

This study had as its primary focus the usability of the ISAAC tool while also paying attention to patient's perspectives as end-users. A variety of data collection and analysis methods were employed. Usability testing methods formed the main approaches to data collection and analysis about the tool, while qualitative description (Sandelowski, 2000) techniques provided further detail about the patient's perspectives as end-users. Observing patients using the tool with the volunteer yielded: field notes, an audio recording which was later transcribed, and a video recording of the activity on the computer screen. Patients were interviewed and notes were taken during the interview which was also audio recorded. These methods provided data for assessing (or evaluating) the tool's usability.

As a follow-up, transcriptions were taken from the parts of the patient's record where they interacted with health care professionals around the use of ISAAC on the day of their clinic visit. This provided data to assess whether the clinicians' charting reflected the patients' concerns as highlighted in the ESAS. All sources of data were transcribed into Microsoft Word documents and then uploaded into NVivo 8 qualitative analysis software for coding via content analysis.

The Participants section below gives an explanation of what patients were eligible and how participants were recruited for the study. A description of the

ISAAC process including diagrams follows, as it was a fairly complex process. The study procedures added layers of complexity, and they are explained as well.

### 3.1.2 Qualitative Description

Qualitative description was the analytical approach used. Qualitative description is a method that uses common qualitative data collection techniques (observation, interviews, focus groups) to describe the events in terms of who, what, and where by presenting “the facts of the case in everyday language” (Sandelowski, 2000, p. 336). Sandelowski considers qualitative description less interpretive than other qualitative methods because it does not require a “conceptual or otherwise highly abstract rendering of data” (Sandelowski, 2000, p.335). In terms of the present study, qualitative description is categorically different from case study, grounded theory, or phenomenology. Findings are presented in narrative form with some level of categorization. I chose this method because of the types of data I was collecting and the nature of my inquiry: my study is exploratory and has several different data sources which are well suited to qualitative description. In terms of sampling, qualitative descriptive studies employ any of the purposeful sampling techniques (Sandelowski, 2000 p. 337). In this case, usability testing of the ISAAC tool and the patient’s experience as users were what drove the research question, so qualitative description is a good fit.

Within the larger context of the pilot project for the BCCA, a sample of patients with a lung cancer diagnosis was selected for invitation to use ISAAC. It was purposeful sampling since stakeholders wanted to gather data from patients who were more likely to be experiencing a greater number of symptoms. Within

their sampling of patients I was able to recruit eight people for my study. I invited anyone who met the eligibility requirements, seeking as many participants as possible in the time allotted. Observation and interviews formed the methods of data collection, which also is a large part of the data collection techniques used in usability testing. In the analysis of the data, codes were generated from the data themselves. This was achieved through content analysis, defined as “a research technique for making replicable and valid inferences from texts (or other meaningful matter) to the contexts of their use” (Krippendorff, 2004, p.18). This means that the same results would appear regardless of the researcher (replicability) and that they would happen every time (validity).

### 3.1.3 Usability Testing

In order to evaluate the usability<sup>2</sup> of ISAAC, information must be gathered about the process of using the system (Kushniruk & Patel, 2004, p.57). Some of the data collection techniques involved with usability assessment include a video recording of a representative user performing a representative task (Kushniruk & Patel, 2004, p.59), an analysis of the recording, and inviting the participant to ‘think aloud’ as they use the system (Kushniruk et al., 2005, p.520) as they perform the tasks. Video recording can take many forms, such as recording the user and the computer, recording the user’s hands and the computer while excluding the user’s face, or screen capture, which tracks only the movements of mouse, cursor and buttons pressed on the screen. ‘Think aloud’ means that while the user is using the system, they are encouraged to speak their thoughts as it pertains to their actions so

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<sup>2</sup> defined as ease of use, enjoyability and acceptability of a system

that the observer can bear witness to the user's thoughts. According to Nielsen (Nielsen, 1993), the strength of the thinking-aloud method "is the wealth of qualitative data it can collect from a fairly small number of users. Also, the users' comments often contain vivid and explicit quotes that can be used to make the test report more readable and enjoyable" (p. 195). Observation and interviews often comprise part of the testing as well. Nielsen states that observation is "really the simplest of all usability methods since it involves visiting one or more users and then doing as little as possible in order not to interfere with their work" (Nielsen, 1993, p.207). Some usability testing occurs in a laboratory setting, but typical users in a typical setting are likely to yield more realistic results.

The setting of Clinic C at the BCCA with live cancer patients is the best possible scenario for observation. ISAAC is meant to be a walk-up and use system, much like someone would encounter in an airport for checking in, or using a bank machine. The interface therefore needs to be extremely simple for the patient or family member to use. Nielsen (Nielsen, 1993) notes "[s]ome user interfaces are only intended to be used by novices, in that almost nobody will use them more than a few times" (45).

Usability studies can be conducted in many ways with different types of users. Nielsen recommends three to five users for the 'thinking aloud', observation and interview techniques used within usability testing (Nielsen, 1993, p.224) because it can help to pinpoint misconceptions about the application under

investigation and because it is inexpensive to do. The systems being tested are always on ‘typical’ users defined as someone “whose work is affected by the product in some way, including the users of the system’s end product or output even if they never see a single screen” (Nielsen, 1993, p.73). In health care, the typical users under study have been primarily physicians and nurses, which makes sense given that access to the information about patients was largely in their hands. In the clinical setting for this study, then, the term ‘typical user’ would include patients whether or not they have access to the screen because they are affected by the work that happens on the ISAAC screen.

### 3.2 Ethical considerations and Approval

This study was seeking information about how patients use a tool and patients’ perspectives about particular aspects around the tool. It did not compromise the patients in terms of health outcomes, and was therefore defined as ‘minimal risk’. There were a few minor ethical considerations:

1) Since I am a non-clinical researcher and I am not employed by the BC Cancer Agency, I was required to sign a confidentiality agreement that states I shall not disclose any patient information to an outside source.

2) For the same reasons as 1), I was not allowed to be the first point of contact for patients to participate in my study. Patients first had to be approached by someone, such as a BCCA volunteer or staff member, who has legitimate access to the patient’s personal information before I could be introduced.

3) I may have met one of the participants before but because it had been so long, I remembered neither the details nor the context of our possible previous encounter.

Because this study was a master's thesis and a clinical study, approval was sought and granted from both the University of Victoria Human Research Ethics Board as well as the BCCA ethics board. Final approvals were granted in November 2008.

The BCCA pilot project for ISAAC was scheduled for Tuesday clinics from November 18, 2008 to January 27, 2009. The health care professionals (the Design Team) involved with the pilot decided that I should delay the start of my study until ISAAC had been in use for a couple of weeks while everyone got used to the new workflow. It was during this time that I realized my original recruitment strategy would not work. The BCCA processes its ethics applications through the University of British Columbia (UBC), and UBC's human ethics policy does not allow for contacting patients for recruitment of a study by telephone. With time running out, I had to revise my data collection plan from two sets of observations and interviews separated by six weeks down to one time only. Due to impending deadlines and ethics approval, the study commenced in the last week of January, 2009. Special permission was granted to extend the pilot period by one week for me to be able to complete my data collection. I was seeking between eight and ten participants, eight patients agreed to participate.

### 3.3 Timing

<b>Date</b>	<b>Research Stage</b>
February 2008	Learn about ISAAC as a potential research project. Meet with Jeff Barnett and Ann Syme to discuss what my research could look like.
March 2008	Review literature and start developing proposal
April 2008	First meeting with committee about early draft of research proposal. Revision of study plan.
May 2008	(May Workshop – intensive courses)
July-August 2008	Finalize Research Proposal with committee and stakeholders from BCCA, submit Ethics Application to UVic
September – November 2008	Meetings with Design Team and Lung Team at BCCA, further refinement of study plan, negotiating access to system and development of BCCA Ethics Application. ISAAC launch and early observation of the setting.
December 2008	Preparation and finalize BCCA Ethics Application
January 2009	BCCA Ethics Approval and begin <b>data collection</b> : observation and interviews of patients
February 2009	Finish <b>data collection</b> : observation and interviews. Begin transcription and early coding of data.
March 2009	Coding of primary data sources and <b>gathering of secondary data sources</b> : oncologists' narratives and nurses' notes. Present early findings at grad student conference.
April 2009	Complete <b>gathering of secondary data</b> ; analysis continues; Begin writing early sections of thesis.
May 2009	Present findings at BCCA Research Day and the BC Hospice Palliative Care Association Conference;

Table 3.1 Timing of Research Stages

### 3.4 Description of ISSAC Process

In Clinic C on the second floor of the Vancouver Island Centre, the setting for this pilot and my study, there was a computer touch screen devoted solely to ISAAC. The monitor is 14 inches but without a keyboard or mouse, which most people who are familiar with computers would be used to.

The opening screen on ISAAC asks for a patient's personal health number (PHN). Early in the design stage of this process, there was a debate around whether to use the personal health number or the patient's BCCA identification number, and it was decided that the PHN would be used for a number of reasons: it was already programmed that way; for future interoperability with larger systems it would make more sense to have the more universal number; and patients were far more likely to have their care card (that has the PHN on it) with them than their BCCA number. The first time the patient uses the system, it asks for the temporary password that has already been generated for them by the technical staff. This was usually the patient's initials and the year of their birth. The next screen then prompts the patient to change their password, which has to be entered twice. Since this is a touch screen, there is an on-screen keyboard that the user needs to press. Once the number and password section are complete, there is a button on the side of the screen that hides the keyboard so the rest of the screen is visible.

The next screen shows a disclaimer that tells the patient that any information they provide for this system stays within the (Cancer) centre, the information goes no further, and the patient must press 'continue'.

What follows is an information screen that explains the symptoms and shows an example of what the next screens look like. The user must press 'continue'.

Patients are asked to consider the symptoms they are experiencing that day. The first symptom that appears is the same as most paper versions of the ESAS,

which is 'pain'. The numbers zero to ten appear on the screen, left to right, each in their own bubble. The bubbles range from no colour on the left to quite dark on the right, suggesting the intensity of the symptom. There is also text on either end, saying for example 'no pain at all' on the left to 'worst possible pain' on the right. Below the number bubbles is a text box that clarifies a bit more about the symptom. For example, 'tiredness' may not be so clear, so in the text box it says "decreased energy level (but not necessarily sleepy)". For each of the symptoms the patient must press a number, which changes colour from a shade of blue to red, and then 'continue'.

Once all of the symptoms have been filled in, there is a screen that asks who the ESAS was filled in by – either the patient or by the caregiver/family member.

A histogram then appears with a listing of all the symptoms and the number that the patient indicated for each symptom that day. At this point the patient can go back to change any of their symptoms by clicking on (or rather, pressing) that symptom on the screen. Once the patient is satisfied the numbers are correct, they press 'done' and are led to the long-term histogram. If patients use this tool over time, they can see the rise and fall of numbers for each symptom which can indicate a pattern or how symptoms were managed. Presently this is done by hand, by a nurse, who fills in boxes with a pencil, but not with any regularity; at the moment it is only completed when the patient presents to the Pain and Symptom Management Clinic. From this screen there is an option to print in the upper right corner, though

the button is not clearly indicated. The print dialogue box appears, the patient can print as many copies as they like, then press 'Print'.

On the other side of this same screen in the upper left corner is the 'Quit' button. At the time of the study, the system would automatically log out after 10 minutes unless 'Quit' was pressed.

A printer sits next to this ISAAC touch screen, a simple bubble jet colour printer. ISAAC was only used on Tuesdays during this pilot period, and neither the touch screen nor the printer was turned off when not in use.

When the patient and volunteer had finished using the tool, I retrieved the external keyboard and mouse to bring up the CamStudio program to stop the recording of screen capture. I also turned off the digital audio recorder.



Figure 3.1: *Clinic C at the BC Cancer Agency.*

### 3.5 Study Procedures

Data collection happened over two days a week apart. The clinic was sometimes empty and other times full, providing a range of noise and activity. Because I was in a rush to recruit as many patients as possible, the pilot period was extended so I could collect my data. There were times when I was observing or interviewing one patient when another potential patient came to the clinic. Due to the time constraints of keeping clinic flow uninterrupted however, I was not able to

catch them for my study. There was a lot of paper-shuffling as I had consent forms, interview schedules, observation templates, and the schedule of patients coming to the clinic that day that I had to keep track of. I also had to stay on top of recording screen activity as well as the audio recordings. I was challenged in keeping track of all this physical information while making sure I was communicating with the volunteers and the patients, while also being present for those patients who needed to have someone listen. The volunteer who worked the morning shift [V01] was a retired school teacher. She was with me for six of the eight patients. Another volunteer [V02] worked the afternoon shift. [V02] was a retired nurse and assisted me with the two patients on the afternoon of the first day. Both of these volunteers had been with the BCCA for more than five years and enjoyed interacting with patients.

Once the consent form was signed by the patient, I set up the screen capture software, started the audio recording on the digital audio recorder, and sat nearby to make notes on my observation. The volunteer provided instruction on how to use the ISAAC tool. This step took between five and 18 minutes, depending on the patient and their symptoms.

After the patient's visit with the oncologist, the patient returned to the waiting room to be interviewed by me about the tool. Each interview took between five and 10 minutes. One patient was unable to stay for an interview after her appointment because she had to drive several hours to get home up-island. We made arrangements for me to call her at home in the evening and conduct the interview then.

After the patients' visit to the clinic, I reviewed the patients' records for any information pertaining to their symptom assessment and treatment. In particular, I reviewed the narrative from the visit with the oncologist and Nurse's Notes for information around pain and symptom management. This was to cross-check to see if what the patient perceives to have happened corresponds with the way the health care professionals documented it.

I was aware before I began this study that since I was looking at patients with lung cancer, that it was possible, if not likely, that at least one of the patients in my study would die during the study period. When reviewing the patient charts after my primary data collection, I came across the chart for 'P05' which had a blue sticky note on it that said "deceased". It was this particular patient that I had connected with the most; she had fallen through many cracks in the health care system and was thankful for the chance to be heard so that her experience may help others.

### Patient Flow

Below is a schematic of patient flow before ISAAC, with ISAAC, and finally with ISAAC and my study.

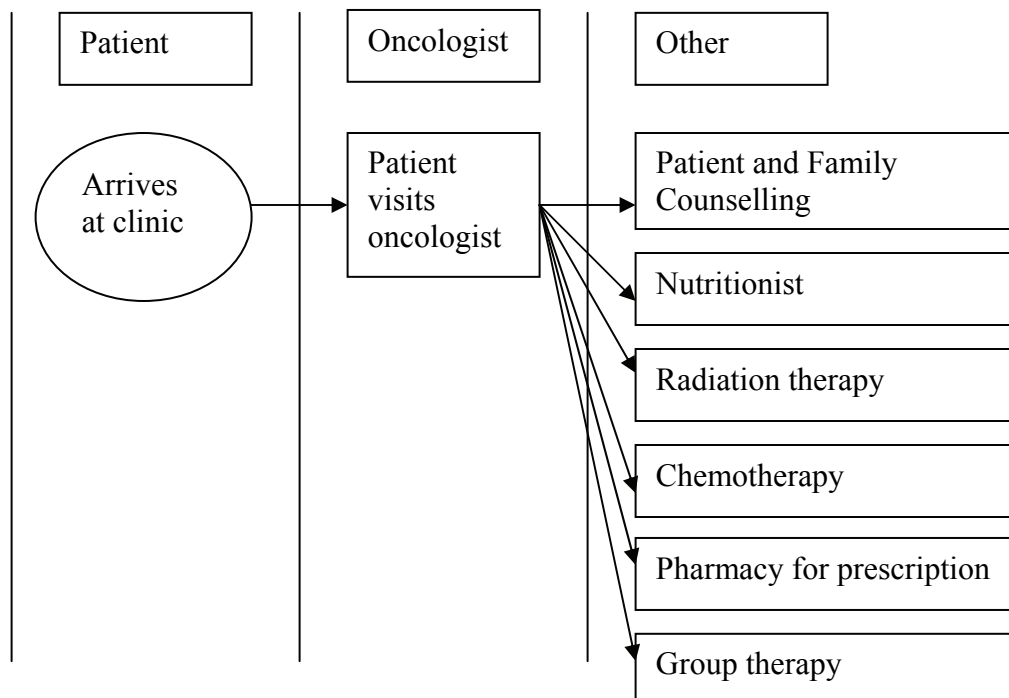


Figure 3.2: before ISAAC

Before ISAAC, a patient would come for their appointment and then do one or more of the following actions that could include having chemotherapy or radiation, seeing a nutritionist, going to the Pain & Symptom Management Clinic (PSMC) and so on. Patients would only attend the PSMC if self-referred or if the oncologist referred them.

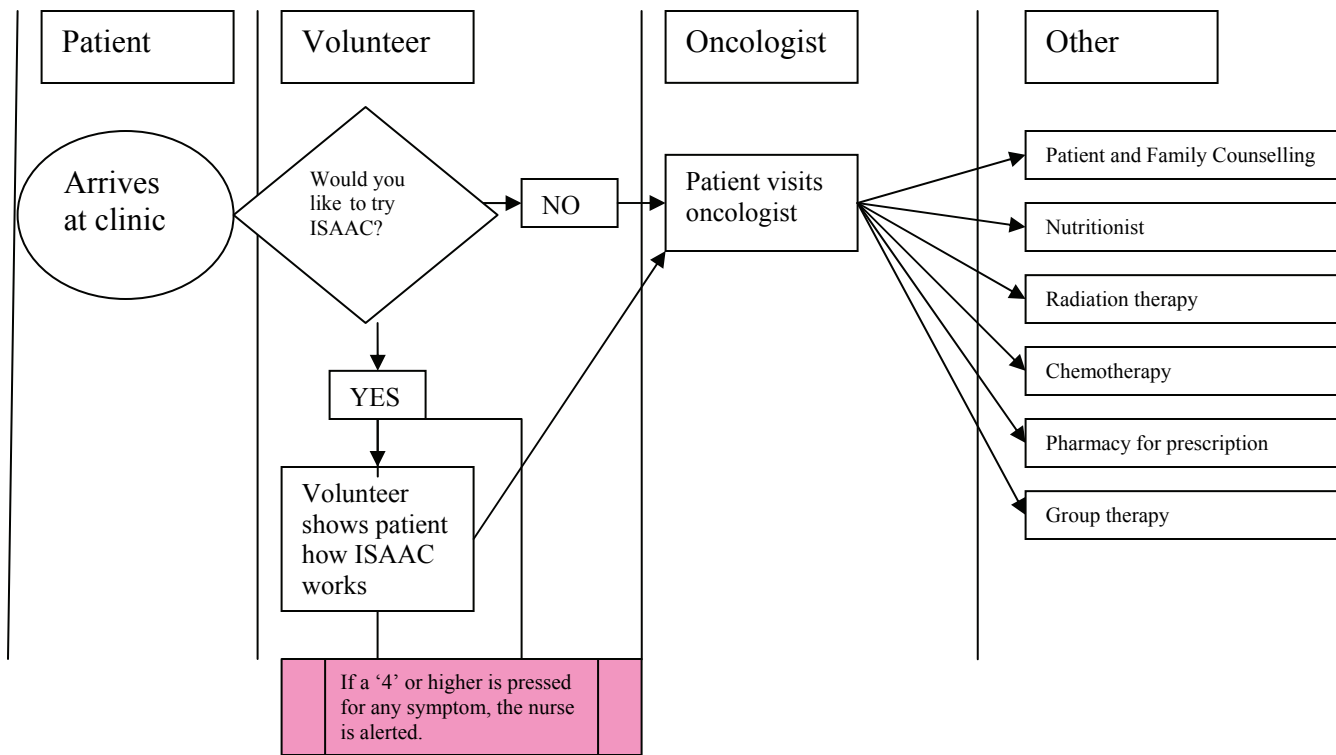


Figure 3.3: with ISAAC

In this scenario (Figure 3.3), after the patient checks in with the clerk, the volunteer approaches the patient and invites them to participate in ISAAC. If the patient declines, the first scenario resumes. If the patient says yes, this may add an extra step or series of steps if the patient enters numbers for symptoms that are above the current threshold, which is a four out of a possible ten. The nurse would either approach the patient before or after the consultation with the oncologist, depending on time, or phone the patient at home.

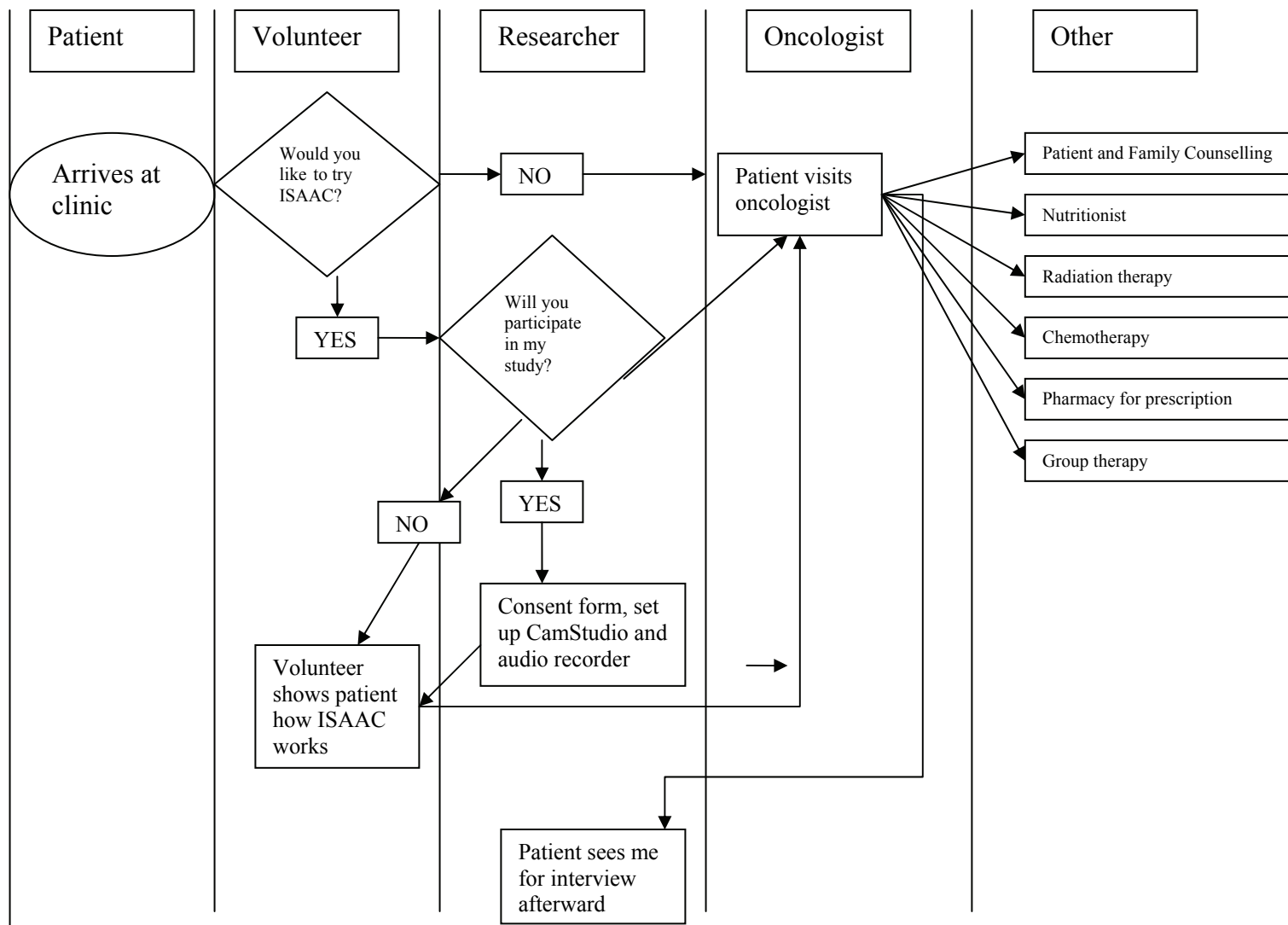


Figure 3.4: with ISAAC and my study

The introduction of my study into this process adds several more layers of complexity. After the volunteer approaches the patient and invites them to use ISAAC, I had a small window in which to also invite the patient to join my study. This had to be done in person since due to the Research Ethics Board at the University of British Columbia through which the BCCA does their ethics

processes, recruitment must be done in person for any study. So in a sense it was surprising to the patient, who had been telephoned beforehand about coming in early to use ISAAC, participating in my study further complicated the matter. This did not seem to deter many patients, however. One patient read through the consent form in its entirety and said he was not eligible because he was not a lung cancer patient. Most patients were content to have me summarize the consent form, which was five pages long, but two patients read it all the way through.

Only one patient [P01] forgot to return after the visit to the oncologist, but it may have been due to the bad news he received from his oncologist about his prognosis. I could not have known that at the time but reviewing the oncologist's narrative revealed the patient had been given only a few months to live.

### 3.6 Participants

All adult (age 18 or over) patients with a lung cancer diagnosis who received treatment or follow-up at the BC Cancer Agency Vancouver Island Centre (Victoria) were identified by the ISAAC Coordinator. Lung cancer patients in particular were chosen because as shown in the 2007 audit, they are among the most symptomatic (Syme, 2007). Purposeful sampling was used because "the ultimate goal" for sampling of this nature, "is to obtain cases deemed information-rich for the purposes of study" (Sandelowski, 2000, p.338). Patients who agreed to participate were English-speaking, over the age of 18, and were willing to be interviewed and audio recorded.

Patients were telephoned the day before their regularly scheduled visit with the oncologist by the ISAAC Coordinator and asked to come in 30 minutes early if they were interested in using a new electronic tool to track their symptoms. Once the patient checked in with the reception clerk, the ISAAC volunteer invited the patient to come use the tool. Once the patient agreed, the volunteer introduced me and I invited the patient to participate in this study. I explained that the study would entail my observing them while the volunteer walked them through the ISAAC tool, that the screen activity and the conversation would be recorded. I told the patients that I would need to see them after their oncologist visit for a brief interview, that the interview would be recorded too. Then we went through the consent form and I had the patient sign. The patient was given a copy of the consent form. Patients were assured that any information they provided was anonymous and confidential. Please see Appendix D for a summary of characteristics of the patients.

### 3.7 Data collection

In total there were seven sources of data: 1) audio recording of the volunteer walking the patient through the tool, 2) software capture of screen activity, 3) my observation notes, 4) my interview notes, 5) audio recording of the interview, 6) the patient record including ESAS score, nurses' notes and oncologists' narrative and 7) my research journal for any data not captured by other sources. The first six sources were transcribed using Microsoft Word; the last was summarized and transcribed so that all could be included in the qualitative data analysis software, NVivo 8, qualitative analysis software that allows for organizing and coding data.

<b>Data</b>	<b>How it was collected and processed</b>	<b>How it was analyzed</b> (All transcripts were uploaded to NVivo 8 Qualitative analysis software)
Video of screen activity	CamStudio screen capture software then transcribed into a play-by-play account	Screen activity and timing of when buttons were pressed were recorded but proved to be less helpful than the audio recordings. Impossible to know who is pressing the buttons.
Audio file of patient using ISAAC with volunteer	Digital audio recorder, file transcribed	Codes emerged from the text . Themes emerged from the codes
Observation field notes	Field note journal, notes transcribed	Same as above
Interview notes	Interview schedule, notes transcribed	Same as above
Audio file of interview	Digital audio recorder, file transcribed	Same as above
Patient record: ESAS score	Spreadsheet provided by ISAAC coordinator	Supplementary data. Not analyzed itself but supported emerging codes and themes by providing background information.
Patient record: oncologist narrative	Accessed through CAIS, the Cancer Agency Information System <sup>3</sup> . Transcribed	Used to compare with the audio recording of observation and the interview.
Patient record: nurse notes	(Paper) chart request <sup>4</sup> . Transcribed.	Compared with observation and interview.
Other environmental and	My research journal, transcribed into notes	Mostly used as support for codes and themes that emerged during

<sup>3</sup> CAIS does now allow for cutting and pasting of text, so I retyped the text on the screen to a Word Document.

<sup>4</sup> Nursing notes at present are handwritten into the paper chart. I transcribed this text into a Word document.

Observational notes		encounters with patient. In a few cases, provided some background data from a non-recorded conversation with the patients.
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Table 3.2 Summary of data, data collection, and data analysis techniques

Of the above techniques for data collection in Table 3, the usability component for this study included the following data sources:

1. screen capture software (instead of video recording) using CamStudio
2. audio recording using a digital audio recorder
3. observation
4. think aloud<sup>5</sup>
5. interview which was audio recorded

A keyboard and mouse were brought in for setting up the CamStudio screen capture software, but then hidden during the volunteer's interaction with the patient. After starting the recording of the interaction with CamStudio, I also began the audio recording with a separate digital audio recorder. From here the volunteers took over with the ISAAC tool on the screen and walked the patients through how to use ISAAC. Patients were encouraged to 'think aloud' as they were interacting with the tool.

An observation template was used to record date, time of day, location of touch-screen, whether the patient is alone or attended, and any other remarkable data that cannot be captured with the software capture tool or the 'think aloud'

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<sup>5</sup> Think aloud was embedded in the observational audio recording.

audio recording. I took notes during the observation and in some cases, afterwards as well.

When patients returned from seeing the oncologist, I started the digital audio recorder once more and went through the interview questions. The opening question was some form of “what did you think of the tool?” Further questions asked if patients would use a tool like this at home, were there any specific challenges or problems they had, and if they had any ideas or concerns regarding applications like this being used in their health care. Nielsen notes “[i]nterviews are well suited to exploratory studies where one does not know yet what one is looking for, since the interviewer can adjust the interview to the situation” (Nielsen, 1993, p.211).

The above techniques also served for the qualitative descriptive component of the research, which therefore served a dual purpose. Further data collection included reviewing the patients’ charts at a later date to compare the oncologists’ narrative and the nurses’ notes to see if they reflected what my contact with the patient had demonstrated.

### 3.8 Data Analysis

Most of the data for this study required content analysis, which is, as Sandelowski notes, is “the strategy of choice in qualitative descriptive studies” (Sandelowski, 2000, p. 338). A step-by-step content analysis process was followed drawing from Neuendorf’s (2007) content analysis scheme (See Appendix C for Content Analysis Scheme).

According to Sandelowski (Sandelowski, 2000),

qualitative research is generally characterized by the simultaneous collection and analysis of data whereby both mutually shape each other. Qualitative content analysis is similarly reflexive and interactive as researchers continuously modify their treatment of data to accommodate new data and new insights about those data. (p.338)

During the process of coding the data, a number of themes emerged over the span of several patients. For some, a theme only arose with one patient but they speak to larger problematic issues in the area health informatics in general, and electronic health records in particular, and therefore I raise them as themes in their own right here. For example, privacy came up as an issue for only one patient but it is one of the greatest challenges health informaticians face when trying to build systems for charting and therefore it is included a theme.

All transcripts, audio files, and CamStudio videos of the screen captures were uploaded to NVivo 8 qualitative analysis software. In reviewing my notes beforehand and during the transcription process, some common themes emerged prior to using this software so I already had an idea of what to code for. Once all documents had been uploaded, I went through each of them systematically and created codes as I went. For example, when I encountered 'keyboard buttons' in P01, I created this as a code. When I encountered 'keyboard buttons' in another patient, it was already there. In going through each transcript, some parts of text fit

into codes that had already been created while new ones emerged. Privacy, for example, did not arise until P07.

Gathering data from the patient record was not as simple as straightforward transcription. As noted above, the Cancer Agency Information System (CAIS) does not allow for copying and pasting of text, so I had to manually retype the text from CAIS into a Word document. Similarly, the nurse's notes at present are only charted by handwriting onto a paper chart, which I had to request from the BCCA's patient records department. Legibility posed little difficulty except in the case of a few words.

The information from the screen capture video through CamStudio proved not to be very helpful. It was clear that the buttons were being pressed and progression through the system was occurring, but there was no evidence of who was pressing the buttons – either the patient or the volunteer. The audio recordings of this process proved to be much more useful in terms of data richness.

## 4 Study Findings

### 4.1 Introduction

To use the criteria from usability assessment, the results below are categorized into Ease of Use, Acceptability, and Enjoyability. Each category consists of themes generated from the data. Not all results fit neatly into these categories, however, and that will be explained below.

Categories	Themes
Ease of Use	Understanding computers Numbers not descriptive Specific usability problems
Acceptability	Attitude of teacher Patient owning experience Progress over time Honesty
Enjoyability	Rapport building Sense of humour Technology bias Privacy
	Patient experience not reflected in chart

Table 4.1 Categories and Themes

In terms of Ease of Use, it was clear that the user must already have an understanding of how computers work in order to use the program as it was. It also

became clear that the numbers themselves were not enough to describe symptoms. Finally, a number of software and hardware-specific problems arose during this pilot study.

Regarding Acceptability, the attitude of the teacher appeared as a potential area for improvement. Patients need to be the ones actually interacting with the tool in order to learn how to use it. Over time with multiple entries, patients could see their progress. Honesty appeared in two conversations as a potential problem.

Enjoyability could prove to be a large factor in whether a system is used regularly. On the positive side, patients who learn to use the tool with someone they have built a rapport with can result in an enjoyable experience. A sense of humour seemed to facilitate enjoyment of the process of learning. However, on the negative side, if a patient-as-user already has a bias against technology, they may not enjoy using it. Furthermore, if a user has concerns regarding privacy of their information, they may be less likely to enjoy using the tool.

Finally, the results demonstrate that for the patient who had ‘fallen through the cracks’ of the health care system, we can learn powerful lessons. This includes how having user-created content like symptom information can be an invaluable source on which health care practitioners base their decisions.

Transcribing the audio and video files took approximately 30 hours. Many of the files to be transcribed were small, resulting in less time. I transcribed the recordings myself. With the audio files, I listened to the recordings in my headphones while I repeated the dialogue, including who was speaking, into my voice recognition software. This process had two benefits: it was a lot quicker than simply typing the audio files and it saved my wrists and hands from repetitive strain injury.

#### 4.2 Ease of Use

A program or application is easier to use or learn to use if we have used a similar application in the past. Windows users may have some difficulty with using Mac computers and vice versa, but the principles of computing are generally similar. For those people who have for whatever reason not gained experience using computer applications, the processes are not yet 'intuitive'. Understanding the principles behind applications can guide the user in how to use the application, which can help when, for example, the number one is required to enter may require some explanation. In this way, the number itself may not be descriptive of the symptom to be represented or the symptom for which the number is required may necessitate further elaboration. Finally, a number of specific problems arose with the hardware and software that proved to be most challenging for the volunteers who were trying to teach the patients how to use ISAAC,

### Understanding computers

Basic knowledge of how computers work seems to be required in order to use ISAAC as it is. In particular, one needs to have knowledge of how a touch-screen computer works, such as a tablet laptop. The regular plug-in keyboard and mouse were removed so that patients and volunteers could get used to using a touch screen or kiosk, and the volunteers referred to the tool as being 'just like a bank machine' or 'just like a microwave'. Problems arose, however, when the keyboard was required on the screen to enter the patient's personal health number and password. There was a button on the screen that could be pressed to retrieve or hide the keyboard, but due to the nature of the sensitivity of touch screens, sometimes this keyboard button was moved almost off the screen and the volunteer seemed unaware of how to retrieve it. I had to drag the keyboard icon from the corner back to the place where the volunteers were used to having it. Furthermore, there was no indication on the button itself what its purpose was: one simply had to know already that that was the button that summoned or hid the on-screen keyboard. In another situation, the page on the screen was larger than the monitor could hold and a scroll bar appeared on the side. Most people would simply use their mouse or an arrow button to scroll down to see all the information but in this case, neither of these were available. I had to come in and use my fingernail to scroll down on the screen. Further details about the keyboard are mentioned below in the 'specific usability' section.

### Numbers not descriptive

There was some confusion a few times about what the numbers mean. One patient rated a four or five on Pain, and was told to do so because the ESAS was supposed to represent ‘the whole patient’, but this patient had broken his wrist two weeks earlier. His pain was unrelated to his cancer and was being treated by his family doctor. He could simply have put a ‘0’ or ‘1’, but since ISAAC is being used as a screening tool, hitting the threshold meant that his cancer care team now knew about his broken wrist. This is more of an issue with the ESAS rather than ISAAC.

There was a lengthy discussion between P06, her husband, the volunteer and even myself about the difference between being tired and being drowsy. In the paper version of the ESAS, all the symptoms are on the same page so it is easy to glance down and see what else will be addressed. With ISAAC, however, each symptom has its own screen and it is not until the end that all symptoms are displayed on the screen at the same time, for review. Below is the discussion about drowsiness and tiredness:

Volunteer: tiredness, are you feeling whole body tired?  
 P06: no, well I’m tired  
 Volunteer: you are tired  
 P06: yeah, I get fatigued very quickly  
 Volunteer: very quickly... OK now how im-important, how much of the problem is that? Obviously it’s not a zero and it’s not sort of  
 -  
 P06: it’s about a, a three  
 Volunteer: a three, so let’s poke  
 P06: let’s press three beep beep

(and later)

- Volunteer: this drowsiness where you're sort of dropping off to sleep sort of always falling asleep for easily mapping half a dozen times a day
- P06: I can't sleep
- P06's husband: it varies though you get tired during the day
- P06: I get tired
- Volunteer: but you don't sleep
- P06: but I don't sleep. I, I you know, I read and I think I might even doze for a, a very short time but I don't
- Volunteer: it's not...
- P06: I don't get any relaxation from it
- Volunteer: OK so then you... This is a difficult one isn't it then Stacey...
- P06's husband: well being drowsy and sleepy are two different things
- Volunteer: yes being not able to sleep is yes it's actually it is a concern isn't it
- P06: yes that's why I take Ativan at night and just, because I've stayed up literally, I didn't take it a couple of times and I had a hard time getting to sleep and when I got to sleep I didn't stay asleep. It's you know, and every 2 to 3 hours I would be awake.
- Volunteer: so I think this is cause for concern that you're drowsy but you would prefer to be drowsy enough to have a good night's sleep
- P06: yes ... but you know I've got arthritis too... Severe rheumatoid arthritis
- Volunteer: so that would cause a sleep problem
- P06: well that would cause a fatigue problem

For the patient who would potentially be filling ISAAC out at home or by themselves in the clinic, this kind of conversation may not have ensued. Further – depending on the numbers entered, this is exactly the kind of conversation the patient would be having with the nurse if ISAAC is to be used as a screening tool.

The issue of numbers not being descriptive are not a problem with ISAAC per se, but with the ESAS. While not the particular subject under study, a number of studies have found shortcomings with the ESAS (Garyali et al., 2006; C. L. Nikolaichuk et al., 1999; Rees, Hardy, Ling, Broadley, & A'Hern, 1998;

Stromgren, Groenvold, Pedersen, Olsen, & Sjogren, 2002), and in particular that it is not an effective screening tool for depression or anxiety (Vignaroli et al., 2006), a common symptom in cancer patients.

### Specific Usability Problems

Prior to commencing my study a number of issues arose for which the volunteers developed workarounds. The keyboard on the screen was particularly problematic in terms of the user's ability to press the button once and have the output only produce the one character the user intended. For example, when pressing the numbers to enter the personal health number, if a user entered '9', sometimes '99' would register. The keyboard on the screen was large enough to block information behind it, and while there was a small button that would hide the keyboard, there was an instance [P04] where the button looked like it was being pressed (according to the screen capture recording) when in fact the pointer was not more than 0.5 centimetres away from where the button *should* have been pressed.

As number of these problems were discovered prior to the study commencing during the proof-of-concept project, a detailed list of these problems is included as Appendix F. The problems that arose within the context of this study are summarized below in Table 4.2

<b>Hardware or software</b>	<b>Main issue</b>	<b>Specific Problem</b>
Hardware	Touch screen	Screen too sensitive
	Printer	Delay in printing

Software	Keyboard	Size (too small)
		Location (in the way)
		Hide/unhide
		Sensitivity
	Printer	Print dialogue box
		Need for keyboard if more than one copy of histogram is wanted
	Login	Patient must be registered to participate
	ISAAC	Button size (too small)
		If one symptom needs to be changed, user needs to cycle through all the remaining symptoms again instead of changing the one symptom and jumping to the end

Table 4.2 Specific Usability Problems

Hardware: touch screen

This was a problem that spans both the touch screen itself and the size and location of buttons from the software. The need to press the buttons precisely in a certain place was not clear, and the volunteers responded by using force. It seems they found force effective, but not for the right reasons. I hypothesize that the reasons they found the use of force to work is not because the screen needs it, but because they were not pressing the buttons accurately. The patients had less difficulty pressing the buttons. This was interesting since it was their first time using it, whereas the volunteers had been using ISAAC every Tuesday for ten weeks. Because there was no video of exactly who was pressing the buttons, I had to rely on my observation and the audio recordings, so I could not say exactly how much the volunteers were using force compared to the patients. In speaking with the technical staff after the data collection period, I learned that even though these particular touch screens were less than ideal, they had to suffice for the moment because of their cost. The key to getting the most out of these touch screens in the future then is making sure the users understand how they work.

### Printer: delay in printing

We are getting used to computers and their accessories responding within milliseconds these days, but by comparison to the average office printer, the printer attached to ISAAC was particularly slow. Furthermore, the printer was left on for the time between the Tuesday clinics where ISAAC was introduced, and had settled into hibernation while not in use. This meant that when the first patient was put through, the printer had to be turned off, then turned on again, and recalibration took more time. The printing of histograms for subsequent patients often took several minutes also. Since the primary intended user for the printout is the clinician (the printout is attached to the paper chart for the oncologist to view before seeing the patient), the page could be networked to print in the clinic reception area. If this kind of connectivity is available, this could speed things up rapidly, but would require an alert on the screen that informs the patient that if they would like a printout, they could ask at the desk.

### Printer: dialogue box

On the last screen of ISAAC, there is a button that says “Print”. When this button is pressed, the Windows dialogue box appears and waits for the user to select how many copies and press “Print”. For a walk-up and use tool, this makes little sense. A person needs to have an understanding of how to print (particularly with a Windows machine) in order to negotiate this section. In most cases, if not all, the volunteer took over the process of printing. If more than one copy of the histogram was wanted, the on-screen keyboard needed to be recalled so that a button could be

pressed. This has changed since my study, and one copy prints automatically (extra copies need to be photocopied). As noted above, the single printed copy is supposed to be attached to the patient's paper record, but the patient might not remember to do this. To save a step, as suggested above, route the printing to go to the reception printer for attaching to the chart.

### Keyboard

Because the design of the ISAAC platform was meant for a walk-up kiosk in a cancer centre, a keyboard that would appear or hide when needed was figured into the design. The program for the original user, Cancer Care Ontario, needed to be modified for the BC Cancer Agency, so technical staff obtained a free on-screen keyboard program and installed it into ISAAC. While a step in the right direction, this keyboard had its challenges. The size of the keyboard was difficult for those whose vision was less than perfect. When I interviewed P08, he started talking about the keyboard even before I began asking him questions, he said he was thinking about the keyboard while waiting for the oncologist. From the interview:

...around the keyboard that the letters on the keyboard for those - I don't have my glasses on today so I'd have an easier time if the letters were larger and probably in capital rather than lower case

There was also difficulty with when the keyboard was needed or not needed: there was a small on-screen button on the side that brought up or hid the on-screen keyboard. This button was movable, however, so when the volunteers were overly forceful with the pressing of the keyboard button, it would migrate towards the edge of the screen and they did not know how to get it back. When I was there, I was able to drag the keyboard button back to its usual place on the screen. Again, a

working knowledge of how computers work in general was required to get this piece functioning. The keyboard was needed initially to enter the patient's health care card number and for their password, and then it was not needed. There was no explanation about how to hide the keyboard so if there was no one teaching a user about this tool, everything would have stopped here. In the redesign process, the keyboard now appears and disappears automatically when needed. The new keyboard also has much larger buttons and the keyboard itself takes up most of the screen.

### Login

Patients with lung cancer that were coming to the clinic for treatment were identified beforehand, and a temporary password was assigned so those patients could get into ISAAC. At the beginning of each Tuesday during the proof-of-concept phase, a list with these patients was printed out for the volunteers who would be teaching them how to use ISAAC. There seemed to be some mix-up, however, with patients who should and should not have been on the list. One patient was on the list but was not a lung patient (he was a prostate patient, he told us this after he read through the consent form). One patient who was on the list and who had agreed to participate in my study had an incorrect login. An error message came on the screen that said "you are not eligible". For this patient in particular, this may have added to the metaphorical salt to the wound – this was P05, who will be described in detail below, felt abandoned by the health care system. Log in errors are a common error for many applications, whether the user has forgotten their log in and/or password, or if that password needs to be changed fairly frequently (staff

at the BCCA are required to change their password every six weeks), so this problem is not that surprising. It is incumbent upon those staff who are setting the patients up in the system to take care that the patients are eligible and for that log in information to be correct.

#### ISAAC: buttons

Once the patient was past the login with the care card number and password, the keyboard was hidden. This left only the 'continue' buttons or the numbers for the ESAS that needed to be pressed. These buttons were about the size of a dime, or the tip of a person's finger. The same problems with the keyboard occurred here – the volunteers used force and suggested that the patients to the same; it was difficult to see for those patients whose vision was not 20/20. Again, the button size needs to be changed but for this application, I was told, there is a lot of difficult coding to change this problem.

#### ISAAC: changing numbers

If a patient needed to go back to change one or more of the numbers, as with P06, at the second to last page that showed the results table, the patient could press the button for the symptom they needed to change. However, once they were back at the individual symptom page, the patient had to press 'continue' all the way to the end – there was no way to simply jump back to the end. Given the response time of some computers, this could take a long time, especially if a patient was accessing it from home on a dial-up connection. This seems to be a question of design. As noted above, the paper version of the ESAS has all the symptoms on one page, but

for some reason, in ISAAC they each have their own page. This problem will also require a large amount of recoding to fix this problem, and as I understand it, there is not yet agreement to what the optimal form should look like.

### 4.3 Acceptability

Having an enthusiastic teacher can enhance the learning experience and impact how likely someone is to accept a particular technology. There must be an appropriate moment where the use of the application is given to the hands of the learner or user. Once the patient-as-user uses the application over time, they are able to see their progress or at least progression of symptom management. Patients may find themselves faced with the challenge of honesty, whether or not they are honest in their self-reporting of symptoms.

#### Attitude of teacher

Early findings of the audio recordings and transcriptions revealed a somewhat negative attitude towards the technology by the volunteers who were teaching the patients to use ISAAC. By that point two months into the pilot, the volunteers had developed a number of workarounds since the beginning. The touch screen proved to be a problem in particular, since the screen was either too sensitive or not sensitive enough. For example, the words the volunteers used to indicate to the patient that they needed to press a button on the screen were often violent in nature. Words like ‘stab’, ‘jab’, ‘poke’, ‘thump’, and ‘bang’ appear in almost every transcript during the observation period. There was a problem with the on-screen

keyboard – a usability issue – but even after two months of using the tool the volunteers were still having difficulty making it appear and disappear when necessary. The largest problem was the printer, particularly for the first patient of the day, since the printer had been left on and unused since the previous week. This caused significant time delays and served as an opportunity for the volunteer to complain about the technology. While this complaining was negative, it also seemed to serve as a means for rapport building, since all of the patients in my study had had some sort of interaction of this nature before with computers, and allowed the patients to sympathize with the volunteer. The usability problems with the hardware then were reflected in the workarounds and the attitudes of volunteer-as-teacher.

#### Patient owning experience

One of the biggest problems identified in the audio files data was that the volunteers seemed to be taking control of the button-pressing process. It may have been that in the early days when they started introducing ISAAC to patients that the volunteers let the patients enter in their own personal health number and password to get into the system, but after two months of struggle with the technology, the volunteers seemed to speed up the process. Below is from five different patients:

- V01: I'm going to plug in just because it's a bit easier these numbers this is your health card number
- V01: To make life easier I'm just going to plug in the numbers for you all right?
- V01: OK here we go so I'm going to enter your healthcare number and we're going to get you into the system beep beep

V02: I'm gonna give you a password that we use to get enter in your own password OK

V02: so the first thing I'm going to do is I'm entering your public health number...

One of these patients had used ISAAC before and still the volunteer entered their information. Only two of the eight patients entered in their own numbers.

### Progress over time

Once patients got the sense that this kind of tool would be more valuable if one used it over time, they really came to see how it would be a good and worthwhile tool. From the interview of the one patient who had used ISAAC previously [P02]:

It's good. It monitors what is happening. The first time it was not much use but now I see that over time it is good to track symptoms. Then you can see which symptoms are changing.

With two other patient interviews:

P03: yeah it's good, it's a good tool and it would do well. Of course it would be more valuable to them if, if there were four or five entries on it, you know, four or five times so you could see the pattern

Researcher: Is this of the kind of thing you think you would do if you had access to it at home?

P08: O yeah! Yes if I could log on from to a web site with that on and uh, even put it in my diary on, you know, which is in the computer if you do it once every what ever you determine is a reasonable interval. It would be like all services - some people would and some people wouldn't.

## Honesty

Another concern for the patients and volunteers was that of honesty. In the beginning of the ISAAC pilot in November 2008, volunteers were concerned that patients would try to be ‘the good patient’ and not bring up their symptoms to the oncologists because they might not get as good care, or that attention would be spent addressing symptoms rather than the disease. This too was one of the arguments for having me do the study rather than someone who already works in the cancer clinic. The issue of honesty did come up for two of the patients as well. During one of the interviews, the patient’s wife spoke up when asked about the usefulness of tools like this, wonders if we really expect people to be honest about their symptoms. Another patient had similar concerns:

- Researcher: do you think tools like this in general will change the way how people communicate with their health care professionals?  
 P08: O I think so if people are honest. That’s the thing though, people have to be honest

## 4.4 Enjoyability

Rapport building and humour may not have any relevance to ISAAC once it is available through the web and patients can use it at home, but for the interactions between patients and volunteers in the clinic, these two factors seemed helpful. However, if a person is predisposed to disliking technology, they may not find the tool so enjoyable. Users who have concerns about privacy may be less concerned

about how enjoyable an application is to use if they are worried about where their personal information will go.

### Rapport building

The humour (discussed below) on the part of the patients, their attending family members and the volunteer led naturally into rapport building. This also seemed to be an important process when learning to use this technology. In many cases there was a lot of physical touching between the volunteer and patient, hands on shoulders or knees, teasing each other. In one case, the patient was teasing the volunteer:

Volunteer: and now you said there was some tiredness  
 P07's son: mm-hm  
 Volunteer: that was a concern?  
 P07: yeah well I could sleep sleep sleep sleep  
 Volunteer: yeah  
 P07: (laughs) I can go to sleep now! (patient laughs again, everyone laughs)  
 Volunteer: says please don't (laughing continues)  
 P07: no, I'm just teasing...I'm just teasing you

### Sense of humour

It was amazing to see how patients could retain their sense of humour in the face of their cancer. For most patients, they settled into using ISAAC about halfway through, and it was usually the Shortness of Breath section that got people laughing.

Two different patients:

Volunteer: any shortness of breath?  
 P02: only when I talk too much (patient laughs)

Volunteer: Okay, shortness of breath?  
 P07: not so much, no  
 Volunteer: but some?  
 P07: Yes, if I've run up the stairs (Volunteer laughs)

Finding text-based evidence around rapport building and sense of humour proved to be a challenge, despite how important they seemed during the observation period. In my observation notes for almost every patient, one or both of these two factors arose from my sensing of their presence, rather than tangible proof that they were important factors.

### Technology bias

There is always a danger of recruiting participants for a study with technology that only the people who like technology would be willing to enrol. Luckily, this was not the case. One patient who agreed to try ISAAC didn't actually like the tool:

Researcher: So what did you think about the tool that you used today?  
 P04: not much  
 Researcher: Okay, you didn't like it?  
 P04: No I found it too subjective rather than objective...yeah so for example everybody's pain - pain tolerance is different  
 Researcher: Yeah  
 P04: So what is pain to one is not necessarily pain to another person

While I was asking about the tool – meaning the electronic tool – the patient associated the tool with the application, in this case, the ESAS. If this patient had filled out the ESAS on paper, she may have had the same objections to the

assessment scale. I thought it was notable that she did not refuse to participate, even though she did not appear to enjoy using it.

### Privacy

Since privacy and confidentiality is a huge concern in health informatics, it is not surprising that it would come up in a study such as this. In the initial version of ISAAC at the BCCA, it took 10 minutes to time out after a patient was finished with it. Given that the patient's personal health number and name is on the last screen before exiting, this is a compromise to the patient's privacy. One patient's son raised concerns just after the observation:

P07's son:     how do you get out of that now? (He is asking how to get out of ISAAC so that his mother's information is no longer on the screen)

This patient arrived at the same time I was conducting an interview with another patient, so I was not able to catch her before she went to see the oncologist. The ISAAC Coordinator took the patient through the ESAS on paper beforehand and asked the patient if she would like to try ISAAC after she saw the doctor. Therefore, the interview followed immediately after the observation period. A brief amount of time had passed then between the son's remarks above and below:

P07's son:     how do we get that out of there? (He is asking again about his mother's personal information on the ISAAC screen still in full view)  
                   Beep (someone pressed the exit button)  
 P07's son:     beautiful

In the time since this data was collected, the 10-minute logout time has since been reduced. If their need for privacy had not been met, it is possible they would not have given ISAAC a second chance and therefore would have had no chance to enjoy using it.

#### 4.5 Patient Experience Not Reflected in the Chart

Acknowledging that this is one participants' experience and cannot be generalized, P05 offers an important case example. It seems she had fallen through the cracks of the health care system in a number of ways before the day I saw her. Her experience that day at the clinic provided further examples of just the kinds of problems she had experienced previously. She was on the list to participate in ISAAC as a patient with a lung cancer diagnosis, but she was not actually enrolled on the database to participate. This is an example of being denied access to potential medical attention.

On the day I saw her, this patient [P05] looked like she was really suffering and was breathing audibly and with difficulty. She told me her story, which I also included in my notes:

It was during this conversation that the patient told me about her difficulties with cancer. She told me that two years prior to becoming a patient at the cancer clinic she had been sent by her family doctor for X-rays of her chest for the pain she was having in her chest and difficulty breathing. She told me that two years went by without a word from her doctor. The patient continued to have chest pain and difficulty breathing, so eventually went to her doctor again. She had forgotten about the first set of X-rays, and was taken by surprise when she had to get another set of X-rays. It was at that time that they found the nodes in her lungs.

This patient felt like her doctor did not do due diligence. That she had lost two years of her life because of not knowing that she had cancer. The

patient appeared to me to be very emotionally worn down. She didn't really say anything about the care she was receiving at the Cancer Agency. Overall though, she did say that she felt like even though there were a lot of people involved in her care, that she as the patient was somehow lost in it. I think this is a very important point. The whole point of the patient care team is patient centered care. So while the patient is that the centre of this care, healthcare professionals need to remember to involve the patient when communicating about the patient's treatment and symptoms.

I found it surprising that what the patient was demonstrating to me, and what she recorded on the paper version of the ESAS that day (since she could not log into the system, the volunteer took her through the paper version) was different from what was recorded by clinicians in her chart.

From my observation notes [P05]:

This patient was obviously in distress and conveyed to me that she had felt abandoned by the healthcare system. Because of what I told her about there not being very much study about patient experience, she seemed very eager to participate in this study. She was aware that she could not be helped herself, but wanted to do anything she could to be able to help others in the future.

From the Oncologist narrative [P05]:

"She has responded surprisingly well to her latest treatments and has improved...She is comfortable but occasionally notices pain coming from her right sacroiliac region..."

From the Nursing Notes [P05]:

Follow up call – pt was sleeping, so spoke with S-----, her daughter who states her mom got 'radiation poisoning' with her last treatment. She is also skeptical about the meds she has been on during RT.

- Reassured S----- that we have no intention of harming her mom only helping her pain

-C----- HCN called; we reviewed the ISAAC. She will be in touch with the pt on Friday.

In the nursing notes for other patients whose symptoms reached the threshold, there were highly detailed notes for each symptom including the number

on the scale for each symptom. There was nothing of the sort for P05 which further reinforced the notion that she had been abandoned by the health care system.

Compare with the nursing notes from a different patient [P07]:

Feb 3/09 ISAAC referral

Tiredness 8/10

Pt currently undergoing chemo. Has noticed decrease in energy levels, worsening fatigue since starting tx. Sleeping well at night, taking short naps during afternoon. Managing well w/ADLs, household chores, cooking. Tiredness fluctuates day-to-day. Son stops by frequently to help out. Discussed prioritizing activities, planning ahead, taking frequent rest breaks.

Pt receptive -----

Anxiety 5/10

Pt states that she worries about the outcomes of her tx, potential of not being cured. Worry is manageable, does not interfere w/ sleep or mood.

Reassurance given that these are normal concerns after Cancer diagnosis.

Encouraged to voice her concerns/fears w/close family/friends for support when needed. Discusses P&FC services.

Drowsiness 6/10

Pt takes Gravol to control chemo S/E when they arise but more commonly for headaches (good relief). Does find Gravol makes her drowsy.

Pt encouraged to continue prn Gravol for nausea but to try Tylenol for headaches – see if effective

Pt agreeable -----

SOB 4/10 Reports SOBOE but has noticed marked improvement in symptoms since starting chemo. Able to catch her breath easily when winded. Is careful to not over-exert herself & monitor activity.

The above passage was all from P07. P05 also had many severe symptoms, including pain, depression, anxiety, tiredness, and shortness of breath, according to her ESAS score, so in comparing the two it seems one patient had very thorough symptom management while another patient's symptoms went unaddressed. While the three goals of usability (ease of use, acceptability, enjoyability) could not be applied to this particular patient because of problems with the system, this is itself an issue. If we want patients to use tools like ISAAC, we need to make sure they can get to that simple first step of logging in. For this patient, having her symptoms

registered in an electronic system could have meant her symptoms would have been handled in a less distressing way.

#### 4.6 Summary

Looking at categories and themes generated through usability methods and a wider lens of qualitative description, the findings provide a snapshot of a number of issues that can arise when patients are asked to enter their own symptom information into an electronic tool. In order to maximize uptake of applications such as ISAAC, the three categories for usability (ease of use, acceptability, enjoyability) can serve as a gauge by which to read how well the tool can serve its purpose. Regarding ease of use, a number of problems arose before the study began in terms of technical difficulty, which in some cases were mediated by the user or someone nearby understanding how computers work.

Another problem was that the scoring numbers could not fully explain what was meant by the user. Gauging how acceptable ISAAC is could be influenced by the attitude of the teacher and whether or not patients-as-users are actually entering their own information. By doing so, they can see their progress over time and thus better appreciate the value of entering their symptom information into ISAAC. This can only be of benefit to the patient if they are honest, an issue that some of the patients in this study identified as a potential problem. In learning how to use ISAAC in the clinic setting, patients had the opportunity to build rapport with the volunteers who were teaching them and express a sense of humour. This may have

helped the learning process and making the experience enjoyable. Enjoyability may have been affected by a person's bias against technology.

Issues around privacy could preclude any enjoyment of using ISAAC. Last, because not all patients go through the health care system seamlessly, opportunities exist to make sure that no patient is left behind. One patient had difficulty accessing care and ISAAC, which could justify the use of tools like ISSAC as a part of clinical routine.

## 5 Discussion and Conclusions

### 5.1 Discussion

The findings of this research are distilled into general messages below, shown in italics. The findings in this study supports what has come before, and some of the findings contribute to a gap in the literature. Below are suggestions for future research and implications for practice.

In 2000, Coiera discussed information needs and conversation needs in the clinical setting. He notes that information transactions among clinicians takes up a lot of the ‘communication space’, and that failures in communication are what often lead to adverse events in the clinical setting(Coiera, 2000). Therefore, if an information need is dependent upon communication, perhaps it could be better managed by different means. In the case of ISAAC, information about a patient’s symptoms could be easily recorded and reduce the time needed for communication about whether a symptom is present and if it requires attention. This is in line with Coiera’s suggestion for responses to the communication paradigm, that “communication tasks are replaceable with information tasks” (Coiera, 2000, p. 278). In order for the information about the patient’s symptoms to be reported and recorded in the electronic record, *patients as users need to be the ones in control of the process*, whether the application in question is used in the clinic or at home. No one knows the patient’s symptoms or experience better than the patient does.

For applications like ISAAC to gain wide acceptance from users, it needs not only to be easy to use but doable by the patient. That is to say, the patient needs

to be able to complete the entry, start to finish, without the assistance of a guide (unless they are functionally incapable). That is ideally what ISAAC BC will be, but at the moment there are a number of technical aspects that need to be changed in order for uptake and compliance in use. For this pilot phase, it was clearly necessary to have the volunteer take the patient through the tool – largely because of the log in information (i.e. the volunteer had the patient’s temporary password at the beginning) but also in explaining some of the symptoms. Some of the patients using ISAAC while I was there (but who were not a part of my study) indicated that they wanted to push the buttons themselves: this should have been a given. But as noted previously, due to time constraints and not wanting to delay clinic flow, the volunteers had developed workarounds to speed up the data entry process.

The act of actually doing the task, rather than watching, can increase the learner confidence and therefore enjoyment of performing the task. Other patients I observed in the clinic who were not a part of my study seemed sceptical about trying ISSAC out but did so anyway on the encouragement of the volunteer or the ISAAC Coordinator. Several of these patients were delighted with how easy ISAAC was to use and some were even proud of themselves for having successfully navigated computer technology. If the task is appropriately manageable and/or challenging, then the user will feel more willing to use the system without fear. Slegers et. al. (Slegers, 2009) note that “many older adults experience difficulties when using modern technologies” (p. 309) and therefore the tools we ask them to use need to be developed accordingly.

This kind of application can be very useful in the clinic setting but as Canada is a geographically large country, *web-based applications that patients can use at home* will become increasingly important as Internet capability increases worldwide.

Patients are not yet used to seeing their information charted electronically and therefore may not yet know the value of being able to see certain data over a time period. With ISAAC, many of the symptoms that cancer patients have are as a result of the disease or treatment or both can be managed by the health care professionals even from a distance. Keeping the application with which to enter symptom information simple is a vitally important factor for achieving buy-in from the patients if this kind of application is to take hold. According to Slegers, an “essential step in the process of enhancing usability is to study the types and causes that older adults face when they use technology” (Slegers, 2009) p. 310). Usability studies such as this one can offer many suggestions on how to develop technologies for patients with a particular set of needs. In the case of P08, he did not have his glasses with him so the size of the buttons on the keyboard proved difficult.

Because more applications are being made available in electronic format, it is easy to assume that most people will be familiar and comfortable with using a simple computer will be an easy thing to use. While this may be true for the younger generation, at the moment we need to be mindful that this older set of patients may not have had the opportunity or interest in learning to use computers

and other technical applications at this stage in their lives. There are many people who have never used a microwave or who still prefer going to the bank teller for their transaction rather than use the bank machine. On the other hand, there are many people who fall within the demographic of the aging population that have embraced information and communication technologies. An article on Microsoft.com (Forrester Research, 2008) discusses the aging population and computer use. In it, the authors mention the generational gap between people who left the workforce before computers were commonplace and those who learned to use computers before retirement. They note that people who learn to use computers before retiring were more likely to continue using computers in their retirement. This is, they say, in part generational and in part due to the sheer numbers of people. While the challenge of not understanding technology is less likely to be an issue beyond more than a decade or so, this is currently an issue with the aging population and therefore must be handled appropriately. In our increasingly mobile world, Internet accessibility will be a necessity. The authors of the Microsoft article go on to suggest that “[a]ddressing the needs of those who are likely or very likely to benefit from the use of accessible technology requires an industry-wide effort.” (Forrester Research, 2008). It is interesting to note that none of the patients in the present study had any physical or cognitive impairment that would hinder their use of ISSAC, but the sample size was small and perhaps uncharacteristically functional for this population.

*Because of the increased need for care in an aging population, human contact is still a very important part of health care provision – patients cannot build*

rapport or joke with a computer program. Patients need to know that their health care is aided and not replaced by computers.

As many clinicians know, patients have the capacity to retain a sense of humour even in the face of life-threatening disease. This may be a way of retaining a sense of normalcy in one's life as well as a reaching out from human to human, and not just patient to health care professional and vice versa. If the volunteers had not been present during the introduction of the patient to ISAAC, this would not have emerged as one of the study's themes. Neither would have rapport-building, which also seemed to be an important process for patients learning how to use this new tool. This raises the question then of whether the symptoms that hit the threshold are treated because of the information provided by the patient into ISAAC or because of the communication between the patient and the volunteer. In discussing responses to the communication paradigm, Coiera notes that communication tasks are different from information tasks, and that information needs often arise as a result of a conversation. He says "the informal and interactive nature of most conversations is essential, since the types of questions we seek to answer might be poorly structured and become clear only through the act of conversation" (Coiera, 2000, p.278). With ISAAC, the intention is to have the information arrive to start that conversation. That is, the information the patient enters will show up on the screen or in the patient's chart. If there is a symptom that requires attention, a conversation begins between the health care practitioner and the patient. So while the computer does not replace talking to a human being, it can be the catalyst of the conversation. However, with some patients' symptoms, they

may not realize they are experiencing symptoms that could be managed until speaking with a clinician about it. Time will tell whether patient symptoms can be managed better through tools like ISAAC.

When the patient is having difficulty even having a conversation, *this kind of self-assessment electronic tool can really benefit patients who do fall through the cracks*. If P05's information had been entered correctly and automatically went to her electronic patient record (which currently is not possible), the patient's real experience of her symptoms would have been charted and hopefully addressed. The study of patient experience requires attention because, as was the case for P05, the chart did not reflect what the patient was truly experiencing. That her cancer went undetected for so long and that the patient felt ultimately abandoned by the health care system should send off warning bells. Not only did the descriptions of her previous experience illustrate her point, but even on the day I saw her in the clinic it seemed she was tossed around. While the volunteer and I were sitting with P05, the care aide interrupted us to announce "the doctor is ready NOW" – and this was a full five minutes before the scheduled appointment. The patient was startled and confused, but left to see the doctor. This type of information does not make it to the patient's health care record even though it was the cause of some distress to an already anguished patient. In order for organizations to use electronic applications like ISAAC to achieve buy-in from the patients who are meant to be the users, the application needs to first be available to the patient *and* the patient needs to feel that it is a worthwhile endeavour. If patients entered their symptom information and

those symptoms that reached the threshold were not addressed, they would simply stop using the system. Getting the patients to the tool is the first step; making sure that tool is easy to use, acceptable, and enjoyable must follow, and this includes attending to the patient's need for privacy.

*Privacy issues must be addressed.* For this pilot project, the ISAAC touch screen was fit in where there was room, but ideally the screen would be located in a more secluded area where the patient could feel a greater sense of privacy. While this issue only came up with one patient – in fact it was not even the patient but the family member, and this is important to note too – privacy is one of the largest issues that hinders progress in the development of an Electronic Health Record. According to Becker (Becker, 2006), “Consumers are far more worried about the security and privacy of their personal information than they are about the speedy adoption of information technology by the healthcare industry” (p. 6). While sensitive patient information may not be subject to the scrutiny of health insurance providers in Canada like they are in the United States, Canadians still want their information protected. In a recent online article on the Canadian Broadcasting Corporation's website about the EHR in Canada (Hadzipetros, 2009), the reporter mentioned criteria for building interoperable systems. Privacy barely made mention and the word ‘privacy’ only appeared twice in the article. The reader comments, however, reflected a much greater concern for privacy than the article would have us believe. For tools like ISAAC, reducing the time it takes for the program to reset after not being used is the first step towards protecting the patient's privacy, but at

this point it is still not a guarantee that the patient information is safe. Privacy may not be an issue for this sample group within this population, but it might be for others.

## 5.2 Synthesis

In a study that looks at usability for a particular application that is to be used by patients, the user experience (in this case the user is the patient) is inevitably part of the data that emerges in the study. At the same time, any study that explores patient experience of a technology is best supported by also examining its usability. Thus, the two methodological approaches used to look at usability and the experience of patient-as-user, qualitative description and usability assessment, seem to compliment each other in terms of the data collection and analysis. To answer the research question then, how does ISAAC stand up to usability testing?

In general the participants, including the patients as well as the volunteers who were teaching the patients how to use it, expressed that ISAAC is a good idea and a useful program, with some changes. The patients themselves did not seem to express much in terms of the usability problems that the volunteers were having – in fact many of the results came from the volunteers, which was unanticipated in the designing of this study. If the volunteers had not been present to introduce ISAAC, the response from the patients could have been quite different, and it is doubtful if so many patients would have agreed to use it if there was not someone available to walk them through it. Patients do have much to tell us, given the opportunity.

The usability problems that surfaced before and during this study were not surprising. Anyone who has ever dealt with a computer glitch knows the grief and frustration of not knowing what the problem is or what to do about it. Fortunately some of the more pressing problems have been addressed or are currently being resolved.

### 5.3 Limitations

The biggest limitation for this study was insufficient time. The window in which I could conduct my study was small. The project's pilot was only 2 ½ months long, and the design team wanted me to wait a couple of weeks before starting so the volunteers could get used teaching the system. In developing the ethics application, I discovered my original recruitment strategy would not work. The BC Cancer Agency does its ethics approval through the University of British Columbia (UBC) which has what they call the Researcher Information System (RISe). I am not a registered researcher with this program. The UBC ethics policy does not allow for recruitment by telephone, because of this the patients had to be recruited in person. This resulted in having to invite the patients to participate on the spot, and with the volunteer introducing the patients to my study rather than doing it myself.

The timing of this discovery meant that I had to revise my study plan as well, so not only did I have to change my recruitment strategy; it meant I could only see the patients in one instance, rather than twice six weeks apart. Time was of the

essence so I decided to go with the interview schedule for what was previously Interview number one. This meant I was not able to gather more detailed responses from these questions since it was only supposed to be the first interview. In the end, some of the interviews were more conversational but a more structured and detailed interview schedule may have allowed for some more substantial results. It would also have allowed for fuller more systematic usability testing of the patients using the system over time.

I did not realize when planning my research how large a role the volunteer-as-teacher would play in introducing the tool to the patients. In one sense this got in the way of the 'think aloud' technique used in usability testing, but it did mean that there was a more meaningful dialogue about the patient's symptoms as the volunteer took the patients through the tool. If I had known how great the role the volunteers would be playing, I would have tried to be involved in the process of training the volunteers have to use ISAAC.

Another limitation was that I am not a clinical researcher and particularly that I am not BC Cancer Agency staff. I was given the physical space (a cubicle in the Physics department with a computer) and access to the system (e-mail and the Cancer Agency Information System, or CAIS), but there was still some ambiguity about the legitimacy of my presence. I encountered some difficulty with BC Cancer Agency staff who were not directly involved with this project. In the end, I was able to request the charts and search for the information I was looking for.

During the data collection process, I invited the patients to return to the waiting room in Clinic C, where we had done the observation, to conduct the interview. This was in the interest of time (mine as well as the patients) and also to make it easier on the patient. Overall the location of this interview did not pose a problem, but in the interview with the last patient (P08), he had some negative things to say about the volunteer who was teaching him (V01), which likely only came up in the interview because by then the volunteer had gone home for the day. This was an oversight on my part: there was a meeting room available nearby where I could have conducted the interviews. If there had been more time for data collection, I likely would not have felt so pressed to try to get as many patients as possible into the last two days of the pilot study timeframe.

### Rigour

Acknowledging that there are many approaches to establishing rigour in qualitative research, Cohen and Crabtree (2008) provide the approach used here. In their discussion they provide four techniques to ensure the verification or “trustworthiness” of research is sound, two of which are described below. The first is triangulation. Patients were observed and interviewed, providing two sources of data there, but these data were also compared with parts of their patient record; namely the oncologists’ narratives and the Nursing Notes. By comparing these different sources of data, a broader picture was painted from which to draw conclusions about the observations made. Second, Cohen and Crabtree discuss peer review or debriefing (p. 334). In the context of the present study, I as the researcher

met with members of my supervisory committee to ensure I considered all possible perspectives. Further, the clinicians on my committee felt that the data presented and the resulting arguments ‘rang true’ for them as clinicians considering electronic tools in the health care setting. While it is not the intention of qualitative research to provide generalizable results, the findings here are nevertheless useful for shaping future practice and developing tools that will benefit patients in the long run.

#### 5.4 Conclusions

The computerization of health care so far has mostly meant that applications have been in the hands of the clinicians. In order to meet the challenges of providing safe effective health care in the 21<sup>st</sup> century, planners and designers are trying to find the best ways to adapt new technologies to the process. With the aging patient population and the thinning of the workforce of health care workers that will be caring for these older people, some of the responsibility of care will be transferred back to the patient and their families. Then we as clinicians and healthcare researchers want to introduce electronic applications into the patients’ care. Does this benefit the patient? Or does it just help clinicians better use their time and make data collection easier? The short answer may be that yes, tools like this (ISAAC) do help the patient, since the person’s experience as a patient is intensified when the patient has a moderate to severe symptoms: we all know that when we are in pain or nauseous to a large degree, everything else stops until that symptom is managed. In this way, ISAAC can go a long way in helping clinicians manage those symptoms so that the patient can deal with the rest of their life, such

as preparing an advance directive, having important discussions with loved ones, and saying goodbye. The goal of the healthcare professionals is to make the patient comfortable so that the patient may enjoy good quality of life for as long as possible.

Assessing usability with patients as users enhances our understanding of these tools in a way that will be increasingly important as patient care and the patient record are increasingly the charge of the patients themselves and their families. The tools and programs we are asking people to use in their home have to be the right tool at the right time for the right application. Apple's iTunes Store already has a mindboggling number of health care applications – almost 600 of them. While most of them (as of June 18, 2009) have to do with diet and exercise, there are such applications as Medication Tracker, Cholesterol Tracker, and Hypertension Awareness. Do these applications actually work? Because they are commercially available to consumers, chances are they are not tested before release to the public. This is why usability testing needs to be completed – not only for the sake of development of future versions and applications but for the safety of the users. Standards must be met to ensure patients-as-consumers are receiving high quality applications that will enhance their health care, not hinder it. If anyone can write an iTunes Application, and they can, then usability testing will become crucial for any application issued by a health service provider. Kushniruk et. al. note

[a]lthough the literature has shown that information systems may decrease error in medicine, the idiosyncratic and varied nature of design of health

information applications argues for the usability testing of *each* of these systems and devices to predict aspects of design that may be related to error prior to their widespread dissemination [*italics the author's*] (Kushniruk et al., 2005, p.525).

Thus, I recommend including the study of the patient experience and usability testing for any application that patients and their families will be using. This type of study will enhance our understanding of the user's needs so we can build safe, efficient, effective and useful tools that improve the quality of health care provision.

### 5.5 Future research

The present study could be refined and replicated a number of ways. Studying patients as they use the tool over time could provide information about how patients use ISAAC, how often they would self-report their symptoms, and if symptoms are managed over time. Looking at patients as they use ISAAC from home would help researchers to understand the patient's needs in terms of software development. A comparison of patients using ISAAC from rural and remote communities to manage symptoms between clinic visits and how that symptom management impacts the rest of the patient's treatment program would be interesting. Last, tracking patients over time and exploring more issues would allow for in-depth interviews as patients participate in and think about the process of actively adding information to their record.

## 5.6 Application to Practice/ Tool Design

A number of the issues raised in the course of this study have already been handled since the end of the pilot phase. The keyboard buttons have been increased to the largest possible size, the keyboard appears and disappears from the screen automatically at the appropriate time, and the timeout period after inactivity has been reduced from 10 minutes to two minutes. Further, card readers have been attached to the ISAAC touch screens that eliminate the need for entering the personal health number, reducing chance of error as well as reducing the time it takes to enter the number. It is important too that those responsible for teaching the application to new patients to have a positive attitude towards the technology.

While I cannot speak from the clinical side of this tool, the most obvious benefit to clinicians and patients alike would be if the numbers entered to the ESAS went directly to the patient's electronic health record. The BCCA is in the process of changing from the Cancer Agency Information System to a Cerner based system to be in line with most of the other health authorities in British Columbia, hence the delay for making this change. Workflow practices will change as a result that will hopefully result in better patient care



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## Appendix A: Sample Interview Questions and Observation Template

### Interview Questions

*(Opening)*

1. Can you tell me about your experience of using the tool today?

*(About the ISAAC tool)*

2. What was the best way for you to learn how to use the ISAAC tool – brochure, volunteer or by simply using the tool?

*(About the care)*

3. How helpful would you say the ISAAC tool is for communicating with your health care professional about your symptoms?

4. Do you feel the symptoms that are causing you difficulty addressed by your health care professional?

5. Do you think that the care team would have recognized your symptoms if you had not used ISAAC?

6. Do you have any concerns about how electronic tools like this might change the nature of how you communicate with your health care professional? How?

7. Would you like to add anything else?

**Observation Notes Patient Experience Study**

Participant ID: \_\_\_\_\_

Date:

Time:

Location:

Patient attended by:

Description of the setting:

Perception of difficulty of tool for patient:

Description of any assistance needed by patient:

Is patient affected or distracted by being in a hallway or waiting room?

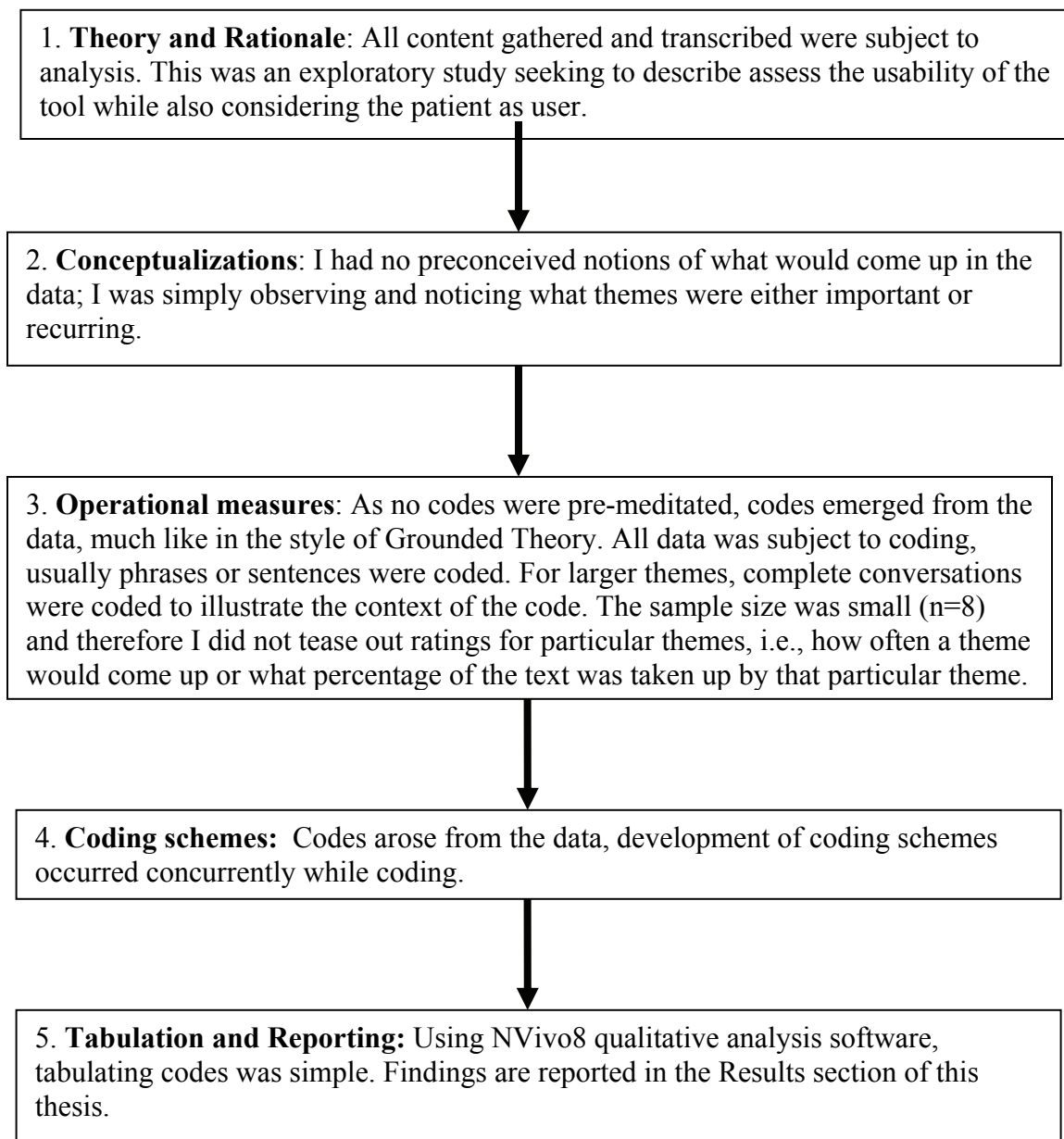
Do ergonomics play a role?

Did the patient ask lots of questions? To whom?

Notes:

## Appendix B: Content Analysis Scheme

Content Analysis Scheme<sup>6</sup>(Neuendorf, 2007)



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<sup>6</sup> Modified from Neuendorf, Kimberley A., 2007

## Appendix C: Summary of Patient Characteristics

	Gender	Age	Attended by	First time with ISAAC	Commuting from
P01	M	74	(alone)	Yes	Greater Victoria Area
P02	M	61	Wife	No	Greater Victoria Area
P03	M	68	Wife	Yes	North Island
P04	F	73	Husband	Yes	North Island
P05	F	62	(alone)	Yes	Greater Victoria Area
P06	F	61	Husband	Yes	Greater Victoria Area
P07	F	76	Son	Yes	Greater Victoria Area
P08	M	73	Wife	Yes	Greater Victoria Area

N = 8 50% male, 50% female  
Age range 61-76, average 73.4

## Appendix D: list of abbreviations

BCCA	British Columbia Cancer Agency
CDM	Chronic Disease Management
EBM	Evidence Based Medicine
EHR	Electronic Health Record
EOL – PC	End-of-life palliative care
ESAS	Edmonton Symptom Assessment Scale
HCI	Human Computer Interaction
PHSA	Provincial Health Services Authority
PHN	Personal Health Number
PSMC	Pain and Symptom Management Clinic
RISe	Researcher Information System
UBC	University of British Columbia
VIHA	Vancouver Island Health Authority

Appendix E: ISAAC Change Requests<sup>7</sup>

ISSAC Change Request Tracking Spreadsheet																													
<div style="display: flex; justify-content: space-between;"> <div style="width: 20%;"> <p><b>Status Legend</b></p> <table border="1"> <tr><td>New</td><td></td></tr> <tr><td>Approved</td><td></td></tr> <tr><td>In Progress</td><td></td></tr> <tr><td>Completed</td><td></td></tr> <tr><td>Postponed</td><td></td></tr> <tr><td>Denied</td><td></td></tr> </table> </div> <div style="width: 40%; text-align: center;"> <p>The next new Request # should be:</p> <p style="font-size: 24px; font-weight: bold;">24</p> </div> <div style="width: 30%;"> <p><b>Priority/Severity Legend</b></p> <table border="1"> <tr><td>1 - Low</td><td>Nice but not important.</td></tr> <tr><td>2 - Medium</td><td>Minor inconvenience, or problem with use.</td></tr> <tr><td>3 - High</td><td>Major functionality or user convenience issue.</td></tr> <tr><td>4 - Critical</td><td>Show stopper, can't go forward without fix.</td></tr> </table> </div> </div>										New		Approved		In Progress		Completed		Postponed		Denied		1 - Low	Nice but not important.	2 - Medium	Minor inconvenience, or problem with use.	3 - High	Major functionality or user convenience issue.	4 - Critical	Show stopper, can't go forward without fix.
New																													
Approved																													
In Progress																													
Completed																													
Postponed																													
Denied																													
1 - Low	Nice but not important.																												
2 - Medium	Minor inconvenience, or problem with use.																												
3 - High	Major functionality or user convenience issue.																												
4 - Critical	Show stopper, can't go forward without fix.																												
Request #	Status	Request Name	App	Request Description	Date Submitted	Submitted By	Priority / Severity	Approved By	Resolution																				
1	New	Clarify scoring scale in patient app	Patient	Adding a graphic that clarifies the scoring (moderate to severe) on the patient input screen, underneath the numerical bar between the scores 4 – 7 (as an example)	30-Oct-08	Blair Newhouse	1 - Low																						
2	New	Remove print dialog	Patient	Have the printing go directly to the printer and not call up a Microsoft dialog box	30-Oct-08	Blair Newhouse	3 - High																						
3	New	Link to review screen	Patient	When doing a symptoms review, if the patient wishes to make a change to any of their scores they have to then step through each screen to get back to the review screen again, Can you put in a link so the patient can go directly back to the review screen after making changes to their score.	30-Oct-08	Blair Newhouse	2 - Medium																						
4	Approved	Add BCCA help material	All	Remove the Ontario material from the help screens and replace it with BCCA specific information.	30-Oct-08	Blair Newhouse	4 - Critical	Jeff Barnett																					
5	New	Make Small text bigger	Patient	Make the all small text, especially in the terms of use agreement larger. Ann and Kathleen were really concerned about this	14-Nov-08	Ann Syme / Kathleen Yue	3 - High																						
6	New	Add explanation of number scale to summary page	Patient	They would like an explanation of what the number scale means for the different symptoms on the summary page. They feel like patients will not be able to assess whether they need to go back and adjust their scores if they don't know what the numbers mean	14-Nov-08	Ann Syme / Kathleen Yue	2 - Medium																						
7	New	Explanation of colors on histogram	All	Add a legend that explains what the different colors on the histogram mean.	14-Nov-08	Ann Syme / Kathleen Yue	2 - Medium																						
8	New	Shared Patient Report	Clinician	The Shared patient report is broken and does not work. It should be removed until it is fixed	14-Nov-08	Dave Greig	2 - Medium																						
9	New	Get Stylus'	All	A stylus attached to the machine would make data entry a lot easier for many patients, especially those with shaky hands etc. This could be any plastic object with a dull point	14-Nov-08	Dave Greig	2 - Medium																						
10	New	Printing indicator	Patient	There is quite a delay between pressing the print link on the histogram page in the patient app and when the print dialog box comes up. They really want some kind of indication to let them know that it is working and that they have actually hit the link. This could probably be accomplished with a color changing mouseover?	14-Nov-08	Dave Greig	3 - High																						
11	New	Return to start from error page	Patient	Add a link or a custom error page so that users can go back to the login page if they happen to get a 'Runtime Error' or other errors. Otherwise they are totally stuck on the error page as they have no 'Back' button	14-Nov-08	Dave Greig	3 - High																						
12	New	Fix French pages	Patient	On the French login page there is reference to Ontario in the text. Also on the Histogram summary there is a CCO logo	14-Nov-08	Kathleen Yue	2 - Medium																						

<sup>7</sup> Reproduced with permission from the author.

13	New	Notification Handling	Clinician	Add additional features for notification handling, such as the ability to indicate that a notification is being worked on, who is working on it, when it was dealt with etc. If the app had capabilities for handling the workflow around the notifications it would make it much more useful to the nurses and clinicians. Having an audit trail of who did what with the notifications would also be very useful	14-Nov-08	Ann Syme / Kathleen Yue	2 - Medium		
14	New	More Reports	Clinician	There were many requests for new reports of various types. EG, summary reports, pts who have been enrolled but have not used the system, adding totals to the clinical aims report, closed notifications	14-Nov-08	Dave Greig	1 - Low		
15	New	View histogram from pt search	Clinician	Add a button to view a patients histogram history from the Patient Search results	14-Nov-08	Ann Syme / Kathleen Yue	1 - Low		
16	New	Partial Name searches	Clinician	Add the ability to search on partial names, i.e. searching on 'Gr' would come up with 'Greig' 'Gronig' etc	14-Nov-08	Ann Syme / Kathleen Yue	1 - Low		
17	New	Print histogram button for clinicians	Clinician	Add a button to print a patients histogram to the clinician app. They can do this by using the browsers print functionality but would like a button like the patient app	14-Nov-08	Ann Syme / Kathleen Yue	1 - Low		
18	New	Notification email link to specific notification	Clinician	Make the link in the notification email take the user to the specific notification that caused the email to be sent	14-Nov-08	Ann Syme / Kathleen Yue	3 - High		
19	New	Add Clinician user procedure	All	Create a stored procedure and script for creating Clinician users that DO NOT have super user privileges. We are currently creating all users as super users with access to both the Clinician and Admin apps.	18-Nov-08	Dave Greig	4 - Critical		
20	New	Create 'Development environment	All	Create a development environment that is an exact duplicate of the production environment. This is critical for any development work, and even for tracking down problems. We absolutely do not want to be mucking around in the production environment	18-Nov-08	Dave Greig	4 - Critical		
21	New	Customize the 'ISAAC not available' page	All	Currently the 'ISAAC Not Available' page is very simple and says nothing except that ISAAC is not available. This page needs to be branded with BCCA stuff and made to be more informative	18-Nov-08	Dave Greig	3 - High		
22	New	Touch Screen Styluses	Patient	Get some styluses that can be attached to the touch screens to make it easier for patients to enter data using the keyboard	25-Nov-08	Dave Greig	2 - Medium		
23	New	Clinician app time out	Clinician	Increase the amount of time before the Clinician app times out and forces the user to log in again. This will allow the nurses etc to have the application open for longer in order to keep an eye on the notifications	25-Nov-08	Kathleen Yue	2 - Medium		

## Appendix F: Example of how raw data was coded into NVivo8

When transcribing the audio files from the observations or interviews, I noticed a number of issues come up and recorded them into my notes. For example, the conversation between P06, V01 and the patient's husband about the difference between tiredness and drowsiness went on for some time. Below is the passage of raw data from the above quoted text in 4.2, where large chunks of text were coded as "numbers not descriptive". Usually a phrase or a couple of lines would form the source for the code, but this *was* a lengthy conversation about the difference between tiredness and fatigue. Embedded within this coded passage are other codes as well, which appear highlighted with the code used in curly brackets { ... }.

00:03:41 V01 says tiredness, are you feeling whole body tired?  
 00:03:45 patient says no well I'm tired  
 00:03:47 V01 says you are tired  
 00:03:48 patient says yeah I get fatigued very quickly  
 00:03:52 V01 says very quickly OK now how im-important, how much of the problem is that? Obviously it's not a zero and it's not sort of  
 00:04:02 patient says it's about a a three  
 00:04:05 V01 says a three so let's poke  
 00:04:08 patient says let's press three and beep beep  
 00:04:10 V01 says oh good and then continue beep beep

(later)

00:05:02 V01 says this drowsiness where you're sort of dropping off to sleep sort of always falling asleep for easily mapping half a dozen times a day  
 00:05:12 patient says I can't sleep  
 00:05:13 patient's husband says it varies though you get tired during the day  
 00:05:14 patient says I get tired  
 00:05:16 V01 says but you don't sleep  
 00:05:17 patient says but I don't sleep. I, I you know, I read and I think I might even goes for a a very short time but I don't  
 00:05:28 V01 says it's not...  
 00:05:29 patient says I don't get any relaxation from it  
 00:05:31 V01 says OK so then you... This is a difficult one isn't it then Stacey because  
 00:05:41 patient's husband says well being drowsy and sleepy are two different things

00:05:42 V01 says yes being not able to sleep is yes it's actually it is a concern isn't it

00:05:48 patient says yes that's why I take Ativan at night and just, because I've stayed up literally, I didn't take it a couple of times and uh, I had a hard time getting to sleep and when I got to sleep I didn't stay asleep. It's you know, and every 2 to 3 hours I would be awake.

00:06:09 V01 says so I think this is cause for concern that you're drowsy but you would prefer to be drowsy enough to have a good night's sleep

00:06:16 patient says yes

00:06:18 Stacey says so you can sleep when you want to be sleeping

00:06:19 patient says yes

00:06:21 V01 says okay

00:06:22 patient says but you know I've got arthritis too... Severe rheumatoid arthritis

00:06:29 V01 says so that would cause a sleep problem

00:06:31 patient says well that would cause a fatigue problem

00:06:33 V01 says fatigue, yeah

00:06:36 patient's husband says and pain

00:06:37 patient says and a pain but I would, on the chemo, I don't seem to experience a whole lot of pain from it. I get stiff but [unintelligible] I get stiff

00:06:51 Stacey says this is where across is that strange line between tiredness and drowsiness

00:06:54 V01 says yes

00:06:55 Stacey says because you can always go back and change are answers if you think well maybe drowsiness isn't the issue, maybe it is tiredness but maybe that isn't the case.

00:07:10 V01 says well

00:07:13 patient says maybe I'm not a good subject (chuckle)  
(everyone laughs) {sense of humour}

00:07:14 V01 says no no no... What you're saying, the computer isn't allowing you to say so there's a problem with the program (everyone is talking at once, everyone is laughing) {numbers not descriptive}

00:07:27 patient's husband says I would say you're more drowsy than you're not drowsy so probably a four, maybe a five

00:07:32 patient says well yeah I, I get very (pause) yeah I get very logy and I, and I wanna do things but I just can't force myself to do them

00:07:48 V01 says okay well I think maybe we need to go back and in a minute and look at tiredness because then that is a tiredness and it's more a sort of - of brain tiredness as well as a body tiredness do you think? Sort of you know

00:08:03 patient says yeah

00:08:04 V01 says okay so you are drowsy some of the time

00:08:05 patient's husband says part of that too like [P06] was saying is that cross over 'cause when she started chemo she had to stop taking um [brand name of arthritis medicine] which is her rheumatoid arthritis

injectable drug and so that was working really well and uh masking a whole bunch of problems or controlling a whole bunch of problems, but now when she went off that the consequences of leaving the [arthritis medicine] gave her some comfort issues and tiredness issues all these other issues that aren't directly related to chemo necessarily, part of it

00:08:49 V01 says but she's the whole patient so we need to you know be treating all of that so shall we give this before and then we'll go back to tiredness at the end? Beep beep

(later)

00:10:30 V01 says OK so beep you filled it in even though I couldn't keep my finger off the keyboard} now let's go back to tiredness OK. Being tired is probably a problem, more than we thought at that time in the sense that you don't feel you are getting enough sleep. Would you say that?

00:10:52 patient says if I don't take the Ativan I don't get enough sleep.

00:10:56 V01 says but sometimes the Ativan doesn't give you a long enough sleep?

00:10:59 patient says no it's I it's only when I go off the Ativan. I've tried going off of it just you know 'cause I, I take enough pills so if I can

00:11:11 V01 says yeah

00:11:12 patient's husband says well even when you take the Ativan like you're not screaming out of bed in the morning you still got some sort of residual from the drug

00:11:20 patient says occasionally I get a by headache and things but other than that

00:11:31 V01 says so what would you think do you think the three was OK?

00:11:35 patient's husband says [unintelligible]

00:11:36 patient says tiredness beep

00:11:39 patient's husband says even with the pill you're not waking up all that refreshed sometimes like this morning he took the pills last night and you weren't all

00:11:45 patient says yet I think it was the anxiety of coming here 'cause yesterday was fine. I got up 8:00 and I was up and [mumbles]

The conversation about tiredness and drowsiness spanned from 3 minutes 41 seconds to 11 minutes 45 seconds – nearly eight minutes with a few other topics in between. What is not mentioned here but was an issue was that the patient had to go back to change scores and then had to flip through each page to get to the end again rather than being able to jump to the end.

Once all the data was coded, NVivo8 allowed for easy searching of all text that was highlighted and tagged with a particular code. When calling up 'progress over time', for example, the selected texts appear with information about their source and what percentage of the document they comprised.