

**PACER REPORTS**

**Understanding How Patients Manage Their Chronic Illness:  
What Works and How**

Marlyn Gill  
with Colin Penman & Susan Nguyen

Primary Investigator: Peter Sargious  
PaCER Supervisors: Nancy Marlett & Svetlana Shklarov

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**PaCER<sup>1</sup> REPORTS**  
**Executive Summary**  
**Understanding How Patients Manage Their Chronic Illness:**  
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**Reason for including PaCER in Project:** Project C of a comprehensive CRIO grant related to transitional supports for those with Complex and Chronic conditions looked to address the issues of self management and technical supports. PaCER was contacted after the project began to test the viability of a patient directed research unit. The PaCER team and the Project C team met regularly to discuss patient led approaches and share data. An interim report was prepared to evaluate direction and focus.

**PACER methods used:** Over seventeen chronically ill patient participants, aged between late thirties, most with multiple chronic diseases, participated in the SET, COLLECT and REFLECT aspects of the PaCER study.

- The SET focus group identified the scope of daily experience and supports available in managing their care and the types of issues that might be raised.
- In the COLLECT phase, the make-up of the first focus group enabled us to explore the fears and concerns about the emerging reliance on computer technology in health among older patients using a grounded theory analysis. The second focus group focused on lived experience of self managing and allowed a discussion of electronic records to emerge. This group included those who were younger and more expert in managing their care led to recruiting six additional patients for in-depth interviews to explore self management. This data were analyzed through two methods: a traditional phenomenological reduction and an investigation of the data using a salutogenic lens.
- The REFLECT focus group reviewed the analyses and were clear that they know certain aspects of their health can only deteriorate, they do not want to sit around waiting for that to happen. Chronically ill patients want to live life to the fullest possible and the attitude of their healthcare providers has a huge effect on their mental and physical wellbeing. They want to be a partner in developing new options.

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<sup>1</sup> This project has been conducted as a research support function of the Patient and Community Engagement Research (PaCER) program at the University of Calgary.

<sup>2</sup> This qualitative study is the patient component funded through a CRIO (Collaborative Research Innovation Opportunities) grant: “W21C: Interdisciplinary Research and Innovation for Health System Quality and Safety” and the hSite Strategic Research Network funding “Iterative Development of a Patient-Centred Care Planning E-Tool.”

**Results:** Please see the full report for detailed analysis.

**What it is like living with and managing chronic illness** (traditional phenomenological reduction) with three categories:

- I. *Patient Experiences of Managing their Chronic Illnesses:*
  - a. Patient Experience of being on a team; b. Patient Experience of a Coordinated Healthcare Plan, i Patient Driven HCP; ii Physician Driven HCP; iii Generic HCP; c. Patient Experience of Follow Up; d. Patient Experience of Being Dismissed by Professionals, i Not being Believed; ii Patients Experts in Own Bodies.
- II. *Benefit to Patients of a Central, Easily Accessed Record of All Patient Health Information:*
  - a. Removal of the Patient as “messenger”; b. Opportunity For Interactive Patient Physician Dialogue; c. Removal of Specialty and System “Silos”; d. Collated drug Information Available to all Caregivers and Patients; and e. Access to Reliable Health Concern Specific Internet Sites.
- III. *Cautions Around a Central Patient Record:*
  - a. Cost; b. Access; c. Security.

**A Plea to be included** (analysis from a salutogenic perspective) which declares, *I Am Not Defined by My Chronic Diseases. I have the Ability to Function Well. Your Job is to Support This*, with four themes:

- I. *I Need You To Recognize Me as a Competent, Functioning Member of My Care Team;*
- II. *I Need you All to Talk with Each Other and Help Me Co-ordinate My Healthcare Plan;*
- III. *I need you to be diligent and Follow Up on All Aspects of Keeping Me Well;*
- IV. *I need You to Advise on and Provide Resources for me to Stay Well and Reach for New Goals.*

**Fearing the Power of “The Box”** (the grounded theory analysis) captures four themes:

- I. *Fear of being Dehumanized, Becoming a Number;*
- II. *Fear of “It is All Out There” – Breach of Security;*
- III. *Fear of being controlled by Information;*
- IV. *Fear of “Medical Divorce.”*

### **Final Recommendations and Goals**

- 1) Goal 1 is to augment and support the patient’s sense of coherence in managing complex and chronic health needs.
- 2) Goal 2 is to improve patient experiences by sharing information from specialists, family physicians, allied health (particularly pharmacy) and patients to avoid conflicting treatments and drugs.
- 3) Goal 3 is to include patients in the development and rollout of the Electronic

Health Records to address fears and the unique needs of older users along with those who are used to technology.

## **Understanding How Patients Manage Their Chronic Illness: What Works and How**

### **Introduction**

This qualitative study is the patient component of CRIO (Collaborative Research Innovation Opportunities) grant, “W21C: Interdisciplinary Research and Innovation for Health System Quality and Safety.” It is well recognized that many patients with two or more chronic diseases may experience difficulty in coordinating their health care plans as they have different specialists for each condition who may or may not be in close communication either with each other or the patient’s family physician (Schoen & Osborn, 2011; McGowan, 2012). Where such difficulties exist patients often find that their overall health may suffer as they work to be the link among all (Wagner et al.; 2001; Newbould, Burt, Bower & Blakeman, 2012).

In an effort to understand the negative and positive experiences of chronically ill patients as they try to coordinate their treatment plans with multiple professional caregivers, with a view to finding ways of making management more efficient and effective, patient and community engagement researchers – team members of the PaCER Program (Marlett, Shklarov et al., 2014) were asked to undertake this research. We encouraged all participants to talk about what really worked for them, what they found difficult and frustrating and what would make it easier for them to be confident they and their professional caregivers were managing their health as well as possible.

### **Background and Context**

As a result of an aging population and increased longevity, there is a large increase in the number of patients with one or more chronic diseases (Wagner et al., 2001; Ralston et al., 2004; Harris & Zwar, 2007). This presents a challenge to both patients and health providers as they struggle to keep the communication channels open among patients, families, primary physicians and multiple specialists in order to provide optimal care (Ball, Smith, Bakalar, 2007; Wagner et al., 2001). The concept of instituting multi-disciplinary team care for the chronically ill is a solution that is gaining popularity, but barriers such as provider availability and funding loom large (Wagner, 2000; Ball, Smith, Bakalar, 2007; Harris & Zwar, 2007). Electronic personal health records with input from a variety of health professionals as well as patients are being suggested as a method of implementing team care with the additional benefit of a high level of patient involvement (Pagliari, Detmer & Singleton, 2007; Tenforde, Jain & Hickner, 2011; Ross et al., 2004). In the United States 87% of primary physicians support team based care while 83% support sharing medical records with patients (Ball, Smith & Bakalar, 2007). Unfortunately, by 2013 a review indicated that only 14% were sharing data with providers outside their organizations while only 24% routinely allowed their patients access to their records online (Furukawa et al., 2014).

Patient involvement or engagement in self-care is seen as a key factor in managing chronic illnesses (Ross et al., 2004; Von Korf, Glasgow & Sharpe, 2002). There are several advantages for chronically ill patients and their families to become less passive in managing their care including providing “a more balanced view of the patient” (Ball, Smith & Bakalar, 2007, p.77), improved health outcomes, improved patient education (Ross et al., 2004; Von Korf et al., 2002), ability to personalize a care plan institute planned follow up, and improved compliance (Rosset al., 2004, Winkelman, Leonard, & Rossos, 2005). Patient involvement in their own care by allowing them to access their medical records and enter data, about mood, psychosocial functioning, and other patient perspectives would allow the chronically ill to better manage their lives and could lead to early identification of issues such as depression (Glasgow et al., 2012).

### **Method**

PaCER uses several qualitative research methods set within the patient engagement research framework outlined in *Grey Matters* (Marlett & Emes, 2010). For this project we integrated a phenomenological reduction analysis (Patton, 1990; Bogdan and Taylor, 1975; Berg, 1989) and, at one of the early stages, also some elements of grounded theory analysis (Glaser & Strauss, 1967) with the patient engagement research methods we use to conduct patient-to-patient studies. We chose this as we wished to explore the experiences of patients with a variety of chronic diseases who were managing their complex health care situations. Our data collection techniques included two methods that have been found effective within the PaCER framework: focus groups and individual semi-structured interviews. All focus groups were facilitated by a group of three trained PaCER researchers, and individual interviews were conducted by PaCER researchers one-on-one with each participant. We used the SET, COLLECT, REFLECT framework outlined in Marlett & Emes (2010).

### ***Recruitment and Inclusion Criteria***

Physicians at several Calgary clinics working with chronically ill patients were asked to inform their patients both by talking to them and by posting information about the study in their waiting rooms. Our inclusion criteria were outlined in the posters, and we provided this information to the physicians. Potential participants were required to have at least one chronic illness, speak fluent English, and be over 18 years of age. Potential participants who were interested were asked to call either an identified Project C team member or the lead PaCER.

### ***Participants***

We recruited eighteen participants, each with at least one chronic condition. Each participant took part in one or more study activities, including focus groups and/or individual interviews. Five participants took part in the SET focus group, seven

participants in COLLECT Group One, three in COLLECT Group Two, six individuals participated in COLLECT-stage interviews, and seven in the REFLECT focus group. Participants' chronic conditions included cancer, diabetes, liver failure, leukemia, bone marrow transplant recovery, heart problems, scleroderma, COPD, thyroid problems, arthritis, depression, bi-polar disorder and anxiety.

### **Data Collection and Analysis**

We collected data using the PaCER framework, which consists of three phases: SET, COLLECT and REFLECT.

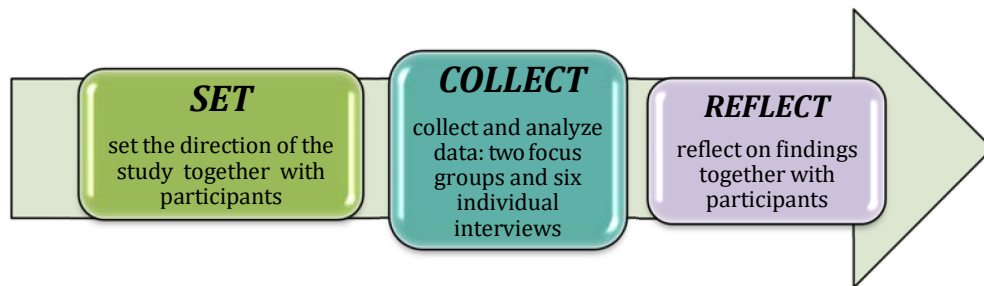


Figure 1. PaCER Research Method

Patient engagement research process is iterative and amenable to changes in direction depending on the information received from any group. In this study we made a decision to slightly shift the focus of data collection questions based on the analysis of the data from one of the COLLECT groups. After the analysis of the COLLECT Group One, where there was a great deal of focus on the fears elicited by discussion of electronic records, PaCERs, in consultation with the larger research group, decided to amend the guiding questions by refocusing on how patients have and are currently managing their chronic illnesses. At this stage, we allowed the topic of electronic records to spontaneously emerge from the patients' discussions rather than formally introducing the concept. This gave the patients an opportunity to fully discuss their past and current situations with respect to what worked, did not work, and what would improve their ability to manage their multiple chronic diseases, without reference to any specific technology.

#### **SET**

The five-hour SET group, held in Calgary, consisted of five patients. There were a variety of chronic illnesses represented by these patients, each with a unique set of conditions. The session was audio taped, process notes were recorded, and flip chart notes were generated.

The facilitator explained that participants were here to talk about what was important to them in maintaining a healthcare plan and the possible role of an



electronic tool to store and distribute healthcare information was introduced. The facilitator asked two initial guiding questions:

1. Share a time when things went well because you had some form of care plan.
2. Share a time when things could have been better if a care plan had existed.

After the participants had shared their experiences, the flip chart notes were posted on the walls and participants were asked to go around and indicate which of the topics were most important to them. We discussed the topics in detail to understand the patients' perspective in choosing the topics.

Before proceeding with the COLLECT phase of the research, the flip chart notes were analyzed to identify the major topics of importance to the participants. (Note: in keeping with patient engagement research protocol, we did not transcribe and analyze the SET group audiotape until we had completed one COLLECT activity.) The analysis of the flip chart notes allowed us to set the direction for the first COLLECT group ensuring that we followed the track indicated by SET group. In patient engagement research, it is the participants who guide the direction of the research.

## COLLECT

We held two COLLECT groups (five hours each) and engaged in six COLLECT individual interviews (60 to 90 minutes each). Following patient engagement research protocol, we developed the question for COLLECT Group One from the flip chart notes originating from the SET focus group.

We posted the flip chart notes for each group on the wall and asked participants to identify those issues of most importance to them. We used phenomenological reduction to analyze both COLLECT groups and the six interviews using the audiotapes, transcriptions, flip chart notes and process recording notes as availability allowed. We sequentially numbered the "bites of information" and coded them into emerging themes. Each theme described similar experiences encountered by participants as they managed their illnesses.

As we were analyzing the COLLECT Group One transcript, we noted that there appeared to be emerging patterns of fear around electronic record keeping being expressed by most of the participants. We noticed that there appeared to be a deep-seated insecurity and resistance to technology from a significant section of participants. We realized that this group, unexpectedly, provided us with the information that did not exactly fit into the question we had intended to answer, and that the data went far beyond the phenomenon we intended to analyze. Intrigued by these emerging concepts, we decided to carry out a grounded theory analysis of the data in an attempt to uncover what was going on in the data, and what were the processes involved that we had not foreseen or predicted when we began this group (Glaser & Strauss, 1967). Grounded theory is an effective analytical tool that allows

unexpected concepts to emerge from the data, which can often help identify and direct the further strategies for data collection (Glaser, 1978, 2002). In this study, this method allowed us to better understand the barriers patients may have around the use of electronic records. It also prompted us to change a guiding question for the second COLLECT focus group in order to deeper explore the emerging issues that were still under-represented.

Following the results of COLLECT Group One data analysis and in consultation with our larger Project C team, we decided to focus back on healthcare plan experiences by allowing the spontaneous emergence of electronic record keeping as part of the solution to improving healthcare planning. We believe, as we will note in our recommendations that the fears expressed in COLLECT Group One should be a separate topic for further research.

Thus, we used the following questions for the consequent portions of the COLLECT stage:

Guiding question for COLLECT Group One:

How would an electronic healthcare records system improve your health care plan?

Guiding questions for COLLECT Group Two and six COLLECT interviews:

1. Can you share with us how you manage your chronic illnesses?
2. Do you have a healthcare plan?
3. What has worked for you and what would you like to be better?

We continued the analysis using phenomenological reduction, and reached saturation after conducting and analyzing two COLLECT groups and six individual interviews.

## REFLECT

The REFLECT phase is a form of member checking as all participants had previously engaged in either a focus group or an interview. The REFLECT group invites participants to review the analysis to ensure that it accurately reflects their experiences. In addition to the traditional member checking, the REFLECT strategy within the PaCER method is also designed to meaningfully engage participants in the concluding stage of data analysis. To achieve this, we posted all the themes identified in the COLLECT phase on the walls. with an explanation of the theme together with positive and negative quotes exemplifying the theme, and invited the group's discussion and input.

Each participant was given a different coloured note pad and asked to affix comments and any related information to each theme. We coded and added the responses to existing analysis. Participants agreed with our analysis as presented, and also invited us to take one step further in our understanding of their

experiences. During the discussion following the notepad exercise, it became obvious that participants wanted to send a message to their healthcare providers with respect to their needs. These needs were documented and recorded.

### ***Research Credibility and Trustworthiness***

We used several strategies to raise the credibility and trustworthiness of the research: (1) The patient or family member researchers facilitating the groups, interviewing patients and family members and analyzing the data are the instruments in the study and each had to understand, reflect on, and state his/her biases (Bogdan and Taylor, 1975; Kirk & Miller, 1986; Patton, 1990, Morse et al., 2002). (2) As patients we had a familiarity with the experiences of the participants (Shenton, 2004). (3) We used research colleagues, academic supervisors from PaCER, and peers to review and discuss the emerging data, coding, and themes (Lincoln & Guba, 1986, Shenton, 2004). (4) We used member checks (REFLECT group) to ensure the accuracy of our analysis. (5) We employed iterative questioning, triangulation (e.g., using a combination of two methods – grounded theory and phenomenological analysis, and two different data collection techniques), and thick description of chronically ill patient experiences. (6) We completed a literature review to assess the congruence of our findings with previous research (Berg, 1989, Guba & Lincoln, 1986; Morse et al., 2002; Shenton, 2004)

## **Results**

As noted in the methods section, during the research process we changed the principal guiding question from: *Tell us what difference an E Tool containing all your health information would make to your health care plan* to *Tell us how you manage your chronic diseases and what might be helpful to make that easier for you*. Approximately half of the participants responded to the first question (SET and COLLECT One groups) with the remainder responding to the second question (COLLECT Two and six interviews). We have combined the data from both questions as there was considerable overlap of information with respect to the experience of the participants' past and current health care plans. Although the later participants did not describe a possible E Tool in the same detail as the first cohort, they did voice a need to have all their health information easily available in one location to all their healthcare professionals as well as themselves.

On analyzing the REFLECT group transcripts in conjunction with participant notes and written comments, we believed there was a consistent message being sent by these chronically ill participants to all of their professional healthcare providers: we are not willing to be identified by our illnesses, we are competent and functioning people and your job is to support us as we manage our lives. Many of the participants were asking for philosophical changes in the way their health caregivers viewed both the patients and the care provided to chronically ill patients. These findings were closely related to Antonovsky's theory of salutogenesis and his

work around a sense of coherence (1979; 1987). We therefore undertook to present patient needs from a salutogenic perspective, using all the available phenomenological reduction data. Patients' attention appeared to be concentrated on their wellness rather than their multiple illnesses. They perceived that health professionals did not understand this and often failed to give patients the support they needed in pursuing as high a quality of life as possible within their own perceptions of their limitations. We believe that this reflects an important aspect of working with chronically ill patients that may often be overlooked or misunderstood by health professionals.

As also noted in the methods section, we used phenomenological reduction for all of the data and extended our analysis with grounded theory only in the COLLECT Group One. We observed during COLLECT Group One that there was a conversation among most of the participants concerning the use of electronic technology in healthcare. Since the language and metaphors used were vivid and somewhat concerning, we decided to do a grounded theory analysis of this group. We believe that attention should be given to this data, especially with regard to any implementation of an electronic central repository of all healthcare records. The underlying themes identified by co-axial analysis in COLLECT Group One is presented separately from the themes emerging by phenomenological reduction from all four groups and the interviews.

### **Phenomenological Reduction Analysis Results**

There are three main categories emerging from the data:

1. Patients' Experience of Managing their Chronic Illnesses.
2. Benefit to Patients of a Central, Easily Accessed Record of all Patient Health Information.
3. Cautions Around a Central Patient Record.

Each of these categories has themes and sub-themes, which will be described in detail. The three main categories contain seventeen themes and sub themes:

1. Patients' Experience of Managing their Chronic Illnesses has four themes and five sub themes (Figure 2).
  - I. Patient experience of being on a team
  - II. Patients' Experience of a Coordinated Health Care Plan
    - i. Patient Driven HCP
    - ii. Physician Driven HCP
    - iii. Generic or Depersonalized HCP
  - III. Patient Experience of Follow Up
  - IV. Patients' Experience of Being Dismissed by Health Care Professionals
    - i. Not Being Believed

ii. Patients as Experts in Their Own Bodies

2. Benefit to Patients of a Central, Easily Accessed Record of all Patient Health Information (Figure 2)

- I. Removal of Patient as a “messenger”
- II. Opportunity for Physician Patient Dialogue
- III. Removal of Specialty and System “Silos”
- IV. Collated drug information
- V. Access to Reliable Internet Sites

3. Cautions Around a Central Patient Record (Figure 2).

- I. Cost
- II. Access
- III. Security

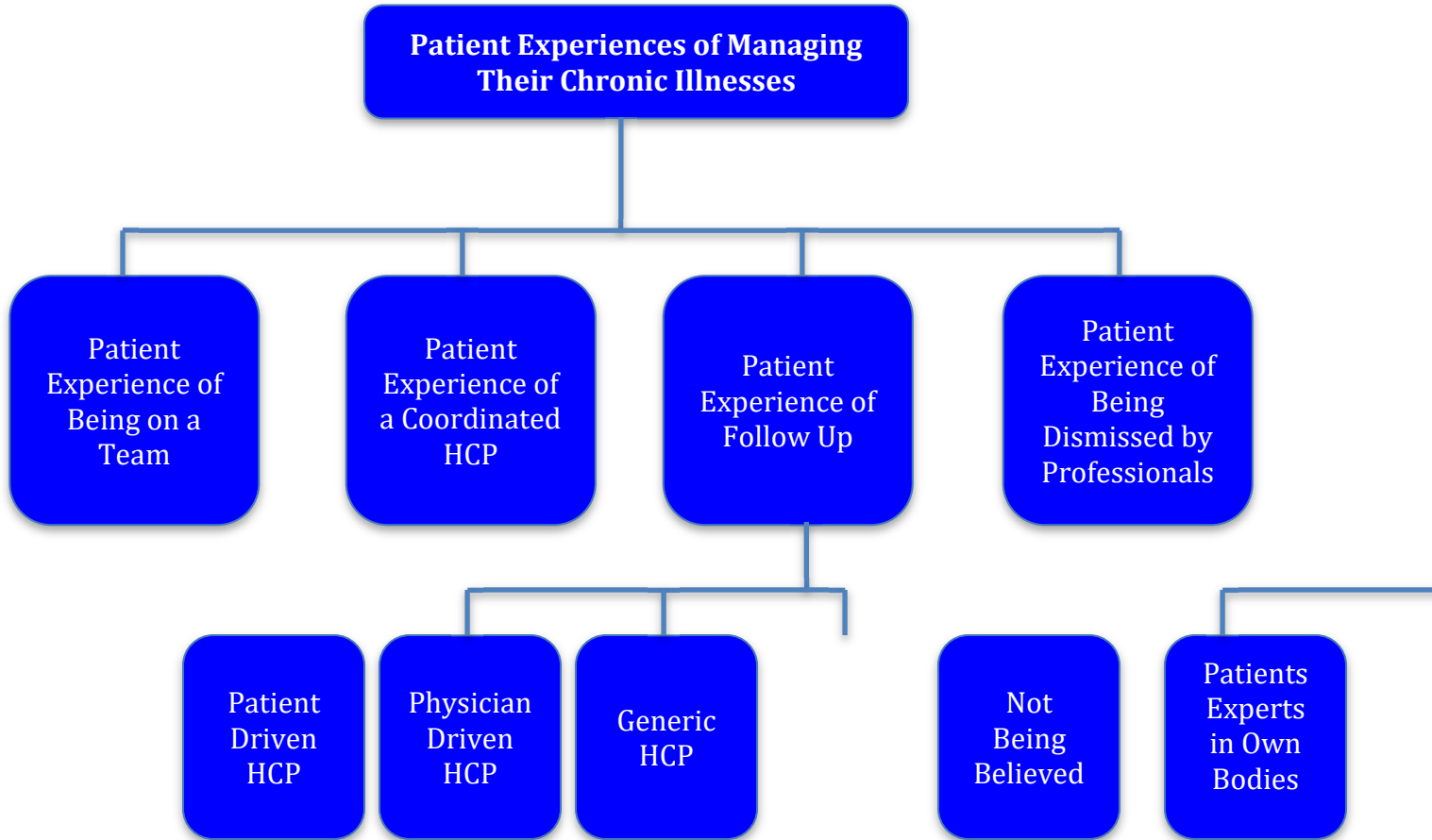


Figure 2: Category 1

**Category 1 : Patient Experiences of Managing Their Chronic Illnesses**

*Theme 1: Patient Experience of Being on a Team*

The first theme in this category outlines our participants’ experiences of being the centre and focus of an organized health care team. These teams were formed around a critical health incident at the start of a chronic condition. It is notable that not all participants experienced the formation of a team as a result of their initial illness and some believed there was a lack of interest in their health. Only one of the teams was fairly long term lasting five years until the GVH (Guest v Host) symptoms had subsided as all the others were in place for only a few weeks or months. We were told that there tended to be an overload of information at the beginning of any illness with chronicity followed by a sharp drop into little organized follow up or support. Patients found the huge amount of information given in a short time span very confusing and difficult as they were still recovering from the initial illness and had neither the energy nor focus to absorb the information.

Only one participant perceived herself to be an integral part of the team, invited to have some responsibility for her care and decision making. All of the others believed that they were told what to do and just followed doctors’ orders. They found this somewhat disempowering.

Our participants had multiple chronic conditions and pointed out that there was no ongoing team in place to help them manage their different emerging health issues. No team, with the exception of the exception of the bone marrow transplant team, had worked with physicians across several specializations in different diseases. All believed that their health would be better and lives more stress free if they had a family doctor and the relevant specialists working with them as a team.

Table 1. *Patient Experience of Being on a Team*

Theme	Exemplar Quotes
Patient experience of being on a team	<p>(7) <i>“They had a team where they gave all the information to the rheumatology patients ... they had exercises, joint care classes, OT...a psychologist or social worker for issues around family and stuff ... this was the most coordinated service I have ever had.”</i></p> <p>(77) <i>“I spent the week in ICU and I had wonderful post treatment for the first three or four months because you have cardiac rehab, classes ... treadmill, bicycle. You do the whole nine yards.”</i></p> <p>(887) <i>“After the bone marrow transplant, I had a team. I had a gynecologist, a psycho-social person, a bone marrow specialist, a dermatologist, an eye doctor... they literally said ‘this is your team’. I want a team now.”</i></p>

	<p>(0020) <i>"I languished for 9 or 10 days without the attendance of the physician."</i></p> <p>(81) <i>"Having coded with a heart attack, it affected my memory ... you have to go to these classes ... who the hell cares what they are saying ... they hand you a bunch of paper work, you don't understand what's going on."</i></p> <p>(43) <i>"The education was overwhelming. He gave me a big book of over 300 pages."</i></p> <p>(2049) <i>"Maybe a more collaborative and interactive (approach). Not doctors dictating to patients but a more collaborative care set up where the patient is a participant in their care."</i></p> <p>(11) <i>"I did what I was told ... I went where they told me to go ... it was a very frightening time."</i></p> <p>(2058) <i>"Sharing information and a collaborative effort and bringing the patient on as part of the team (would be ideal)."</i></p>
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### *Theme II: Patient Experience of a Coordinated Healthcare Plan*

Our participants experienced various levels and intensity of being able to access a coordinated health care plan for their post crisis chronic illnesses. Many admitted that there really was no "plan" as such. They simply tried to access service when they believed they needed medical attention, while others outlined the challenges they faced in attempting to patch together a plan for their continued health.

#### Subtheme i: Patient Driven Healthcare Plan

Most of our participants believed that they were totally responsible for initiating and keeping their health care plan running smoothly, although they all noted both the frustration and exhaustion levels inherent in this job. They saw themselves as the "messenger" the only person who carried all the knowledge as they tried to orchestrate connectedness among their various healthcare providers. Most noted that, no matter how hard they tried, remembering and relaying accurate information was at best "hit and miss."

#### Subtheme ii: Professionally Driven Healthcare Plan

Some participants were happy with their ongoing healthcare plans set up by their physicians. These participants observed that they recognized their responsibility in keeping healthy, but were content to rely on their professionals to organize and make decisions. Unfortunately, these participants were in the minority and highlighted why most had chosen to work with a patient driven healthcare plan.

There was general agreement that the ideal way of planning was shared responsibility, but there was distrust that the professionals would follow through.

Subtheme iii: Depersonalized Healthcare Plan

Participants whose chronic illnesses had either started or been added to with some form of cancer expressed their dislike of the generic, depersonalized method used to give them information about their illness and what treatments would be put in place. They described being given large binders covering multiple types of and sites or organ involvement for cancer and their inability to find or understand what did or did not apply to them. They also described being “herded” into a large auditorium to be given general non-specific information and advice. They believed this approach had caused even more stress in their already chaotic lives. All had wanted more private, individually focused plans.

Table 2. Patient Experience of a Coordinated Healthcare Plan

<b>Theme / Subtheme</b>	<b>Exemplar Quotes</b>
Patient experience of a coordinated healthcare plan	<p>(16) <i>“In Alberta, since I have been here, I have never been able to have any sort of coordinated health care plan at all – quite frankly.”</i></p> <p>(805) <i>“The expectation in Calgary is that all the doctors are in Health Net and like for example my GP wasn’t he wasn’t getting my results from Calgary. Like when I go to the bone marrow clinic in Calgary, what they do and what they are very aware of are long term effects from the bone marrow transplant. Like my GP is not aware of that. Really at all. He doesn’t have that knowledge. So they need to communicate, but there doesn’t seem any easy way for that to happen.”</i></p> <p>(2016) <i>“Depression related to all of this (lack of communication and support). I felt really like I had been abandoned by the system.”</i></p>
Patient driven healthcare plan	<p>(28) <i>“What you end up doing ... making sure I had copies of all my records, hospital notes, MRIs, X rays, you know I have a big folder, you know like an art student, and I would go from physician to physician with the whole package ... it’s a bit tiresome having to do that and it’s very tiresome having to repeat your story over and over again. I think when you are really ill, it is really one of the most irritating things ... to bowl up, arrive at another physician and give your life story again.”</i></p> <p>(656) <i>“Well, in fact sometimes I feel like a messenger because you know, I’m taking stuff from one doctor to the next. The other one says make sure that you keep me in the loop and all this stuff. It’s almost like I’m trying keeping track so that</i></p>



	<p><i>everybody knows everything.”</i></p> <p><i>(699) “I find it silly in this day and age that we have to do this ... Like I might not think that something is important and they may.”</i></p> <p><i>(835) “...so you still have to start phoning, you have to start phoning the people ... It takes a lot of energy. Almost all of it I would say. It’s a real struggle.”</i></p>
<p>Professionally driven healthcare plan</p>	<p><i>(41) “I must say I have had a great experience over the last 18 months ... I went to PLC and the doctor I have is wonderful ... he really is proactive – in that if he wants something done he gets it done immediately ... within 24 hours I am having it done ... I mean within 24 hours”.</i></p> <p><i>(297) “I’ve been under the care of Dr. ___ in the pulmonary unit here ... for seven years and I’ve been well looked after by my medical people.”</i></p> <p><i>(841) C10 talked about the panic she had that she couldn’t go to the appointment she needed to have before she could go on to do the next thing “and the problem is, so if that happens to you in the system you are immediately powerless, like totally powerless. You can’t get the next thing done and you know you need to get the next thing done and you feel like your life’s depending on it and you can’t do anything.”</i></p> <p><i>(0021) “Dr. ___ arrived almost immediately (my wife called) and reviewed the charts and recognized that although there was testing done, no one was doing anything. And I spent about 9 or 10 days sort of close to death, being given bags of morphine to manage extreme pain.”</i></p>
<p>Depersonalized healthcare plan</p>	<p><i>(881) “I got a folder with so much information, like it was all booklets and so I would open the first and I saw a drain hanging out of a person ... I thought ‘a drain, I don’t want a drain.’ Next page and there was then something else that was not directly for me. But it’s a bundle of information all about cancer, about all possible treatments of cancer, about all these health groups, about physio ... You are bombarded with so much information. I went through a couple of leaflets and I thought ‘I don’t want all of this, so I put it all in with the binder, closed the zipper and I put it away.”</i></p> <p><i>(818) “I had to go to one of these big meetings, which I hated like the plague. I didn’t want to be part of a group of sick people. So I had to go to that big meeting in the auditorium and I felt as long as I did not have to go through that big door at the Tom Baker... if you go through there then ... and I thought, the next thing you are going to do is put a star on my coat. You know just because you had...”</i></p>

*Theme III: Patient Experience of Follow Up*

There appeared to be little, if any, professionally instigated follow up or ongoing support for these patients managing their chronic illnesses. Many explained that they saw their physicians for a yearly scheduled check in, but that they found this insufficient and often had to try to make appointments to see their caregivers when they encountered difficulties managing their wellness. They commented that they often had long waiting periods before being seen.

Table 3. *Patient Experience of Follow Up*

Theme	Exemplar Quotes
Patient experience of follow up	<p>(14) <i>"It would be really great to have ongoing contact. Because when you are, you know, you have a person for a little bit of time, but you know, for me anyway, I don't think of everything at once and then to access them again is difficult because you have different people you work with."</i></p> <p>(R22) <i>"I have discovered that I, the patient have to take control of my illness, self advocate and follow up on your own care and treatment."</i></p> <p>(853) <i>"Well I've had that experience with my family doctor where I have had a test and I've had to go back and ask him why he hasn't given me the results. 'Oh, first he said well I don't think you had that done' and I said 'Oh yes I did.'"</i></p> <p>(3310) <i>"Well you've got this condition, nothing's happening, we'll see you again in 6 months or next year." "You feel like you're in limbo. You're thinking 'Oh shit, should I be expecting something?' Whereas I suppose to some degree having that mental thought of okay, maybe if we're going forward with treatment maybe that kind like of constantly wanting to do something so you're not feeling like you're in limbo."</i></p>

*Theme IV: Patient Experience of Being Dismissed by Professionals*

We were told that one of the most disheartening experiences for all patients occurs when they perceive that healthcare professionals dismiss or "brush off" their input, opinions and beliefs. Not only is it depressing and embarrassing, it also fuels anger, setting up the seeds for an adversarial relationship. Depending on the patient, the outcome can be a descent into depression and inaction or a determination to be heard by someone somehow.

Subtheme i: Not Being Believed

Patients perceived that many times their physicians did not believe they were giving accurate accounts of their experiences and really did not listen to what they were

saying. This made them feel discounted, unimportant and that they were somehow wasting the doctor’s time.

Subtheme ii: Patients are the Experts in Their Own Bodies

There was a deep belief among all of our participants that, as they continue to live with multiple chronic diseases, they become more attuned to their bodies. While they acknowledge that they are not experts in the diagnosis or treatment of their various medical conditions, they believe that they can accurately relate what is happening in their bodies. They are convinced that professionals’ acceptance of their expertise is vital in their quest to function as well as possible. They have crucial information that no one else can access.

Table 4, *Patient Experience of Being Dismissed by Professionals*

<b>Theme / Subtheme</b>	<b>Exemplar Quotes</b>
Patient experience of being dismissed by professionals	<p><i>(2042) “I did see a naturopath for a little while after the allergist blew me off and my doctor blew me off and all of these things and nobody was really listening – you kind of become desperate ... People become desperate when they feel like they are not being heard and if they feel like they are being left to fend for themselves and sometimes the naturopath kind of route can seem very appealing.”</i></p> <p><i>(R12) “...before, I could call the bone marrow transplant clinic and they knew I was a good, intelligent and compliant patient and I got instant response. Now with the carotid artery issues I get pooh-pooed don’t know anything etc. Very disconcerting and disheartening.”</i></p>
Not being believed	<p><i>22 “Being quite stoic in my illness ... when I would report what had happened in the previous days they just physically would not believe me – they wouldn’t believe me because they didn’t see it on that day. When you are really ill you go through this huge preparation to get yourself to hospital ... you are vomiting, whatever ... so you draw on everything you can to get to these appointments ... In the end you find well, okay, I’ll go in with soiled clothing and vomit down my front without having a wash ... which wasn’t difficult because I would vomit in the car on a regular basis going to the hospital. So it was almost like you had to get into that state for recognition ... a lot of unnecessary battles when you are already battling a serious illness.”</i></p> <p><i>(2052) “It feels belittling (not being believed), it feels like you are being a liar or that you are a hypochondriac or something like that and I think those terms are labels that get applied very quickly.”</i></p>
Patients are	<p><i>(2040) “...Who spends more time with the patient than the patient</i></p>

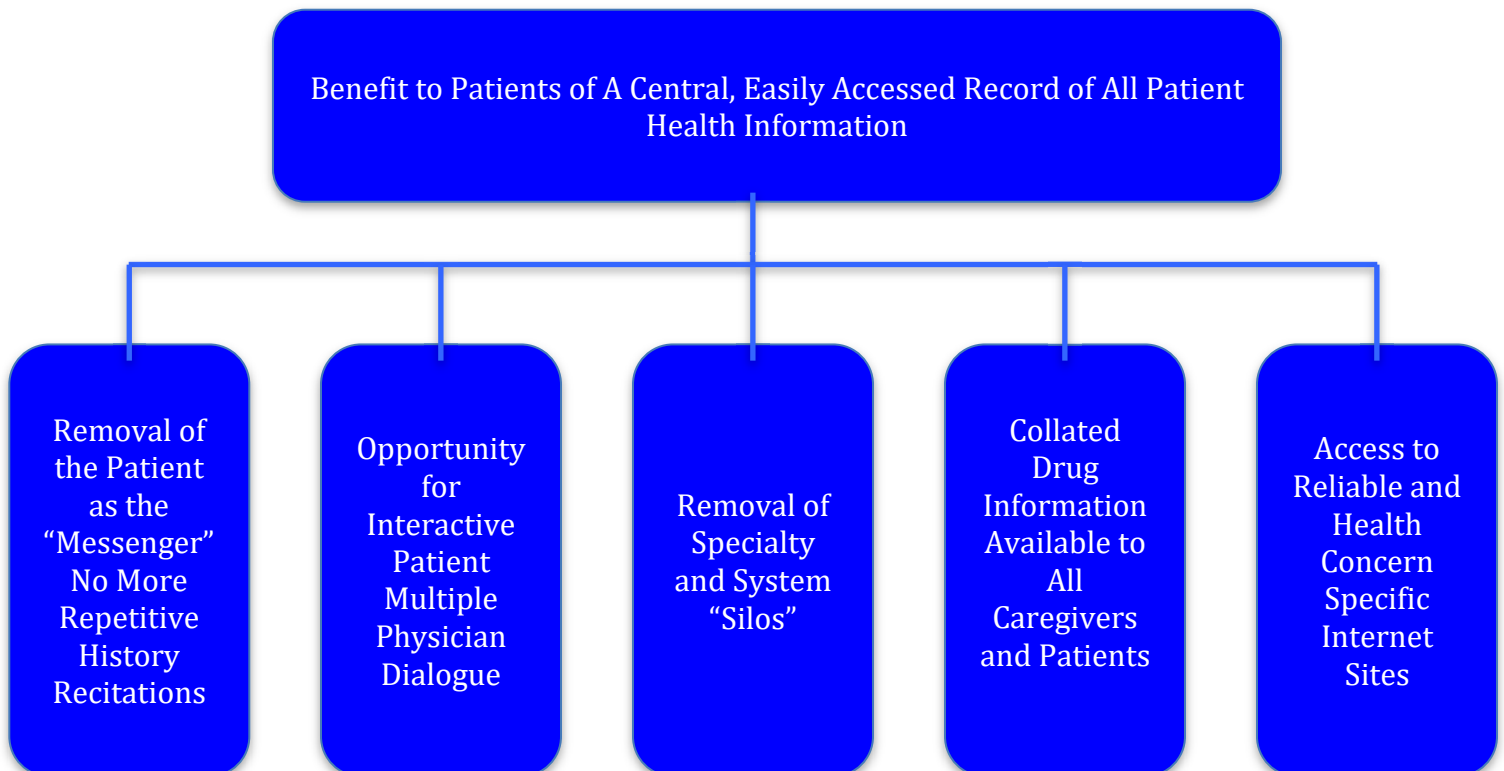
<p>experts in own bodies</p>	<p>– who is acutely aware of what is going on from minute to minute than the patient, but whenever my medication dosage is changed, I could tell you that it was eight days from the time I started taking it till when I started noticing the effects.”                  (0024) “It’s day 4, nothing has changed. Oh hasn’t it? If they don’t ask me how do they know that the treatment plan is not working?”                  (118) “So when I say when this and this is going on I’m not pulling your ears. So we need to have doctors / our providers /the system listen to the patient.”</p>
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**Category 2: Benefit to Patients of a Central, Easily Accessed Record of All Patient Health Information**

*Theme I: Removal of the Patient as “Messenger,” No More Repetitive History Recitations*

Our participants found two aspects of the present system of record keeping extremely onerous. The expectation that they would be the connecting link among all of the professional caregivers and pass along all the relevant new information each time they visited a different specialist and the necessity of repeatedly giving their medical history to new physicians was time consuming, time wasting and extremely exhausting. These are people with multiple chronic illnesses with a low finite store of energy that they believed could be spent more productively. Instead of being supported in their efforts to manage their health and lives, they perceived that they were being asked to perform tasks well outside their capabilities.

Figure 3. Category 2



*Theme II: Opportunity for Interactive Patient-Multiple Physician Dialogue*

Most participants believed that, if there were some central record keeping system available to all caregivers (not simply physicians) and patients, their overall care and subsequently health would improve. Caregivers could read and discuss reports and test results across the different diseases suffered by the patient, both among themselves and with the patient. There was a fairly general consensus that some type of patient access to this forum would be useful and a belief that such access would improve patient understanding of their various illnesses as well as encourage patient responsibility for wellbeing.

*Theme III: Removal of Specialty and System “Silos”*

Our participants were very aware of the perceived isolation within which most of their specialist caregivers worked. They believed the isolation functioned as a barrier to access as well as non-coordination of plans to manage all of their illnesses. It was like an orchestra with no conductor, each musician playing their own tune in their own time. Patients were left struggling to try to find some harmony.

*Theme VI: Collated Drug Information Available to All Caregivers and Patients*

There was a great deal of anxiety expressed around prescription drugs. Many participants related experiences of having taken contraindicated drug combinations prescribed and dispensed by various specialists and pharmacies. Some were life threatening while others were less lethal. Patients found that no one appeared to be responsible for monitoring the drugs apart from themselves and no one ensured that a drug was eliminated from the treatment plan when it was no longer useful. There was unanimous agreement that all of these practices were unsafe and that the person most qualified to monitor and question drug use was the pharmacist who should have access to any centralized health record keeping system.

*Theme V: Access to Reliable, Reputable, and health Concern Specific Internet Sites*

Few, if any, participants had not accessed some health related internet sites and there was concern around the reliability of the information they had found. They believed that it should be possible for their caregivers to post good information sites for their specific illnesses and/or combination of illnesses so that they could be confident that they were following approved health practices. They also believed that time should be offered for discussion of their findings with their healthcare providers.

Table 5. *Category 2: Benefit to Patients of a Central, Easily Accessed Record of All Patient Health Information*

Theme	Exemplar Quotes
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<p>Removal of the patient as “messenger”, no more repetitive history recitations</p>	<p>(27) <i>“I think a central repository for all the information from every physician you are dealing with because invariably with a long term chronic condition ... I for one had had a number of physicians for a number of different areas – joint, blood, bone, the MRIs etc...”</i></p> <p>(746) <i>“So I really believe there has to be something where all your information, your doctors’ notes, test results and ... like if your doctor is not there, there’s a new doctor, they come in look at the stuff, the thing is they don’t have to make assumptions they don’t have to spend time asking you questions.”</i></p> <p>(0012) <i>“It’s like ... when I was really having some respiratory issues last week and my doctor was out for 3 days. (They said) go to a different physician; I said I can’t ... because there is no way that I have the time to go through everything that I’ve gone through the last six months; all the tests; all the problems; all the results; I just wasn’t willing to do that ... and I probably couldn’t.”</i></p> <p>(28) <i>“... it’s very tiresome having to repeat your story over and over again. I think when you are really ill, it is really one of the most irritating things ... to bowl up, arrive at another physician and give your life story again.”</i></p> <p>(0015) <i>“... And then you go through oh well, by the way, I also have this, I take medication for migraines, I take estrogen. I take ... you know you’re going through a complete history over and over again.”</i></p>
<p>Opportunity for interactive patient – multiple physician dialogue</p>	<p>(R64) <i>“This is the best idea of all, doctors should be talking to each other.”</i></p> <p>(R65) <i>“Dialogue with a multidisciplinary team will have benefits we just got to get it all started right.”</i></p> <p>(27) <i>“The ability for a dialogue around all those pieces of your condition to be had in one open forum between yourself and your care givers is very helpful. You know, open access to all your results, all the various physicians thoughts.”</i></p> <p>(651) <i>“Somehow they (heart and lung and GP) should get together and develop a system where it’s good for both organs.”</i></p>
<p>Removal of specialty and system “silos”</p>	<p>(2064) <i>“...the only connection between all of these people (specialists) was me and I was writing down as a copy to the other people so that they would have these numbers as well.”</i></p> <p>(2065) <i>“If there had been a central repository with all of this information accessible to everyone who is on my team rather than (having them in) silos that I have to go and repeat and repeat.”</i></p> <p>(2088) <i>“... you know, these PCNs where you have a pharmacist a behavioral psychologist, you have a dietician and you have, you know, your family doctor and you have whatever else in the same office and they work together and they all share and have</i></p>

	<p><i>meetings about their patients and stuff and you can email the pharmacist and work through the solution, that kind of thing. It's beautiful when it happens and it's a sigh of relief. (big sigh) I don't have to fight so hard for this to happen."</i></p> <p><i>(0031) "And he (GP) doesn't get access to my medical tests because he doesn't have rights (privileges) at the Rocky View Hospital, I'll burn the damn building down, that's ridiculous! He is my doctor... my case was a communications breakdown."</i></p>
<p>Collated drug information available to all caregivers and patients</p>	<p><i>(70) "My family doctor had never heard of Bosentan and didn't have a clue what it did ... The drug store would possibly have known but they didn't know I was taking it because the two drug stores were not hooked up. I just got my regular drugs from London Drugs and the Bosentan from PLC (hospital). There was no connection between the two drug dispensers... I was getting 8 times as much Lasix and 16 times as much Lisinopril for a whole year (as I should have been taking)... The kidney specialist ... he was more or less saying that your kidneys were ready to crash because you were way, way overmedicated."</i></p> <p><i>(232) "That's where the pharmacists have said to me, I have in the past taken two pills and the pharmacist said to me, why are you taking these together this makes this one worse, but the doctor never told me that. So I went off one. There were interactions. The doctors don't know about interactions like the pharmacists do."</i></p> <p><i>(0011a) "The big thing for me is making sure that nothing I'm taking or doing interacts with medication for other illnesses I have."</i></p> <p><i>(0038) "He said are you aware it conflicts with that med? And he ran down the list of conflicts...one doctor prescribes one thing, the other prescribes something else and I'm the little Petri dish that gets to take them both and try to adjust to them."</i></p>
<p>Access to reliable, reputable, and health concern specific Internet sites</p>	<p><i>(20) "...there are so many forums, many sites ... this drug is bad, this drug is good, so many negative stories ... then you start going on this sliding scale to the ground sort of thing ... if you start reading all this stuff and believing it then you are in trouble."</i></p> <p><i>(R71) "Any information should be validated by the health care system. Should encourage patient involvement for self-improvement in self-care with no kookie info, i.e. which are good sites, point to and indicate the good sites."</i></p> <p><i>(R75) "People will look for information via the www so why don't provide a good site (for each patient. Can circumnavigate site issues by enabling time for patient and caregiver dialogues."</i></p>

**Category 3: Cautions Around a Central Patient Record**

Most of the data for this category were found in the SET and COLLECT One groups since they were the participants asked to comment on a possible electronic tool.

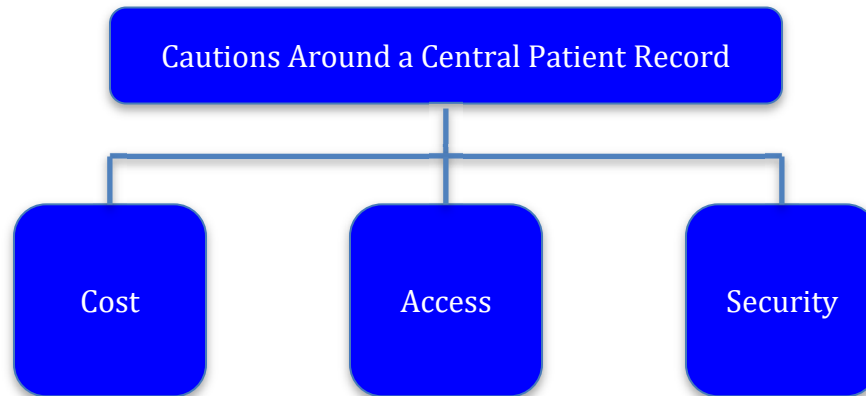


Figure 4. Category 3

*Theme I: Cost*

The discussions around cost focused on either the cost for implementing an easily accessible central record system and whether there would need to be a change in the fee structure to accommodate the caregivers input and reading time. There was no consensus around these issues. Participants either thought such a tool would be useful or that it was a waste of money with the nay-sayers being in the minority.

*Theme II: Access*

Once more there was a spirited discussion around access to a central record keeping system with all gradations of caregivers and patient access being promoted. There was no consensus or even majority view emerging and this will be a difficult issue that will merit more research before implementation. People were very fixed in their views and this could be a make or break issue for patient uptake.

*Theme III: Security*

Apart from the notable views put forward in the COLLECT One group which will be analyzed in depth later, there were few concerns about security from most of the participants. Some attention was paid to the possibility of hackers, in general this was shrugged off as an acceptable risk as there would be little useful personal information recorded.

Table 5. *Category 3: Cautions Around a Central Patient Record*



Themes	Exemplar Quotes
Cost	<p>(49) <i>"It's the funding for all these things like with (a central repository) if it's in place whoever gets it is taking a lot of funding dollars away from other things. Is it going to continue or is it something that is not going to pass ... presenting it in a way that's not going to cost billions and billions of dollars ... to tie up all these computers."</i></p> <p>(510) <i>"If your physician, or chiropractors, caregivers or whatever or dietician were actually inputting into this site, it would take time for them. How would they be paid? Should they be paid for doing it? Remember, these are your caregivers"</i></p>
Access	<p>(403) <i>"But I just don't think that from your home computer that you should have access to those types of files (medical records)."</i></p> <p>(36) <i>"There can't be any us and them, where the patients can see 20% and the physicians can see 100%. It has to be open."</i></p> <p>(80) <i>"We have to be careful who has access to this and I think it needs to be really finite – the doctor, the patient. If you want information – ask my doctor because I have told my doctors to use her discretion. Alberta Health does not need the information, it is not Alberta Health's mandate and it is not their responsibility."</i></p> <p>(586) <i>"(Family access) only if they have power of attorney. That's the only time they should have access."</i></p>
Security	<p>(56) <i>"In terms of people hacking in to the medical record, I think it is unlikely and I don't think a central repository system would be at any more danger than the current file systems they have, they are incredibly well protected."</i></p> <p>R26 <i>"This is not a problem to me hackers will get little information other than medical concerns."</i></p> <p>(3155) <i>"Most people go digitally now but I find I'm a little bit paranoid to some degree with having all my information floating about on a cloud."</i></p>

**Analysis from a Salutogenic Perspective**

As noted above in the methods section, the REFLECT group not only verified all of the emerging themes as being relevant to their experience, but also identified four major categories which were central to their prerequisites for satisfactory service from professionals. These were: (1) Patient Healthcare; (2) Collaboration; (3) Patient Input, Beliefs in Own Competence; (4) Security and Access Issues. We analyzed the REFLECT group notes and recordings in conjunction with all of the preceding transcriptions and saw a recurring well-defined message emerging. Our chronically ill participants were consistently telling us: *I am not defined by my*

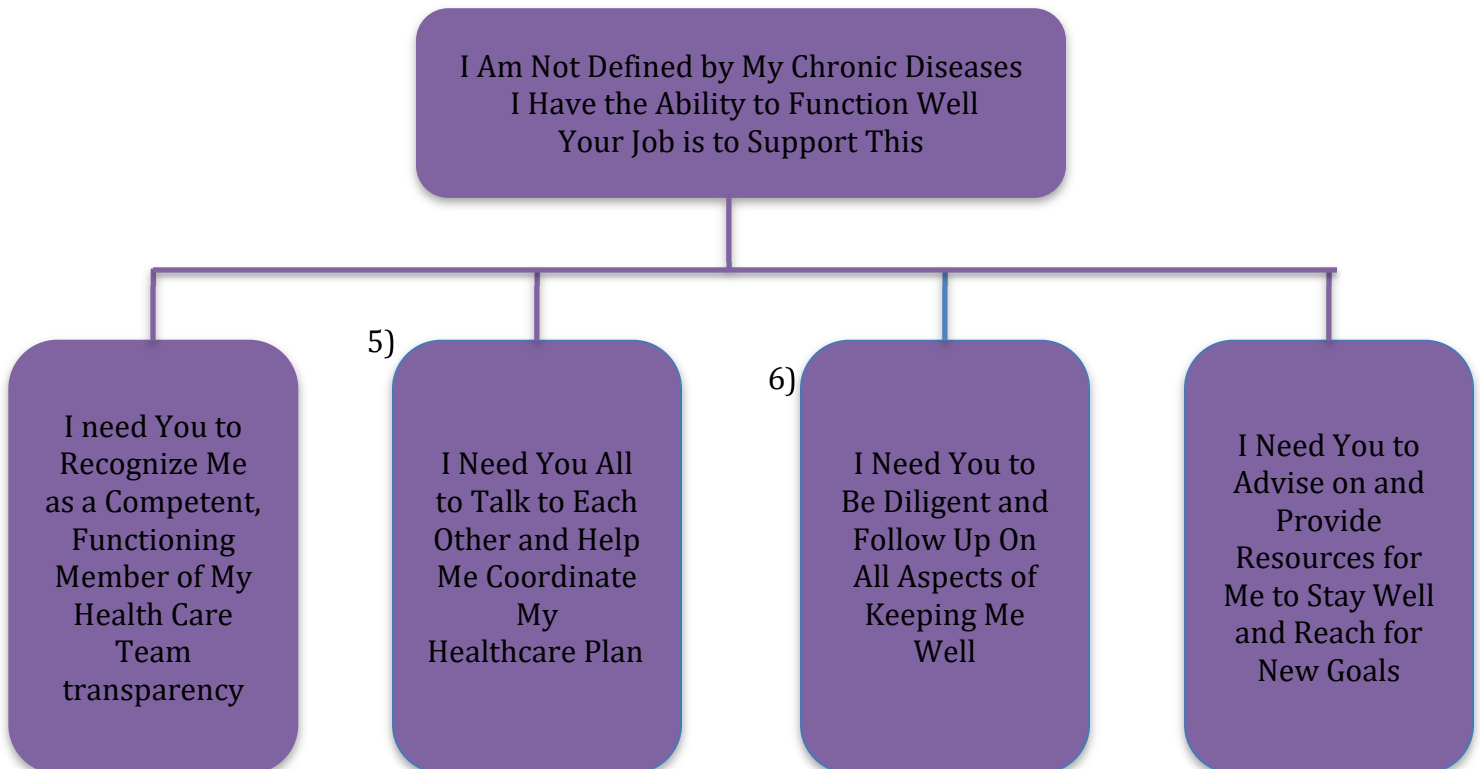
chronic diseases. I have the ability to function well. Your job is to support this. This message was supported by four themes:

- 1) I need you to recognize me as a competent, functioning member of my healthcare team. I want transparency in all my contact with healthcare professionals.
- 2) I need you all to talk to each other and help me coordinate my healthcare plan.
- 3) I need you to be diligent and follow up on all aspects of keeping me well.
- 4) I need you to advise me and provide resources for me to stay well and reach for new goals.

We were interested to discover that these emerging themes, outlining the messages from our participants to their professional caregivers, correlated with the Salutogenic Theory advanced by Antonovsky (1979):

Salutogenesis, the origin of health, is a stress resource orientated concept, which focuses on resources, maintains and improves the movement towards health. It gives the answer why people despite stressful situations and hardships stay well. It is the opposite of the pathogenic concept where the focus is on the obstacles and deficits. (Center on Salutogenesis, n.d.)

Figure 5: Salutogenic Framework



Our participants were demonstrating that, despite living with multiple chronic diseases, they were ultimately focused on endeavoring to live as well and fully as possible and were inviting their healthcare professionals to become part of their resources to improve and support what Antonovsky (1993) called their Sense of Coherence:

A global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment. (p. 727)

One of our participants, a fifteen-year bone marrow transplant survivor with multiple increasing health problems, illustrated the importance and power healthcare providers have over a patient's sense of coherence:

*"So I had my yearly bone marrow clinic appointment and I left all the specialists floating on air and knowing I could accomplish what I wanted. Everything was stable, there was no deterioration in any area. Two days later my new GP called and asked to see me. He told me my creatine level was dire, my blood pressure was concerning, my remaining kidney was under stress,, and I had a really bad cataract in one eye. I left his office sad, depressed and wondering when I would die." (C9)*

The general practitioner and the specialists from the bone marrow clinic were looking at the same results, yet seeing them from totally different perspectives. Stability meant nothing had got worse, a circumstance for rejoicing. Indeed, one specialist continued to marvel at the patient's high bone density level, which he ascribed to her decision to keep her identity as a Taoist tai chi student and teacher and to continue exercising as much as she was able throughout her treatment and recovery. One input was focused on strengths, the G.P.'s on deficits. It will take this patient time and effort to erase the negative input. Our participants wanted their healthcare providers to focus on all aspects of their physical and psychological health not just identify and focus on deficits and disease.

### **Results from a Salutogenic Perspective**

The overall message from our participants to their care providers was that they were not willing to be categorized as diseases, that having chronic illnesses did not totally impair their ability to manage their lives and that their expectations were that their physicians and other professional care givers would work to support them in their efforts to live as well as possible. They saw this as not only treating their diseases but also from a holistic perspective. Each of four themes outlined below

supports the main category by outlining some aspect of these patients' needs and expectations.

Table 7: Salutogenic Perspective Data

<b>Category</b>	<b>Exemplar Quotes</b>
<p>I am not defined by my chronic diseases. I have the ability to function well. Your job is to support this.</p>	<p><i>(2020) "So, in the meantime I was also feeling like kind of that my brain wasn't working right. I would get instructions from my boss and between the boss's desk and my desk I would completely forget what was said. I couldn't write a sentence, because I would forget what I was writing from the beginning of the sentence to the end and I was like okay there is something definitely wrong ... I tried talking to my doctors and they went "no there's nothing wrong here" So I'm going, okay so what's really going on here? ... started taking some Zinc supplements. Within 24 hours my brain came back ... I am like – what is going on here. I worked out that Zinc actually promotes the conversion from T4 to T3, which suggested to me that there was something wrong with the conversion to T3 and I really did need a supplement of the T3. 22 I got threatened to be thrown out of hospital for being a difficult patient for asking questions and I wanted second opinions."</i></p> <p><i>(0022) "I found it an interesting experience because doctors would come and doctors would go, but no one would talk and consult or tell me what they were doing. So there was more than once when they would try things with me that would almost kill me."</i></p> <p><i>(916) "Well, I think most doctors think, like you're not capable of managing yourself."</i></p>
<b>Themes</b>	<b>Exemplar Quotes</b>
<p>I need you to recognize me as a competent, functioning member of my healthcare team and I want transparency in all our communications</p>	<p><i>(2049) "(We need) more collaborative and interactive care, not doctors dictating to patients but more of a collaborative care set up or whatever, where the patient is a participant in their care."</i></p> <p><i>2089 "...Sharing of information and a collaborative effort and bringing the patient on as a member of the team .... making patients feel like they are part of the team and having things not hidden from them, like resources and no secrets."</i></p> <p><i>924 "I think being at the bone marrow clinic kind of trained me (to function well) ... and really that training, in hindsight started back when I was out at Medicine Hat and after a certain time the doctors just said 'okay, you're managing this. If your numbers are good you go down (Prednisone) so they</i></p>

were aware of letting people do that and that piece of “I’m managing this and I have control over this” was crucial to my getting better.”

(928) “You have to be able to drive your own bus in order for all of us to manage our diseases.”

(734) “I asked my doctor could she do an A1C every three months so that I could keep track of what was happening so that I could see when my A1C went up or down, I needed to do more exercise or I needed to do more of this or that.

(0028) ... If they are going to sit in a room 40 feet from my room and talk about my care, they can move the meeting 40 feet. I will get the Petroleum Club to cater us. And they can tell me what the hell is going on because if I’m the one that gets to die, I at least get to attend the meeting. These are the things we are going to try. If I had known they were going to stop off the draining of my abdomen through my nose I wouldn’t have drank water! At 3.30 in the morning agonizing rising pain, pain I’ve never experienced in my life.”

(784) “I’ll tell you an example. I went for a stress test I had a meeting afterwards with a cardiologist. He said to me stop eating bread. I looked at him and said what makes you think I eat a lot of bread. Just because I’m fat doesn’t mean I eat a lot of bread ... If he had had my file he would have been able to see I was seeing a nutritionist, I was on a diabetic diet, he would see how many carbs I was on, he would know okay maybe we have to go at it from a different—but he didn’t believe me.”

(2085) “Maybe if speak up loud enough, long enough and persistently enough then medical people might just listen. I mean with the combination thyroid treatment it’s happening.”

(0023) “Without the patient, everyone can go play golf, and I’m the guy who knows what’s going on with me because I’m the only guy that’s spending 100% of his time with the patient ... I know what my body needs to do, and no-one would include me in the discussion.”

(26) “You want to work with the experts because they are aware of the illness and it’s trajectory ... However being part of patient centred care in my mind is a collaboration piece where actually we are the expert on what we go through day to day, minute to minute and how our body actually feels. I think when you have been a long term chronically ill person you intrinsically know what is going on in your body ... you really start to understand your own feedback that your body gives you about where you are at moment to moment, day to

	<p><i>day, and what you can or can't physically do ... I think it's very important."</i></p>
<p>I need you all to talk to each other and help me coordinate my healthcare plan</p>	<p><i>(887) "...how I would like to see it work was, after the bone marrow transplant I had a team. I had a gynecologist, I had a psycho - social person, I had my bone marrow specialist, I had an eye doctor, I had a team and they literally said 'this is your team' and I want a team now."</i></p> <p><i>(R2) "... success represented by truly multidiscipline team approach."</i></p> <p><i>(3143) "So it's kind of almost like a three way street. He (GP) knows that I understand with what's been going on with my treatment. I can relate to him understanding this is what's going on forward. The doctor that I've just seen sends the letter this is exactly what we did and this is what we've talked about, these are my opinions as to how's she's doing ... but we will always talk about it which is good."</i></p> <p><i>(846) "So that was an ultrasound on my thyroid ... and I never got those results because that was through the bone marrow clinic and I only see them once a year they ordered the ultrasound. So when the bone marrow clinic ordered the ultrasound then nobody wanted to touch it. The GP didn't want to touch it ... I didn't have anybody to meet with to talk about the results... and so it showed that I had plaque inside my carotid arteries ... but in the meantime, I saw my GP, I saw an ENT specialist, and it wasn't until I saw the internal medicine guy who manages my blood pressure that he said we should have this looked at."</i></p> <p><i>3126 "He was getting everything sent to him from each doctor and each doctor would send all their correspondence to everybody else that was important. So over the years it has become my family doctor, my lung doctor, my rheumatologist, if applicable my kidney guy ... eye specialist, eye surgeon ... liver guy ... everybody at the very least will email my family doctor."</i></p> <p><i>(27) "I for one had had a number of physicians for a number of different areas - joint, blood, bone, the MRIs etc ... The ability for a dialogue around all those pieces of your condition to be had in one open forum between yourself and your care givers is very helpful. You know, open access to all your results, all the various physicians thoughts."</i></p> <p><i>(R64) "... doctors should be talking to each other... Dialogue with a multidisciplinary team will have benefits."</i></p> <p><i>(0039) "Get organized! Talk to one another and get organized. And somebody needs to take responsibility for clients care. I'm only ever going to use the word client. I am</i></p>

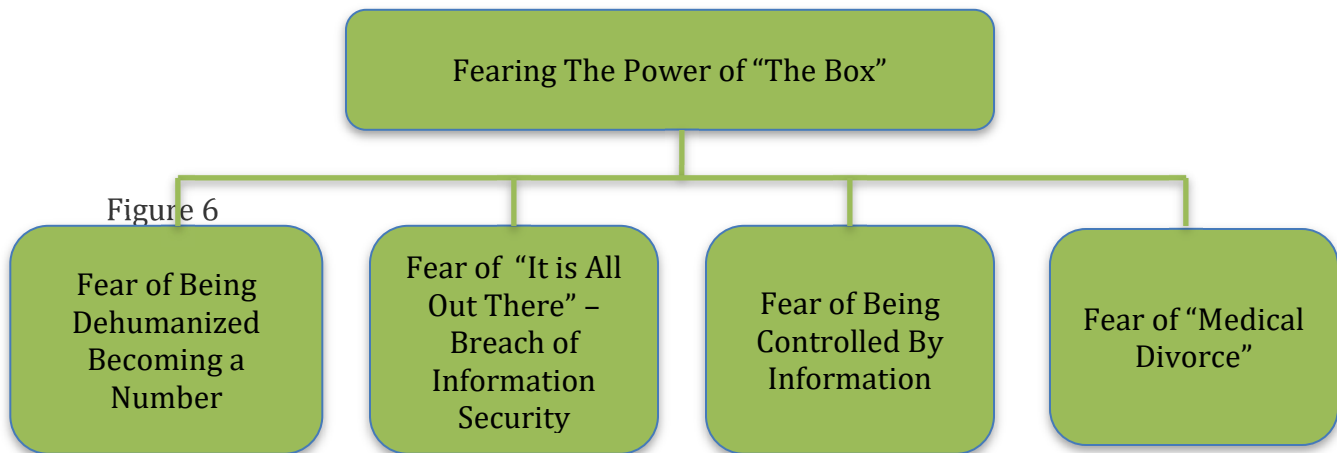
	<p><i>not somebody else's patient, I am their employer."</i>  <i>(648) "I've got two doctors. I got my cardiologist. I got my pulmonary specialist. The cardiologist isn't really worried about my lungs. All he's worried about is my heart. The pulmonary guy isn't worried about my heart. His job is to look after my lungs. So unless the two of them get together, work together, I could find myself between a rock and a hard place."</i></p>
<p>I need you to be diligent and follow up on all aspects of keeping me well</p>	<p><i>(8) "The support didn't last...the team support was short term and I can't quite remember how many weeks it was. It was a few weeks though."</i>  <i>R22 "I have discovered that I, the patient, have to take control of my illness, self advocate and follow up on my own care and treatment."</i>  <i>(3029) "At that point, he said 'nothing has gotten worse. We've sort of got you stabilized, not in a great way but you're sort of, kind of stabilized.' So at that point he's like 'If something gets worse again call me, we'll just start things up again from scratch.' I was kind of in limbo at that point."</i>  <i>(3119) "My husband and I we have a name for it. My old endocrinologist, we call him a cow stamp doctor ... You come in and he stamps you on the head and you leave. We call him cow stamp doctor."</i>  <i>(814) "...what I found most difficult was that for every appointment I had to make the appointment, for otherwise I wouldn't hear from anybody. So you have the surgery and they have to see you again at a certain time and they tell you a lot of things the morning before you get released and some things you miss. So I was just waiting, are they going to call me, do I have to go back? Not knowing what the next step is. I'm a very big believer in planning so the moment I know I have a date, I'm totally fine. If I don't know I have a date I go berserk."</i></p>
<p>I need you to advise me and provide resources for me to stay well and reach for new goals</p>	<p><i>(822) "... if you need a psychologist, you need to see the psychologist now. It is now you are in a big mess not in 4 weeks and the next appointment."</i>  <i>(828) "(I want) someone that's willing to give me more information and help me rather than saying I shouldn't be doing this and I shouldn't be doing that ... some of things he's telling me I shouldn't do, I don't think that's the answer."</i>  <i>(128) "Everyone's goals change as our illness gets worse or better. Goal setting is like hope. You need hope to set goals. They go together. A lot of people would say no it doesn't go together. I've had goals all my life. Now the goals are hope."</i>  <i>(2090) "That big picture. I want to do this in six months help</i></p>

	<p><i>me get there. I need to apply for a new job in 6 months but I need my brain back first.”</i></p> <p><i>(R57) “Patients’ experience of healthcare treatment should be care that generates hope.”</i></p> <p><i>(3210) “She said, ‘Okay, we have a starting point. I can help you with some of those (goals). Some of those we will work towards.’ She started off with things, have you seen a physiotherapist, have you seen an occupational therapist ... I’m like ‘Yes, no, ages ago ...’ She kind of went ‘Okay, let’s start with these things. If you don’t have this, we’ll get this for you.’”</i></p> <p><i>(2024) “It was hell on earth. I also ended up with incredible stress levels from all of this and ended up with ringing in my ears that I hadn’t had before the surgery. So I said – What can I do about this? So I figured out, well okay there seems to be some sort of connection with zinc in trying to get rid of that so let’s just try taking a zinc supplement – Is that going to harm me? – No, Okay so again Dr. Internet you know, but I feel like my doctors aren’t supportive so – I kind of have to resort to the internet, It’s kind of what you do...”</i></p>
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### **Grounded Theory Analysis of COLLECT Group One: Fearing The Power of “The Box”**

As we engaged in our phenomenological reduction analysis of COLLECT Group One in which we asked the original question (*How could an electronic tool be helpful in managing your healthcare plan?*), we noticed that there appeared to be a deep-seated insecurity and resistance to technology from a significant section of participants. We realized that this group, unexpectedly, provided us with the information that did not exactly fit into the question we intended to answer, and that the data went far beyond the phenomenon we intended to analyze. Intrigued by the participants’ language, evasions, and redirections, we decided to carry out a grounded theory analysis of the data (Figure 6) to attempt to uncover what was going on in the data, and what were the main processes involved that we had not foreseen or predicted when we began this group? As most important emerging categories, we discovered the patients’ fears, anxiety and concerns (Glaser & Strauss, 1967).





### Grounded Theory Framework

We found four themes supporting the fear of technology, which were centred around the perceived “power of the box”. The box became the powerful metaphor for any electronically stored medical information. We were told that we had already started down a “slippery slope” with respect to medical records. The four themes were:

- I. The fear that technology would be dehumanizing by reducing patients to a number. There was speculation about what an e tool might be which clearly has little resonance with the actual technical reality
- II. The fear of “it all being out there”. There appeared to be a great deal of magical thinking with respect to what technology could do and where information was stored, showing that fear may have been seated in a lack of understanding.
- III. The fear of being controlled based on your individual information was uppermost in participants’ minds. They were fearful that there would be discrimination because of mental illness, they would be forced into a situation because their medical conditions were widely known, would be denied insurance or other negative consequences There was a great deal of discussion around the power of “the box”. “The box” appeared to be almost a code name for any type of computer that could store what they perceived to be private information and there was a great deal of discussion around the security of the multiple “boxes” used in healthcare.
- IV. The last theme was the fear of medical divorce, that they would lose all warm human contact with their caregivers and that the present level of service would be severely eroded by the introduction of technology that would store all of their medical data.

Table 8: Fear of Technology Grounded Theory Data

Theme	Exemplar Quotes
Dehumanizing, becoming a number	<p>(163) <i>"The spread sheet would have your name, and then there would be categories and spaces for other things, everything would be compartmentalized."</i></p> <p>(190) <i>"From a patient discussing a recent hospitalization. The nurse never came in to my room until she wheeled up that computer that was outside my room. I don't know what she did, everything was there, the pills, when my blood pressure should be taken..."</i></p> <p>(195) <i>"This could be a slippery slope if it got into the wrong hands."</i></p>
"Out there" magical thinking	<p>(213) <i>"I have a computer and I'm on line and I don't know what to do with it ... I don't know anything about it but these things are powerful ... They are susceptible to tampering and you have stories out there every day, people are sweating everyday about how they are going to get the codes to launch missiles on the US. Is some guy going to figure it out, I don't know. "</i></p> <p>(465) <i>"Just imagine anything you are putting on your computer that there is somebody looking over your shoulder because potentially there could be. "</i></p> <p>(193) <i>"I used to look down (in hospital) and see all the little pushcarts outside of all the rooms. I don't know if it's all hooked up to one major network. They don't step into your room until they know all about you. I guess that is from the computer. I presume that all this information is sent to one major computer... everything but your fingerprints are in those electronic records. They know you like they don't know yourself."</i></p> <p>(477) <i>"I don't think it's anyone sitting here necessarily, but there may be others, they've been blackmailed. "</i></p> <p>(52) <i>"...I mean people, hackers, there is always hackers...most probably wanting drugs ... could come to our homes and steal them or find our prescriptions and get them taken care of."</i></p>
The power of "the box" to take over	<p>(167) <i>"What they have in my doctor's office is an actual box ... it's like this thin, and it's this wide ... Everything is written into that little box ... everything in my entire history is in that little box. There are no more big thick files. "</i></p> <p>(182) <i>"You would click on it and something would open and it would be like the little box, everything would be there. "</i></p> <p>(197) <i>"I'm a diabetic and all of a sudden I had a low. Next thing I know I have an EMS guy standing there ... they took me to hospital and their hospitals are set up so if they take your blood pressure or whatever it automatically goes to a computer. Everything is recorded right away through the computer. They</i></p>

	<p><i>don't enter anything. The machine does it automatically and tracks everything. "</i></p> <p><i>(746) "...because it's in the computer there is always the risk of your personal information going out there and one of the things that came up (Speech slows, less sure, frowning rather than smiling). If you ever have ever have treatment or been diagnosed by any kind of mental illness ... (Voice slower, a bit hesitant) there have been cases at the US border where the border people know that you have been treated for depression and they won't let you into the US because you are a suicide risk."</i></p>
<p>"Medical divorce" fear of taking away service</p>	<p><i>(199) "It (E tool) would save the government money because then you wouldn't have to go the doctors and they don't have to charge for the visit."</i></p> <p><i>(210) "Is that going to lead down the road where you don't have a doctor anymore? You just tap on your computer and say what your symptoms are and they would diagnose and prescribe...it's a slippery slope when you put that much in a mainframe. "</i></p> <p><i>(401) "You should be able to go to your doctor and get all the information you need in one visit...that is where they need to expand is in the doctor's office, not on your home computer. "</i></p>

**Discussion**

This study highlights the flexibility of PaCER's *Set-Collect-Reflect* framework. Using the *Set* and *Collect* Focus Group One data, we were able to identify some data collection problems and make adjustments between *Collect* Focus groups One and Two. We were also able to note an emerging fear around electronic record keeping that surfaced during *Collect* Focus Group One and were able to conduct a grounded theory analysis of the relevant data to produce information that might be key when introducing any electronic record programme. The *Reflect* group opened the door to understand the salutogenic nature of the needs of chronically ill patients. This information is important when considering overall health management. PaCER methodology allowed three differing perspectives of the data to be accessed.

All of our participants, whether prompted or unprompted by a guiding question, noted that the use of electronic records, accessible to both patients and professional caregivers, would make management of their various chronic conditions simpler, more efficient and more effective. This is reflective of earlier findings (Ross et al., 2004; Von Korf, Glasgow & Sharpe, 2002; Tenford, Jain & Hickner, 2011). They expressed their difficulty in managing their illnesses across the care of several different specialists (Ball, Smith, Bakalar, 2007) and many suggested the use of a multidisciplinary team (Harris & Zwar, 2007) to improve all aspects of their care. They noted that the health system was better able to manage the acute phase of a disease than help with day to day living with the chronic phase. Most of our

participants wanted to have input as well as access to their electronic health records, believing that they had ongoing, important information for professionals that would enhance their care plans (Winkelman, Leonard & Rossos, 2005, Glasgow et al., 2012).

We believe that the salutogenic findings prompted by the *Reflect* focus group are of major importance when considering the management of chronic conditions. Participants noted that how they were perceived and treated made a huge difference in their ability to function and manage their various diseases (von Korf, Gruman et al., 1997; Wasson & Coleman, 2014). This is congruent with Antonovski's (1979; 1987; 1993) sense of coherence, a concept that seeks to understand the differing abilities of people when managing the stress of illness within their lives. Our participants asked to be seen and supported from the perspective of ability (what they could do) rather than through the lens of their disability (what, because of chronic conditions that were medically not amenable to change, they could no longer do). This, they said, gave them the confidence to manage their lives and constantly reach for new goals.

### **Strengths and Limitations**

This study was conducted through all phases of the research by patients with chronic diseases who, as noted above, were continuously reviewing and discussing their biases. Recognition by participants that the researchers shared their experience of living with chronic disease, may have allowed participants to openly share their lived experience at a deeper level than would have been possible with "traditional" health care researchers. There was no perceived power imbalance and both researchers and participants were focused solely on patient concerns and perspectives (Gillard, Simons et al., 2012; Berger, 2015).

While the study had a small number of participants (18), they presented with a broad spectrum of chronic diseases and were recruited from different sources. Consistency of experience was noted through the focus groups and interviews. Transferability of the findings may be limited as the participants were all from the same large healthcare system (Alberta Health Services) and tertiary level treatment was confined to one large urban centre, so there may be differences in service delivery within other systems. Participants from different cultural, ethnic and socioeconomic groups may have different lived experiences and further research is recommended.

### **Conclusion**

This study points the way toward a more inclusive model of managing chronically ill patients. Patients expressed a need for a true partnership with professionals who were in open and constant communication with each other. They believed there was potential in the concept of electronic records to relieve them of the responsibility of keeping all of their physicians updated with treatments and drugs. They also believed that it would allow for more patient input and participation in their wellness plans.

### **Final Recommendations and Goals**

- 1)** Goal 1 is to augment and support the patient's sense of coherence in managing complex and chronic health needs.
- 2)** Goal 2 is to improve patient by sharing information from specialists, family physicians, allied health (particularly pharmacy) and patients to avoid conflicting treatments and drugs.
- 3)** Include patients in the development and rollout of the EHR to address fears and the unique needs of older users along with those who are used to technology.

## References

- Antonovski, A. (1979). *Health, stress and coping*. San Francisco: Josey-Bass.
- Antonovski, A. (1987). *Unravelling the mystery of health: How people manage stress and stay well*. San Francisco: Josy-Bass.
- Antonovski, A. (1993). The structure and properties of the sense of coherence scale. *Social Science & Medicine*, 36(6) 725 -733.
- Ball, M.J., Smith,C. & Bakalar, R.S. (2007). Personal health records: Empowering consumers. *Journal of Healthcare Information*, 21(1) 76-86.
- Berg, B.L. (1989). *Qualitative Research methods for the social Sciences*. Toronto: Allyn & Bacon.
- Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research*, 15(2), 219-234.
- Bogdan, R. & Taylor, S.J. (1975) *Introduction to Qualitative Research Methods*. New York: John Wiley & Sons.
- Center on Salutogenesis. (n.d.). *Salutogenesis*. Retrieved from <http://www.salutogenesis.hv.se/eng/Salutogenesis.5.html>
- Furukawa, M.F., King, J. et al., (2014). Despite substantial progress in EHR adoption, health information exchange and patient engagement remain low. [http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/February2014\\_SummaryReport.pdf](http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/February2014_SummaryReport.pdf)
- Glasgow, R.E., Kaplan, R.M., Ockene, J.K., Fisher, E.B., Emmons, K.M. (2012). Patient-reported measures of psychosocial issues and health behavior should be added to electronic health records. *Health Affairs*. 31(3), 497-504.
- Harris, M.F. & Zwar, N.A. (2007). Care of patients with chronic disease: The challenge for general practice. *Medical Journal of Australia*, 187(2) 104 -107.
- Kirk, J. & Muller, M.L. (1986). *Reliability and Validity in Qualitative Research*. Newbury Park: Sage.
- von Korf, M., Gruman, J., Schaeffer, j., Curry, S.j., Wagner, E.H. (1997). Collaborative management of chronic illness. *Annals of Internal Medicine*. 127: 1097-1102.

von Korf, M., Glasgow, R.E. & Sharpe, M. (2002). Organizing care for chronic illness. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1123637> .

Lincoln, Y.S. & Guba, E.G. (1986). But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. In D.D. Williams (Ed.) *Naturalistic Evaluation* (pp. 73-84). San Francisco: Josey-Bass.

Marlett, N. & Emes, C. (2010). *Grey Matters: A Guide to Collaborative Research for Seniors*. Calgary: University of Calgary Press.

Marlett N, Shklarov S, Marshall D, Santana MJ, Wasylak T. (2014). Building new roles and relationships in research: A model of patient engagement research. *Quality of Life Research, November 2014*. DOI 10.1007/s11136-014-0845-y <http://link.springer.com/article/10.1007/s11136-014-0845-y> .

McGowan, P. (2012). Self management, education and support in chronic disease management. *Primary Care: Clinical Office Practice*. 39(2), 307-325.

Morse, J.M. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2), 13-22.

Newbould, J., Burt, J., Bower, T. & Blakeman, T (2012). Experiences with care planning in England: Interviews with patients with long term conditions. <http://www.biomedcentral.com/1471-2296/13/71> .

Pagliari, C., Detmer, d. & Singleton, P. (2007). Potential of electronic personal health records. *British Medical Journal*, 335(7415): 330-333.

Ralston, J.D., Revere, D., Robins, L.S. & Goldberg, H.I. (2004). Patients' experience with a diabetes support programme based on an interactive electronic medical record: Qualitative study. *British Medical Journal*, 328:1159.

Ross, S.E., Moore, L.A. et al. (2004). Providing web-based online medical records with electronic communication capabilities to patients with congestive heart failure: Randomized trial. <http://ncbi.nlm.nih.gov/pmc/articles/PMC1550594> .

Schoen, C., Osborn, R. et al. (2011). New 2011 survey of patients with complex care needs in eleven countries finds that care is often poorly coordinated. *Health Affairs*, 30(12), 2437-2448.

Shenton, A.K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22, 63-75.

Tenforde, M., Jain, A., Hickner, J. (2011). The value of personal health records for chronic disease management: what do we know? *Family Medicine*, 43(5), 351-354.

Wagner, E.H. (2000). The role of patient care teams in chronic disease management. *British Medical Journal*, 320(7234), 569-572.

Wagner, E.H., Glasgow, R.E., Davis et al. (2001). Quality improvement in chronic illness care: A collaborative approach. *Journal of Quality Improvement*. 27(2) 63-80.

Wagner, E.H., Austin, B.T. et al. (2001). Improving chronic illness care: Translating evidence into action. *Health Affairs*, 20(6), 64-78.

Wasson, J. & Coleman, E.A. (2014). Health confidence: A simple essential measure for patient engagement and better practice.  
<https://howyourhealth.org/static/HealthConfComboHYH.pdf> .

Winkelman, W.J., Leonard, K.J. & Rossos, P.G. (2005). Patient perceived usefulness of online medical records: Employing grounded theory in the development of information and communication technologies for use by patients living with chronic illness. *Journal of the American medical Information Association*, 12(3), 306-314).