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Exploring the Design of Visualizations to Facilitate Patient-Provider Communication

by

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ABSTRACT

Establishing strong patient-provider communication during clinical visits can have positive impacts on patient health outcomes. On the other hand, miscommunication between patients and healthcare providers can cause harm or in extreme cases cause death to patients. Factors such as healthcare providers' limited time, inefficient clinical environments, and patients' difficulties in communicating their concerns can be the causes of this miscommunication. In this thesis, I explore the design of visualizations to facilitate communication between healthcare providers and patients during clinical visits.

In the first part (i) of this thesis, I present the results of a literature review I have conducted to expand our understanding of patients' and providers' communication challenges during in-clinic visits. In the second phase (ii) I discuss the results of interviews with healthcare providers and I contrast and compare patients' and providers' perspectives in the context of each other to unveil the roots of their communication challenges.

Among the communication challenges we identified, I focus on exploring the challenges and the realities patients and healthcare providers face tracking and sharing patient-generated health data. In the third part of this dissertation (iii), I discuss the results of a series of interviews and focus groups with patients and healthcare providers I have conducted to gain a better understanding of patient-generated data communication challenges. I leverage this understanding to propose potential visualization designs representing patient-generated data collections to improve the process of reviewing and communicating these data between patients and healthcare providers.

In the fourth part of this dissertation (iv), I discuss the results of the interviews with healthcare providers seeking their reflection on the proposed visualization designs. Finally, in collaboration with our healthcare provider team in Alberta Healthcare Services, I implement the prototypes of a number of carefully selected visualization designs.

In the last part of this dissertation (v), I outline insights, lessons learned, and future research directions that arise from these studies and the design process. I hope this research provides more support for considering patients' and healthcare providers' individualities when designing technologies and visualizations in healthcare settings.

PUBLICATIONS

Some ideas and figures have appeared previously in the following publications:

Rajabiyazdi, F. Designing and Developing Technologies to Facilitate Clinician-Patient Communication, *Proceedings of the 2016 ACM Companion on Interactive Surfaces and Spaces, 2016.* ©2016 ACM. Reprinted with permission.

Rajabiyazdi, F. and Perin, C. and Vermeulen, J. and MacLeod, H. and Gromala, D. and Carpendale, S. Differences That Matter: In-clinic Communication Challenges, *Proceedings of the 11th EAI International Conference on Pervasive Computing Technologies for Healthcare, 2017.* ©2017 ACM. Reprinted with permission.

Rajabiyazdi, F. and Perin, C. and Oehlberg, L. and Carpendale, S. The Challenges of Individuality to Technology Approaches to Personally Collected Health Data, *Proceedings of the 11th EAI International Conference on Pervasive Computing Technologies for Healthcare Workshop, 2017.* ©2017 ACM. Reprinted with permission.

Rajabiyazdi, F. and Perin, C. and Oehlberg, L. and Carpendale, S. Personal Patient-Generated Data Visualizations for Diabetes Patients, *Electronic Conference Proceedings of the IEEE VIS, 2018.* ©2018 IEEE. Reprinted with permission.

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INTRODUCTION

In the complex healthcare system, miscommunicating information between patients and healthcare providers can cause substantial harms or even death among patients Ong et al. (1995); Cegala and Post (2009). It is important to work towards improving clinical communication to present healthcare providers with access to the best, the most focused, the richest information about the patient's condition and provide patients with all the information related to their conditions MacLeod et al. (2015); Ong et al. (1995)

One way to support healthcare providers and patients communicate the right information is to design effective technological solutions. However, designing the right technology for facilitating patient-provider communication is far from a solved problem; the questions of what type of technologies to design remain not fully answered. Visualization that can accurately summarize data could be one possible solution to improve the information exchange between patients and healthcare providers.

The main objective of the research presented in this dissertation is to explore the possibilities of using visualizations as a communication technology medium to facilitate patient-provider communication during clinical visits. Identifying communication challenges in the scope of healthcare system can be looked at from different perspectives. For the purpose of this dissertation, I will focus on the communication challenges between patients with chronic conditions and healthcare providers during their routine non-emergency visits in medical clinics or provider offices.

In this chapter, I first provide an overview to this dissertation research problem and my approach towards this research problem. In Section 1.1, I explain the importance of addressing this research problem and in Section 1.2, I walk through the context of my research. In Section 1.3, I state the thesis statement and the three main objectives of this research. In Section 1.4, I outline the scope of this research problem in an intersection of human-computer interaction, information visualization, and healthcare, and list the contributions of this dissertation to each field. In Section 1.5, I explain the overall methodological approaches undertaken to address this research problem. In Section 1.6, I list the contributions of this research. Finally, in Section 1.7, I provide a map of this dissertations' parts and chapters.

One of healthcare providers' primary sources of information comes from patients' descriptions of their conditions during clinical visits. However, patients are not always able to communicate all the necessary information to healthcare providers, which can make it challenging for providers to make informed medical decisions and recommendations. On the other hand, healthcare providers sometimes fail to communicate the necessary information that patients may need.

Studies showed that effective patient-provider communication can have a positive impact on patient care and patient overall quality of life Detmar et al. (2002); Stewart (1995); Wright et al. (2004). These benefits include improving elements of the patient's mental well-being, such as: decreasing anxiety Evans et al. (1987); Fallowfield et al. (1990); Rainey (1985); Thompson et al. (1990), controlling depression Fallowfield et al. (1990); Egbert et al. (1964), enhancing mood Johnson et al. (1988); Rainey (1985), and raising patient hope for the future Wright et al. (2004); Kerr (2003).

In addition to improving patients' mental states, studies have shown that effective communication can improve patient physical and functional health outcomes, such as: reducing patient physical limitations Greenfield et al. (1985); Johnson et al. (1988), balancing patient vital signs Kaplan et al. (1989); Orth et al. (1987), shortening the length of hospital stay Egbert et al. (1964), controlling chronic disease symptoms Bass et al. (1986); Heszen-Klemens and Lapińska (1984); Hulka et al. (1975); Egbert et al. (1964), increasing patient engagement in their care Cegala and Post (2009), and strengthening treatment outcomes Ong et al. (2000); Buller and Buller (1987).

In summary, patient-provider communication can greatly impact patients' lives and health outcomes. To deliver better care, both patients and healthcare providers need to work towards establishing strong patient-provider communication. As technology designers, we can design technological mediums that could support patients and healthcare providers in facilitating effective communication.

1.2 CONTEXT

One way to support patients and healthcare providers to establish strong communication is to design effective communication technology mediums. However, designing the right technology or visualization to facilitate patient-provider communication has not been fully investigated. The first step towards designing effective communication technologies or visualizations is to gain a better understanding of patient-provider communication challenges and barriers. Thus, in this dissertation I review literature and conduct qualitative studies to identify patient-provider communication challenges in clinics.

The results of these investigations revealed a series of patient and healthcare provider communication challenges. With the collaboration of a healthcare provider team, we discussed each of these communication challenges and proposed possible technological and visualization solutions. Although all these challenges are important and need to be addressed, the evidence from the literature and the expertise of my healthcare provider team suggested to focus on presenting and reviewing patient self-generated health data during clinical visits.

The number of patients with chronic conditions is increasing every day in the world [1]. The nature of chronic conditions requires close monitoring and self-managing care for these patients Fox and Duggan (2013); Heitkemper et al. (2004). This care taking leaves patients and their healthcare providers with a large amount of patient health data moni-

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[1] http://www.who.int/chp/about/global_forum/en/

tored at home. Communicating these data during short clinical visits can be challenging. According to David Eddy, "*It is simply unrealistic to think that individuals can synthesize in their head scores of pieces of evidence, accurately estimate the outcomes of different options, and accurately judge the desirability of those outcomes for patients*" Eddy (1990b,a).

Thus, for the scope of this dissertation I focus on understanding patients' perspectives when monitoring, collecting, and presenting their data to the healthcare providers. Based on this understanding, I propose visualization designs to represent these data and will redesign and modify these visualizations through phases of iterations based on healthcare providers' feedback along the way. Finally, I explore the possibility of transferring these visualization technologies to the healthcare systems for patients' use.

1.3 THESIS PROBLEM

Studying communication challenges in the scale of the entire healthcare system is challenging. I focus on the communication challenges between patients and their healthcare providers when they discuss patient data during routine clinical visits. In particular, I explore how to design visualizations that can potentially facilitate the communication of patient-generated data between patients and providers during clinical visits.

Given the importance of patient-provider communication in healthcare settings, there have been studies in the literature to better understand the patient-provider communication challenges and attempts to design technological solutions to improve patient-provider communication. However, there is not enough information on if and how visualization can facilitate communication between patients and providers. Thus, in this dissertation, I will focus on,

Thesis Statement: *Exploring the possibilities of using visualizations as a communication technology medium to facilitate patient-provider communication during clinical visits.* I divide this problem into the following three objectives:

Objective 1: Expand our current understanding of patient-provider communication challenges during in-clinic visits from both patients' and healthcare providers' perspectives to identify opportunities and gaps where patients and providers can benefit from the use of visualizations. I address this objective by reviewing the literature and conducting qualitative studies to identify, compare, and contrast patient and provider communication challenges in the context of each other.

Objective 2: Explore the reality of patients monitoring and recording their health data and understanding the challenges they face for presenting their self-generated health data to healthcare providers during clinical visits. After discussing the communication challenges identified in Objective 1 with the healthcare provider collaborators, I chose the focus of this objective; communication challenges between patients and healthcare providers when discussing patient-generated data. I address this objective by reviewing samples of patient-generated data collections and conducting interviews with patients. Then, I leverage the understanding gained in the patients' interviews to map out a design space of potential visualizations to represent patient-generated data.

Objective 3: Investigate healthcare providers' perspectives and goals when requesting and reviewing our proposed patient-generated data visualizations. I address this objective by conducting interviews with healthcare providers and receiving their feedback on our various designed alternative visualizations representing patient-generated data.

1.4 SCOPE

This dissertation is broadly situated within the research areas of Human Computer Interaction, Information Visualization, and Healthcare Technologies (Figure 1). This research is set in the context of communication challenges during clinical visits between patients and healthcare providers. This includes patients' visits to discuss their medical issues with a primary care physician or a specialist for their advanced care in the clinic or in the healthcare providers' offices. However, the scope of this research is constrained to non-emergency clinical visits and when patients and healthcare providers discuss patients' symptoms, diagnosis, and treatment plans. This excludes communication challenges that happens in the emergency, ICU, and surgery rooms and the topics related to end of care plans, delivering bad news, faith and spirituality, and financial issues.

1.5 METHODOLOGY

In this dissertation, I look into the communication challenges between patients and healthcare providers during in-clinic visits. This research problem is a *wicked* problem (a problem that cannot be solved with linear methodologies Rittel and Webber (1973)), as a result the nature of this research is highly exploratory. Thus, I employ a combination of research methodologies including literature reviews, interviews, focus groups and iterative design. Patient-provider communication is a two-sided interaction, thus throughout this research, I include both healthcare providers and patients and I compare, and contrast both perspectives.

The combination of methodologies I used for this research and the inclusion of both perspectives in the process of design made it possible for me to uncover subtle consider-

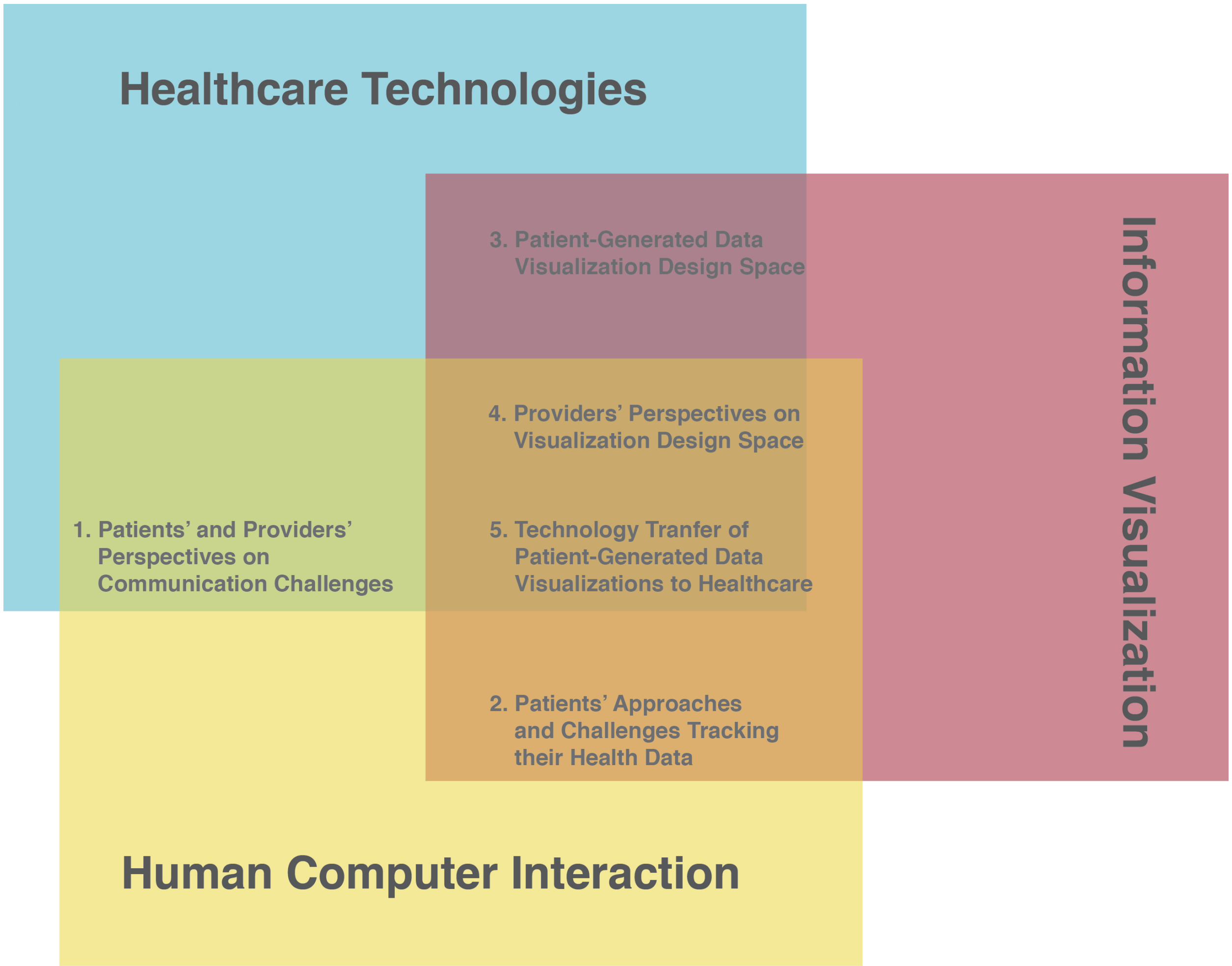


Figure 1: The contributions of this dissertation situated between Human Computer Interaction, Information Visualization, and Healthcare Technologies research areas. The numbers in this figure refer to the contributions listed in Section 1.6.

ations that can play important roles when designing visualizations to facilitate patient-provider communication. In each chapter of this dissertation, I provide detailed information about the methodologies I used to conduct the research.

1.6 CONTRIBUTIONS

This research is situated at the intersection of human-computer interaction, information visualization, and healthcare technology. Figure 1 shows how the contributions of my dissertation feed into these areas. The numbers at the beginning of each paragraph refer to the numbers shown in Figure 1. In the following section, I outline my contribution.

1. Patients' and Healthcare Providers' Perspectives on Communication Challenges

I conducted a literature review studying computer science and medical science to identify patients' and healthcare providers' communication challenges during clinical visits (Chapter 2). My findings showed while patients' perspectives are well represented in research literature, far fewer studies have reflected healthcare providers' perspectives on clinical communication challenges. To fill this gap, I conducted interviews to better understand healthcare providers' perspectives. *From the findings of both the literature review and our healthcare providers' interviews, I reveal subtle differences between patients' and providers' perspectives on communication challenges and discuss how these subtle differences exacerbate the communication dynamics during clinical visits* (Chapter 4).

2. Patients' Approaches Tracking their Health Data

One of the patient-provider communication challenges I identified was reviewing and making sense of patient-generated data during clinical visits. To shed light on this challenge, I first studied eight patient profiles with chronic conditions and their approaches to collecting and presenting their health data to healthcare providers during clinical visits. *Through use of semi-structured interviews, I unveil eight independent approaches patients taken to self-managing and tracking their health data*. (Chapter 5).

3. Patient-Generated Data Visualization Design Space

The results of our studies with patients showed the uniqueness and the individualities of each patients' approach when tracking and presenting their health data. I designed various visualizations for each patient that can be used to represent patient-generated data based on patients' profiles, their own challenges, and individual needs. *I demonstrate a design space of these patient-generated data visualizations* (Chapter 6).

4. Healthcare Providers' Perspectives on Visualization Design Space

I conducted studies to gain a better understanding of healthcare providers' reflections on the visualization design space. I investigated how healthcare providers envision using these visualizations in their practice. *I discuss the healthcare providers' different perspectives, their preferences on the presentations, and the use of the patient-generated data visualizations during in-clinic visits* (Chapter 7).

5. Technology Transfer of Patient-Generated Data Visualizations to Healthcare

Based on the results of healthcare providers' feedback on the design space and with help of our healthcare provider collaborators, I selected four visualizations from the design space to implement for patients on a web-based platform. These visualizations were professionally implemented from my prototypes as part of patient-centered care plan called MyCareCompass, for patients registered in Alberta Health Services. *I explain the details of our visualization designs and the process of transferring these designs into the professional implementations for the patient platform*. For the current phase of the project, this platform will be available for use among a selected group of patients. Based on these patient' and the healthcare providers' perspectives, the future iterations of the project will be implemented and available to the public. (Chapter 8).

Summary

Throughout my dissertation work, the results of all the studies I have conducted with patients and healthcare providers revealed the importance of designing for individual patient while considering their healthcare providers and their particular relationships.

There is often the notion of designing with a generalization mindset in software and technology design, research, and businesses. The idea of designing one software or one visualization tool that can address everyone's problem may be appealing and cost efficient, but as mentioned by Bertelsen et al. (2018), it does not always bring validation. In here, I would like to echo the voice of the authors in their recent work Bertelsen et al. (2018) that I came across in the last week of writing this dissertation and point to the necessity of designing for particulars, *individuals*.

Designing for individuals can be even more critical in the field of medicine and when designing for patients and healthcare providers. As introduced in the biopsychosocial model Engel (1981), biological, psychological, and social factors need to be considered all together when caring for patients. Each patient has a unique body, a highly individualized lifestyle, a different set of goals, and a personalized patient-provider relationship Topol (2011). How can we design only one visualization solution that can consider all these differences in patients? Can one design fit all?

In this dissertation, I included the perspectives of a small number of patients and healthcare providers. I am aware that other important perspectives may have been not included in these studies. Thus, I encourage the (human computer interaction, visualization, healthcare) communities to work towards repeating these studies by including more patients and healthcare providers and explore designing visualizations for each individual. Then, as a community, we need to move towards accumulating these perspectives and designs to empower individuals with accessible design variations.

1.7 THESIS OUTLINE

This dissertation is structured into five parts (Figure 2):

Part i: CONTEXT & BACKGROUND, introduces the background of this research and its methodological approaches. This part includes two chapters. In Chapter 2, I present the results of the literature review conducted to identify the patient-provider communication challenges previously discussed in the literature. In addition, I discuss the potentials and limitations of technological and non-technological approaches previously proposed to improve in-clinic patient-provider communication. Chapter 3 provides an overview of the methodological approaches that I applied in my research on understanding the patient-provider communication challenges and how to design effective technologies to enhance this communication.

Part ii: UNDERSTANDING & IDENTIFYING PATIENT-PROVIDER COMMUNICATION CHALLENGES, discusses patient-provider communication challenges. In this part, Chapter 4 expands the current understandings of patient-provider communication challenges. As part of this chapter, I identify opportunities where patient-provider communication can benefit from the supports of technological tools or data visualizations.

Among the opportunities for possible technological or visualization solutions identified in Part ii, I focus on designing visualizations that can facilitate reviewing patient-generated data between patients and providers. I chose to focus on this communication challenge after extensive discussions with the healthcare provider team. Part iii: DESIGNING VISUALIZATION TO ENHANCE PATIENT-PROVIDER COMMUNICATION, maps out a series of preliminary visualization designs representing patient-generated data. This part includes two chapters. In Chapter 5, I introduce eight patient profiles and in Chapter 6, I explain the rationales behind my visualization designs for each patient.

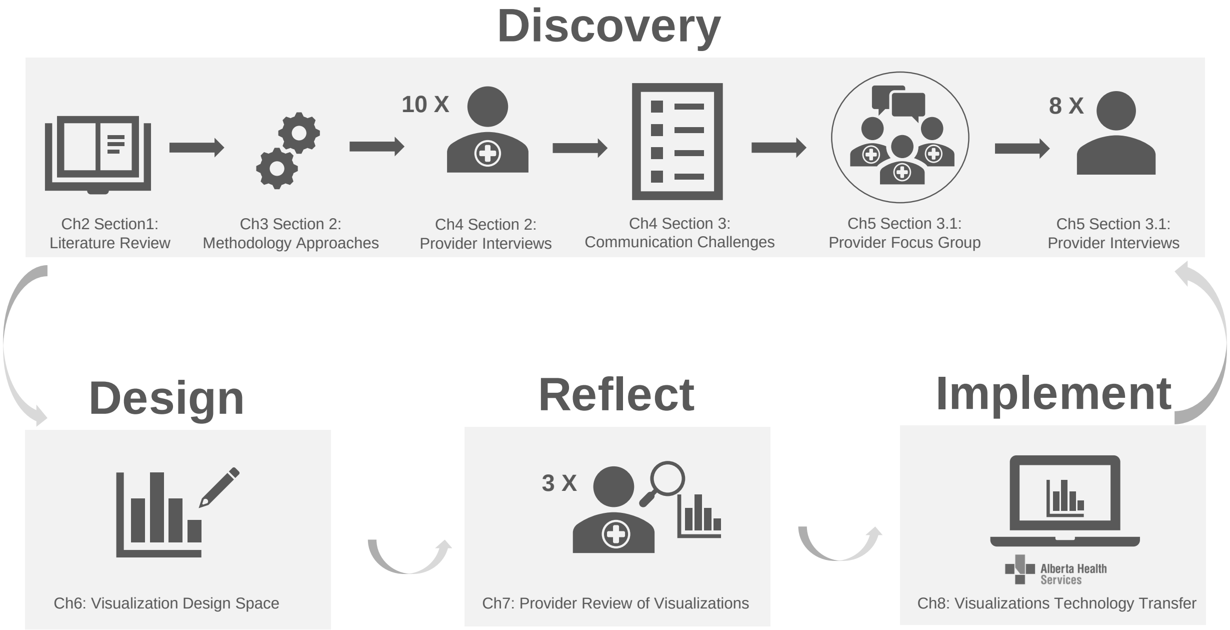


Figure 2: Thesis Structure and Methodology Phases - Discover, Design, Reflect, Implement

Part iv: PROVIDERS REFLECTIONS’ ON VISUALIZATION DESIGNS AND TECHNOLOGY TRANSFER, discusses the providers’ responses to the patient-generated data visualization designs (Chapter 7). In Chapter 8, I present the process of selection and implementations of the patient-generated data visualizations for technical transformation to the healthcare service system. I discuss how these designs will be integrated into the patient-centered care platform.

Part v: CONCLUSIONS, concludes this dissertation by summarizing the future directions (Chapter 9) and the contributions of this research (Chapter 10).

Part I

CONTEXT AND BACKGROUND

2

BACKGROUND AND LITERATURE REVIEW

Patient-provider communication has a significant effect on healthcare outcomes. A healthy patient-provider communication can improve both emotional and informational components of this communication Kelley et al. (2014). However, establishing a strong patient-provider communication can be challenging. Previous studies explored the challenges and the approaches to building effective patient-provider communication.

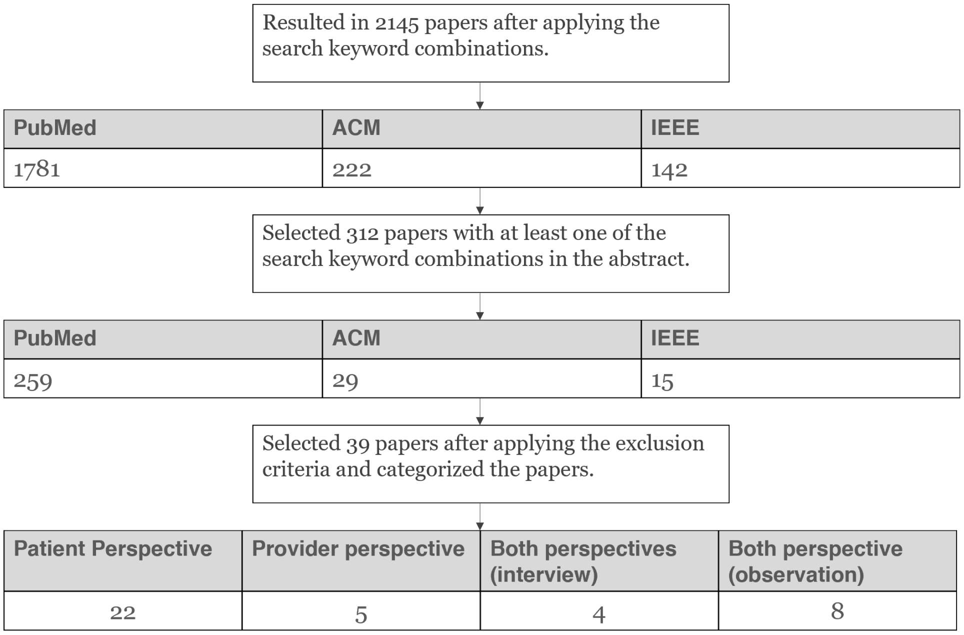
In this chapter, we first present the results of our literature review studying both medical science and computer science literature to identify patient-provider communication challenges. More specifically, we will focus on the challenges patients and providers face communicating patient data during in-clinic visits.

Next, we discuss the non-technological approaches we found in the literature to improve patient-provider communication. Last, we discuss technological tools and visualization representations designed to facilitate patient-provider communication, as well as the limitations of these technologies when used in clinical settings.

To identify patient-provider communication challenges discussed in literature, we started our literature search with a broad set of keywords to collect papers that investigated the challenges patients and healthcare providers face when communicating during in-clinic visits. We searched PubMed, the ACM Digital Library (DL), and IEEE Xplore for all combinations of the following keywords: "physician/clinician/doctor + patient + communication/interaction + challenge/problem/issue/difficult". This search resulted in an initial set of 2145 articles: 1781 from PubMed, 222 from ACM DL, and 142 from IEEE Xplore. We went through all papers' abstracts and selected 312 papers that contained at least one of the search keyword combinations in their abstract (Figure 3).

Given our focus on day-to-day clinical visits, we excluded articles on patient-provider communication in extreme medical cases such as ICU care, surgery care, delivering bad news to patients, and end of life discussions. In addition, since we are focusing on a more general patient population, we have not included papers discussing circumstances such as caring for patients with cognitive/physical disabilities, patients with extreme financial issues, and patients with different spirituality beliefs. We further excluded papers that only focused on the design and development of technology and have not investigated the communication requirements or challenges that patients or providers may face.

This process reduced the 312 papers to 39 relevant papers. We divided the remaining papers into four categories: papers that discussed only patients' perspectives (22 papers); papers that only investigated providers' perspectives (5 papers); papers that included both patients' and providers' perspectives via interviews (4 papers); and papers that included both patients' and providers' perspectives via observation studies (8 papers).



Resulted in 2145 papers after applying the search keyword combinations.

PubMed	ACM	IEEE
1781	222	142

Selected 312 papers with at least one of the search keyword combinations in the abstract.

PubMed	ACM	IEEE
259	29	15

Selected 39 papers after applying the exclusion criteria and categorized the papers.

Patient Perspective	Provider perspective	Both perspectives (interview)	Both perspective (observation)
22	5	4	8

Figure 3: Literature Review Process

We carefully read these papers to identify communication challenges using open coding techniques Strauss and Corbin (1997). Here, we discuss seven main communication challenges we identified in the literature from both patients' and providers' perspectives.

2.1.1 *Challenge (C1): Patients Feeling Anxious during Clinical Visits*

Anxiety is one of the factors that interferes with establishing smooth clinical visits' communications between patients and providers. Patients may feel anxious when they come to the exam rooms. Patients stated external factors such as the exam room environment and the organization of the room Fonville et al. (2010) and lack of time during a clinical visit Howie et al. (1991) as causes of their anxiety. They also feel anxious when providers use computers during the medical visit, which can interfere with the communication dynamic and activities in the medical visit Chen et al. (2011).

2.1.2 *Challenge (C2): Patients Sharing Emotions Tangled with Factual Information*

Another challenge that often arises during clinical visits between patients and providers is keeping a balanced conversations sharing both emotional information and medical facts. Patients usually like to share their emotions while describing their symptoms or conditions to their providers Chung et al. (2016). In the literature, we found different reasons for this patient need. Some study results suggest that patients share their emotions with the providers since they may think providers need to know. On the other hand, some patients think sharing positive emotional information with their providers will make providers happy to know they are doing better Sun et al. (2013). Or in some cases they just want to share their frustrations and emotional downfalls to get more attention from their providers and make sure they know how bad their problem is Detmar et al. (2002, 2000).

2.1.3 *Challenge (C3): Patients and Providers Having Different Expectations*

Patients sometimes have different expectations than providers on their care plan. In the literature researchers found that patients' unrealistic expectations come from their lack of knowledge, their vulnerability due to illness, or their previous experience with other diseases that were treated easily or with their relative or friends who have had similar diseases treated easily Kravitz et al. (1996); Mancuso et al. (1997, 2003).

Discrepancy between patients' and providers' expectations can be due to individuals' characteristics. This includes patient low education levels, difficulties in understanding providers Schillinger et al. (2004), cultural differences with their providers Schouten and Meeuwesen (2006), the lack of consideration of their age and gender by providers Hall and Roter (1995), language barriers, and misunderstanding medical documents and medical terms Liu et al. (2011).

2.1.4 *Challenge (C4): Patients Disengaging during Clinical Conversations*

Before the 20th century, medical paternalism Thomasma (1983) was the most common model, where providers expected patients to follow their lead and apply the prescribed treatment plan Bodenheimer et al. (2002). Patients were willing to cede authority to providers, entrusting their well-being to providers who know best. Since the late 20th century, expectations of both providers and patients have changed towards a model of less passive patients Thomasma (1983); Bodenheimer et al. (2002). However, increasing patients' engagement in their care and in the clinical conversation still is a communication challenge. The literature identified several factors that disengage patients from a medical conversation. Patients think that sometimes the speed of information exchange is too fast causing them to lose track of the conversation Unruh et al. (2010). This is an even more serious issue for patients who do not speak the same language as their providers Julliard et al. (2008); Weibel et al. (2013). Although there is an option to ask for an interpreter or a family member to translate, some patients are embarrassed to express their need for a translator Julliard et al. (2008) and feel like they may lose direct interaction with their providers Hudelson et al. (2013).

2.1.5 *Challenge (C5): Patients and Providers Exchanging Information*

Exchanging the right information between providers and patients is another communication challenge during clinical visits. It can be challenging for patients to accurately transfer necessary information to providers explaining their symptoms. Patients understand that providers want to know more about their disease symptoms than their emotional states which can be challenging for patients Detmar et al. (2002).

One the other hand, providers may face difficulties informing patients about their conditions and educating them about how to manage their conditions. For instance, in the case of patients with rare diseases, some providers' unfamiliarity with their case or their disease may cause difficulties in the communication MacLeod et al. (2015).

2.1.6 *Challenge (C6): Patients Seeking Information from Invalid Resources*

Patients often need to know different information than they have been given by their providers Aarhus and Ballegaard (2010). Patients want to know more about their condition and ways to manage their disease, thus they look for more information often searching the Internet. Previous studies confirmed the positive effect of patients using Internet as their main source of information Broom (2005). The benefit is empowering patients in making their care decisions. However, patients and provider are both aware of some of the negative effects, such as an increase of stress levels in patients looking for information on the Internet White and Horvitz (2009).

Patients and providers may not agree on the information that patients should search on the Internet. Providers prefer patients look up information is relevant and necessary.

However, patients want to know more about how to live with their disease in real life and how to turn this knowledge into practice Aarhus and Ballegaard (2010).

2.1.7 *Challenge (C7): Patients Misusing Medical Terms*

Patients sometimes feel left out of clinical conversations. Thus, one way for patients to get involved in the conversations is to familiarize themselves with their condition's medical terminologies. This way, patients feel more of an expert in their disease, sound intelligent, and feel more in control of the clinical conversations MacLeod et al. (2015). However, patients do not always use medical terms correctly Castro et al. (2007) which can interfere with the clinical communications.

2.1.8 *Summary*

As mentioned in the previous sections, numerous studies have explored challenges and barriers towards effective patient-provider communication from the perspective of patients. As a result, there is a relatively good understanding of how and why patients experience communication challenges with providers. Some researchers address these challenges by proposing non-technological and technological solutions. In the following section, we will go through some of the successful solutions and their characteristics.

2.2 NON-TECHNOLOGICAL APPROACHES TO IMPROVE PATIENT-PROVIDER COMMUNICATION

Establishing communication between patients and healthcare providers has three main purposes: building a personal relationship between patients and providers, exchanging information, and making medical decisions Ong et al. (1995). In this section, we look into the previous research that took steps towards improving these aspects of patient-provider communication.

2.2.1 *Building a Smooth Patient-Provider Personal Relationship*

Creating a good personal relationship between patients and providers can leverage communication during medical visits. However, there are obstacles to smoothly building this relationship. Patients usually experience emotional burden resulting from their conditions which may lead to feeling frustrated and unsatisfied with providers MacLeod et al. (2015). On the other hand, providers reported feeling guilty and ungratified for not being able to deliver the care patients may expect from them Rajabiyazdi et al. (2017b).

One way to improve this relationship may be for providers to understand patients' personal goals and their everyday lifestyles. Providers showed interest in knowing about patients' personal data such as goals, feelings, moods, past life changing experiences, perceptions about their own medical condition, upcoming social events that could affect their conditions, and quality of life Huba and Zhang (2012). Patients also were interested in sharing information about their personal life and even preferred to set their health goals in the presence of the providers to prevent underestimating or overestimating their abilities van der Weegen et al. (2013). To facilitate the process of goal setting and personal data sharing, some patients even started using self-tracking tools to record their health data for presenting to providers Ancker et al. (2015b). Providers mentioned that looking into patient-generated data gives them more insight about patient's goals and expectations for their care Huba and Zhang (2012).

2.2.2 *Including Patient Self-Collected Data in Care Planning*

Lack of clear information about patient conditions can cause difficulties in establishing smooth patient-provider communication during clinical visits. Providers reported that they are missing patient health information in approximately 13.6 percent of medical exam visits Smith et al. (2005). This number is negatively affecting patients 44 percent of the time and 59.6 percent of the time results in delayed care or additional resource utilization Smith et al. (2005). When patients are experiencing multiple conditions missing information is a more serious problem Smith et al. (2005). One approach to address this information gap is to include the health data that patients track themselves outside clinical spaces Sands and Wald (2014). Health data monitored and recorded outside clinical space by patients or their caregivers with the purpose of improving patient health is defined as patient-generated data (PGD) Zhu et al. (2016).

A survey study in 2013 showed at least seven out of ten adults in U.S track a health indicator for themselves or someone for whom they take care Fox and Duggan (2013). People track their health data in various forms including memorization, personal electronic records, personal paper records, original artifacts, and through electronic patient portals Ancker et al. (2015a); Moen and Brennan (2005). An increase in availability of wearable sensors, mobile health apps, and novel portable technologies provided patients an extra boost to track more personal health data Almalki et al. (2015). Studies showed that patients found using personal technologies useful for tracking health data and starting discussions about their health and their needs with the providers Zan et al. (2015); Torbjørnsen et al. (2014).

2.2.3 *Involving Patients in Decision-Making Processes*

To support patients and providers in building a smooth relationship Matthias et al. (2010) suggested efforts in creating more patient-centric care, actively engaging patients in developing their own health goals, and involving patients in the decision-making processes.

Before the 20th century, healthcare providers had a more paternalistic role and attempted to make most of the medical decisions for patients Thomasma (1983). Recently this approach has shifted towards including patients in the decision-making process Bodenheimer et al. (2002). Patients are willing to put more efforts in seeking more information about their conditions to make informed medical decisions Milewski and Parra (2011); MacLeod et al. (2015); Choe et al. (2014). Providers are also more keen to engage patients in their care and making informed decisions Rajabiyazdi et al. (2017b).

However, making crucial medical decisions is not always an easy task for patients Fallowfield et al. (1990); MacLeod et al. (2015). For example, decisions about major surgeries, lifetime medication intake, or screening tests with major risks can be difficult to make for patients without any support from healthcare providers Gonzales and Riek (2013a). To make informed decisions, patients need access to tailored information about their conditions explained to them in simple and non-medical terms Gonzales and Riek (2013a). Healthcare providers can help patients understand the risks and the benefits of patients' different medical options during clinical visits Barry and Edgman-Levitan

(2012). Clear clinical communication can facilitate shared decision making between patients and providers Stacey et al. (2011).

2.3 TECHNOLOGICAL APPROACHES TO IMPROVE PATIENT-PROVIDER COMMUNICATION

Although patient-provider communication can greatly impact patients' lives and health outcomes, establishing effective communication is challenging as both patients and providers experience communication barriers. In recent years, there has been an increasing trend of supporting healthcare services using technology. Researchers and designers have created several technologies for healthcare services including, electronic medical records Fitzpatrick and Ellingsen (2013); Zhou et al. (2012), visualizing patient record histories Plaisant et al. (1996); Wongsuphasawat et al. (2011), collaboration technologies among healthcare providers Lee et al. (2012), communication technologies for hospitalized children Liu et al. (2015), and self-monitoring technologies to support patient engagement Kaziunas et al. (2013); Li et al. (2011).

There is evidence that technology *can* support providers and patients in improving the quality of communication Leong et al. (2005); Sullivan and Wyatt (2005). Here, we report on several patient-provider communication technological tools with promising results that considered both providers' and patients' perspectives in their design.

2.3.1 *Patient-Provider Communication Technologies*

The HCI community has taken steps towards designing technologies to facilitate patient-provider communication. We found several successful targeted tools each aiming to improve one aspect of this communication. Here, we discuss the details of these tools.

Patients sometimes have a hard time communicating their pain to providers. BodyDiagrams [1] is an online interface that allows patients to annotate the severity and temporal nature of their pain over a body mocked-up along with a description of their pain. Patients found BodyDiagrams useful, giving them more confidence that their pain will be correctly interpreted. Providers also found BodyDiagrams descriptions more informative Jang et al. (2014).

Ni et al. (2011) explored the use of a projection-based handheld device for educating patients about their injury during their in-clinic visit. AnatOnMe projects body anatomy on patient's knee. Researchers found AnatOnMe useful in educating patients for physiotherapists and they were keen to include more medical content for different injuries. Their results show that the system was better suited for patients who recently had surgery than patients with chronic disease.

To support sandtray therapy, a form of art therapy, Hancock et al. (2010) presented an iterative design of a virtual sandtray for a tabletop display to support youth patients and their therapist communications. Their results show that the prototype was sufficient for therapists to gain insights about patients' psyche through their interactions with the virtual sandtray.

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[1] https://idl.cs.washington.edu/papers/bodydiagrams/

2.3.2 *Patient-Provider Communication Visualizations*

Similar to HCI community, the visualization researchers also took initiatives and employed the power of information visualization to better present the information during clinical visit.

Monologger is an interactive visualization that represents provider and patient conversations including interruptions, questions, affirming speech, monologues, and repeated words. This visualization offers feedback to providers on their communication skills and helps them identify their flaws in long discussions Cook and Hirsch (2014).

Ananthanarayan et al. (2013) created a wearable knee rehabilitation device to facilitate patient-provider communication by visualizing patients' knee bend. While patients found the visualization intuitive and correctly correlated to their knee angle, the researchers in this study did not evaluate their system from physicians' or physical therapists' perspectives.

Establishing a smooth communication with patients with hearing disabilities is challenging. Piper and Hollan (2008) designed a tabletop display that shares visual information and incorporates keyboard entry from a deaf patient and speech input from the providers. Their results show that such technologies can be a substitute to using an interpreter (limited due to cost, availability, and privacy) and facilitate medical interviews while maintaining patient privacy.

2.3.3 *Summary*

We reported on several patient-provider communication technologies with promising results Ni et al. (2011); Piper and Hollan (2008); Hancock et al. (2010); Cook and Hirsch

(2014); Ananthanarayan et al. (2013). Looking into their design processes and evaluation studies, there is a higher chance of success when these technologies are designed with consideration of both providers' perspectives and patients' needs. However, only a few patient-provider communication technologies considered both perspectives in their design; these were usually successful, particularly in the physiotherapy domain. The limited number of communication technologies for physicians could be due to lack of physicians' involvements because of their busy schedule. Perhaps, a deeper investigation is needed into the reasons behind physicians' low engagement in the process of communication technologies.

2.4 DISADVANTAGES OF USING TECHNOLOGICAL TOOLS DURING PATIENT-PROVIDER COMMUNICATION

While communication technologies do seem to offer advantages to both patients and providers, there are also concerns that these technologies can negatively impact communication. The presence and the placement of the technologies in the exam rooms can affect the quality of patient-provider communication and it may limit face-to-face interactions. Researchers investigated the limitations of using computer in medical exam rooms on patients' outcomes and on providers' practices Chen et al. (2011); Shachak and Reis (2009); Fonville et al. (2010).

Nowadays, most healthcare services across the world use electronic health records to archive patients' conditions. Although these electronic medical records assist physicians in exchanging the right information with patients, it lowers the rate of oral counseling since physicians have to look at the screen or keyboard Shachak and Reis (2009). To examine this negative effect during patient-physician interactions, Chen and his colleagues evaluated placements of a computer in three distinct positions: exclusive (the screen only faced to the physician), collaborative (both patient and physician can see the screen), and neutral (the screen is optionally viewable by patient). They found that the best placement is dependent on the activities in the medical visit for engaging patients in the communication Chen et al. (2011). However, exam rooms are often designed considering available resources rather than communication dynamics Fonville et al. (2010).

Studies show that improper layout of clinical settings and the inadequate communication technologies in healthcare facilities unnecessarily add to the time healthcare providers need to invest on retrieving and recording patient data Page (2004). This leaves providers less time to spend on patient care Page (2004). Therefore, designers need to consider the clinical setting environment when designing technologies for facilitating patient-provider communication.

2.5 SUMMARY

The examples we discussed in the previous sections show that technology *can be* a solution to some patient-provider communication challenges when carefully designed to consider patients' needs, healthcare providers' perspectives, and the clinical environment layouts. While promising, these technologies were designed for specific use cases. In order to facilitate the design of in-clinic communication technologies in a general context, we need to have a broader and more comprehensive understanding of the communication challenges faced by patients and providers.

3

METHODOLOGY

In this dissertation, we explore how to design visualizations to facilitate patient-provider communication during clinical visits. In such communication dynamics, there are multiple parties involved – patients, healthcare providers, and healthcare systems – that all need to be considered when designing visualizations. This complexity makes it challenging to find a definitive solution that can work for every individual. As mentioned in Chapter 1, we think of this thesis research problem as a wicked problem, a problem that cannot be solved with linear methodologies. Thus, to address this research question we employ a series of exploratory methodologies in an iterative design approach.

In this chapter, we first discuss the characteristics of a wicked problem and how it applies to our research problem. Then, we describe the research methodologies we used to address this problem. We take qualitative approaches (interviews and focus groups) to better understand this wicked problem from both patients' and providers' perspectives. From this understanding, we employ an iterative design cycle approach exploring how to design visualizations for each individual patient and healthcare provider based on their unique needs and challenges. Last, we reflect on the insights and experiences we gained through this exploratory design process.

3.1 DESIGNING FOR PATIENT-PROVIDER COMMUNICATION: WICKED PROBLEM

The term "wicked problem" was originally used in social planning by Rittel and Webber (1973). There are many examples of wicked problems such as climate change, obesity, and indigenous rights. Wicked problems cannot be tightly defined or solved with traditional linear analytical approaches. There are three approaches that have been discussed addressing wicked problems: authoritative, competitive, and collaborative Roberts (2000). In the authoritative approach, a few people take all the responsibility for solving the problem and make all the decisions. Although solving the problem with authoritative approach can be less complex due to fewer number of people involved in the process, the disadvantage of this approach is the lack of perspectives from all parties involved. In the competitive approach, different parties come up with solutions and oppose against each other. The disadvantage of this approach is knowledge sharing is not recommended, thus there is less incentive to find the best solution. The last approach is the collaborative strategy, where all parties are involved in the problem solving and decision making processes. To address our research problem in this dissertation, we took a collaborative approach aiming to include perspectives of the parties involved in the problem.

Rittel and Webber listed a series of characteristics to define a wicked problem Rittel and Webber (1973). Here, we discuss the wicked problem characteristics that specifically apply to this dissertation research problem, exploring the design of visualizations to facilitate patient-provider communication.

1. *"There is no definitive formulation of a wicked problem."* (Rittel and Webber (1973), p.161). To formulate a problem, we first need to fully understand the problem in order to propose potential definitive solutions. Understanding a wicked problem and anticipating all the possible solutions are tightly related. To gather all the information required to

understand a wicked problem, knowledge of all possible solutions is needed, which is not easy.

Designing visualizations to facilitate patient-provider communication requires a full understanding of this problem from patients, providers, and healthcare systems. It is difficult to fully understand this problem. Patients have different conditions, goals, and lifestyles; healthcare providers have different expertise, practices, and goals. Each party has a distinct understanding of this problem, it is difficult to clearly define how to design the right facilitator visualizations. Thus, without a complete knowledge of the problem, we can't anticipate all the possible technological solutions and visualizations to be able to formulate this problem.

2. *"Wicked problems have no stopping rule and solutions to wicked problems are not true or false"* (Rittel and Webber (1973), p.161). As described above, there is no concrete definition of a wicked problem; therefore, it is not possible to find a definitive solution to a wicked problem and there is always room for finding better solutions.

For designing visualizations to facilitate patient-provider communication, the same characteristics also apply. There are often conflicting goals and understanding of how to design the right communication visualization between different parties (patients, providers, administrators etc.). Many parties involved in the process of finding solutions are equally entitled and equipped to judge the proposed solutions and express their critiques. Thus, no technological or visualization solution for this problem can be considered complete, definitely right, or wrong rather they are better, worse, or good enough.

3. *"There is no immediate and no ultimate test of a solution to a wicked problem"* (Rittel and Webber (1973), p.163). Solutions proposed to a wicked problem are not entirely under the control of a few people and may generate consequences over time to an extended group of people. Thus, a complete evaluation of solutions is extremely difficult.

There is no easy way to track all the advantages and disadvantages of the proposed technological or visualization solutions for facilitating patient-provider communication. Testing the effects and the consequences of the proposed solutions on patients' health outcomes, family and caregivers' lives, or providers' practices is not entirely possible.

4. *"Every solution to a wicked problem is a one-shot operation"* (Rittel and Webber (1973), p.163). There is no opportunity to find solutions by trial-and-error, every attempt has irreversible consequences and counts significantly.

When a new technological or visualization tool is introduced in patient-provider communication dynamics, it can affect patient care and healthcare provider practice. Thus, many people's lives including patients, family and caregivers, and healthcare providers will be influenced. These effects cannot be undone or easily tracked.

5. *"Wicked problems do not have an enumerable or an exhaustively describable set of potential solutions"* (Rittel and Webber (1973), p.164). There is no set of criteria to definitely state that all the solutions to a wicked problem have been identified. It is up to the parties involved or affected by the problem to choose and to implement one solution over another. Factors such as budget, time, and resources can play roles in making these decisions.

Designing all the right technological and visualization solutions for facilitating patient–provider communication is not possible. Rather, it is a matter of discussion, resources analysis, and judgment to decide on going forward with one potential solution.

6. *"Every wicked problem can be considered to be a symptom of another problem"* (Rittel and Webber (1973), p.165). A wicked problem can be described as "discrepancies between the state of affairs as it is and the state as it ought to be" (Rittel and Webber (1973), p.165). To resolve this problem, one may start with finding potential solutions for each discrepancy or each sub-problem. However, finding solutions for each sub-problem with the hope to

aggregate these solutions to eventually address the wicked problem as a whole is not entirely possible.

Patient-provider communication during clinical visits have many aspects that each may influence or be a symptom of another. For instance, using a computer in the exam room may solve the problem of recording patient information more accurately, but it can cause disengagement between patients and providers. With proposing a solution for increasing patients' and providers' engagement during communication, we may lose the ability to record the information exchanged. Thus, designing ad-hoc technological or visualization solutions to facilitate different aspects of patient-provider communication cannot simply lead us to solve this research question as a whole.

7. *"The existence of a discrepancy representing a wicked problem can be explained in numerous ways. The choice of explanation determines the nature of the problem's resolution"* (Rittel and Webber (1973), p.166). The explanations of a wicked problem can be arbitrary and each party involved may choose the explanation that is more plausible to their perspectives. Due to unique properties of a wicked problem and inability to rigorously experiment a solution, there is no way to test an explanation.

For example, one can say the communication challenges between patients and providers are caused by short clinical visit times. Let's assume that there will be a strategy to increase the clinical visit times. In several years, there will be an increase in the quality of clinical communication, there is no way to test if increasing clinical visits was solely the reason for quality improvement. Was that the effect of increase time? Or was it due to the disease control in those years? Or any other factors?

3.2 DESIGNING FOR PATIENT-PROVIDER COMMUNICATION: PATIENT-CENTERED DESIGN

People-centered design (commonly referred to user-centered design [1]) is a cyclic design methodology of *discovering* the context of use and the requirements, *designing* through fast prototyping, *reflecting* through getting feedback, analyzing, and refining the design, and last *implementing* the designs. The goal of this method is to bring people and the system design closer together Pea (1987). When people do not have a concrete idea of what they should expect from a design/product, using a people-centered design approach can be an inexpensive way to incorporate unpredictable needs and behaviors that may arise through the process of design.

In this dissertation, we focus on exploring how to design visualizations to facilitate patient-provider communication during clinical visits. Patients and providers may not have a clear idea of what to expect from technological or visualization solutions that could help improve their in-clinic communication. Due to these uncertainties and complexities, designing technologies to improve patient-provider communication cannot be solved by taking a linear approach. Thus, to address our research question, we took a people-centered design.

In 1998 the American Institutes of Medicine formed a committee of researchers to provide guidance to healthcare services on how to improve the quality of care for patients Wolfe (2001). As one of the steps into healthcare improvement, the committee offered several aims, one was to deliver patient-centered care, *"providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that*

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[1] Based on the literature Bradley et al. (2015) studied and discussed the word *people* is more gender neutral and is thus more inclusive than the word *user*. So, in this dissertation we refer to this method as people-centered design.

patient values guide all clinical decisions" (Wolfe (2001), p.234). Later, the Ontario Medical Associations reviewed the challenges of implementing a truly patient-centered care in Ontario Healthcare System and policies to address these challenges Care (2010).

Considering all these movements in medicine towards delivering patient-centered care Organization (2008), and similarly to improving the design of technological or visualization solutions for healthcare settings; we, as designers, need to take a more personalized approach that considers each individual patient with their unique and complex needs, we call it *patient-centered design*. To achieve this goal, we need to invite patients as equal partners with healthcare providers in the process of design to better uncover their unmet needs Donetto et al. (2014).

Taking a patient-centered design approach, we first conducted a series of semi-structured interviews and focus groups to understand patients' and providers' needs and communication challenges during clinical visits, *discovery*. Then, through an iterative approach, we designed a series of potential visualizations with the goal of facilitating patient–provider communication while considering both patients' and healthcare providers' perspectives, *design*. Next, we took these designs back to healthcare providers seeking their reflections on the designs, *reflect*. Lastly, we implemented the selected visualization design, *implement*. As a whole, we used the results of these studies to shed light on how to design visualizations to facilitate patient-provider communication during clinical visits.

3.2.1 *Discovery: Interview and Focus Group Studies*

For the discovery phase, we primarily used qualitative research methods. Qualitative research can be used when researchers are looking for the *why* and *how* questions of human experience Given (2008). Qualitative researchers engage in naturalistic environments and gather data directly from real-world settings using methods such as observation, in-depth open-ended interviews, and analysis of gathered documents Quinn (2005). Qualitative research has moved into healthcare through a group of nurse anthropologists in the mid 1980s Denzin and Lincoln (2011). However, until now there has been resistance to accept the results of qualitative studies. It is still more common in medicine to employ quantitative research and focus on patients' diseases, their vital readings, and lab results rather than "the patient's experience" Denzin and Lincoln (2011).

In this thesis, we conducted qualitative research with a three-fold purpose: identifying opportunities for designing patient-provider communication tools, investigating patient experiences and communication challenges during clinical visits, understanding healthcare providers' perspectives and communication challenges in contrast to patients.

Each empirical research method has its own characteristics, benefits, and limitations. We chose to employ qualitative methods to get real and rich understandings of patients' and providers' experiences McGrath (1995). However, gathering data via qualitative methods about patients and providers can be difficult Denzin and Lincoln (2011).

As in all good design, it is important to understand this problem from both patients' and healthcare providers' perspectives. However, there are limitations in working with these two parties. Here, we discuss some of the challenges we faced when working with these two parties.

Recruiting: Patient interviews can reveal patients' real experiences at collecting, maintaining, transferring, and discussing their health data with providers. However, recruiting patients who are willing to give their time and discuss their condition and their collected data is difficult. When using iterative design methodologies, recruiting the same patients for the second or third time to gain their feedback is even harder or in some cases impossible due to the patients' sever conditions.

Privacy: Some patients are reluctant to share information about their interactions with researchers since they may be concerned the information could be revealed to their providers Denzin and Lincoln (2011). Despite informing patients about the research ethic rules of keeping the patient data private, this hesitancy can still exist.

Accessibility: In some cases it is helpful to look at patient data to get a sense of real world examples of data. In these circumstances, it is even harder to find participants. Many patients rely on their memory to keep track of their health data, so they do not have any written record of their data to share with researchers. Also, among those patients who do collect, record, and maintain their data many use apps or tools that do not provide an easy way to export or share their data.

Organization: Hand collected data is in the patient's control, there ca be no limitation in the type of access they have. However, hand collected data can be less organized, thus it is hard to see important insights such as trends, and changes. Conversely, hand collected data may need an extra step in order to store it in digital format. As a result, the data is often stored on paper, in notebooks, or in journals where it can be interspersed with different types of personal information. Even if they have their data saved and accessible, many patients are not willing to share their personal data with researchers.

Time Constraints: To understand the communication happening between providers and patients, we need to include healthcare providers; however, finding providers willing to give interview time is also a challenge. Providers who regularly see patients in their office/clinic for diagnosis or treatment purposes are usually very busy due to the nature of their practice.

Technology Reception: In addition, some providers are skeptical of the value of technology research. Thus, they may not be receptive to the idea of participating in research studies for designing new technologies. However, interviewing this group of providers may reveal many technology challenges that limit their practices.

Although interviewing patients and providers has limitations, it can provide us with valuable rich data to better understand their perspectives. Observing patient-provider communications during clinical visits in real-time is another valid methodology. However, it also comes with limitations.

Finding patients and healthcare providers who are willing to participate in an observational study at the same time can be challenging. Due to extreme sensitivity of the topics discussed during a clinical visits, patients and healthcare providers may not be willing to discuss their routine topics or show hesitations when sharing in the presence of a third party (a researcher). In addition, patient-provider communication challenges may only appear after lengthy observations of many clinical visits. In an interview or focus group study, we have the advantage of asking direct questions relevant to the topic of interest and obtain patients' and providers' perspectives over a period of time. Thus, we decided to interview patients and healthcare providers individually or in the form of focus groups, compare, and contrast their perspectives.

3.2.2 *Design, Reflect, and Implement*

Upon gathering the patients' and the healthcare providers' needs and challenges during clinical visit communications, we moved to the next stage of our patient-centered design process, exploring the possible design of visualizations.

Based on the results of the interviews and focus groups (*discovery*), we started sketching potential visualization representations, *design*. Our entire process of design was an iterative process. We went through several phases of seeking reflection on our designs and refining the designs, *reflect*.

Upon analyzing the feedback we received, we refined our designs and started the process of implementations. Our implementation phase was also an iterative process done with the support of our healthcare provider collaborators. We went through several phases of refining the designs based on feedback and constraints of the development team as well as the healthcare provider project management team, *implement*.

3.3 THOUGHTS ON THE PROCESS OF DESIGN AND RESEARCH: SUMMARY

To address our research question, we started with the mindset of designing targeted technological or visualization solutions that can improve aspects of patient–provider communication dynamics. Our goal at first was to introduce more point solutions until eventually we reach a general solution. Instead, through qualitative research methods and iterative design process, we came to the conclusion that we need to design individualized solutions by considering each patient and their providers.

Each patient has a unique body, a highly individualized lifestyle, a different set of goals, and a personalized patient-provider relationship. All these factors need to be considered while designing for patients. While we see values in designing for generalization, we first investigate designing for each *individual* patient and the technological possibilities to accommodate customization.

Part II

UNDERSTANDING AND IDENTIFYING THE PATIENT-PROVIDER COMMUNICATION CHALLENGES

In this part, we address Objective 1: Expand our current understanding of patient-provider communication challenges during in-clinic visits from both patients' and providers' perspectives via reviewing the literature and conducting a series of qualitative studies. In addition, we identify the patient and provider communication challenges in context of each other (Chapter 4), *discovery*. This process is in part of the first step in the patient-center design. For convenience and for ease of reference, I include the citation for my relevant publication for this part as footnote [2].

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[2] A version of this chapter was previously published at PervasiveHealth 17 (see Rajabiyazdi et al. (2017b)) and is distributed in ACM Digital Library. Excerpts included with permission from Rajabiyazdi, F. and Perin, C. and Vermeulen, J. and MacLeod, H. and Gromala, D. and Carpendale, S. Differences That Matter: In-clinic Communication Challenges, Proceedings of the 11th EAI International Conference on Pervasive Computing Technologies for Healthcare, 2017.

4

EXPANDING OUR UNDERSTANDING OF PATIENT-PROVIDER COMMUNICATION CHALLENGES

4.1 INTRODUCTION

Extensive research has demonstrated that effective in-clinic patient-provider communication is essential for building good relationships between healthcare providers and patients, as well as achieving the best results in improving patients' health Ong et al. (1995); Cegala and Post (2009). While effective provider-patient communication can positively impact patients' lives, misunderstandings between providers and patients can cause substantial harm to patients, at worst, even death Mentis et al. (2010). Thus, it is important to work towards the improvement of patient-provider communication; both to cater providers with access to the best, the most accurate, and the richest information about the patients' conditions and to ensure patient comprehension and perception of support Ong et al. (1995); Coulter (1997); Asan et al. (2015).

In this chapter, we focus on expanding our understanding of the patient-provider face-to-face communication challenges that occur during a day-to-day clinical visit. For example, we are interested in visits in which a patient presents their medical issues to a provider, who tries to understand the patient descriptions, diagnose them, and suggest a possible treatment. This type of interaction happens in the circumstances in which patients need to relay information to a provider, whether with a primary care physician or a specialist during a clinical visit.

Research in HCI has shown that technology *can* help mitigate communication challenges between providers and patients (e.g., Ni et al. (2011); Ananthanarayan et al. (2013); Piper and Hollan (2008); Hancock et al. (2010)). However, these successes focused on specific medical problems. To explore whether a more general approach is possible, we need to expand our understanding of the communication challenges that providers and patients face in a day-to-day clinical visit.

To this end, we conducted a structured literature review (Chapter 2) to gather the discussed patient-provider communication challenges that occur during in-clinic visits. It became apparent that a large proportion of the literature focused on understanding communication challenges from the patient's perspective.

To more fully grasp the whole spectrum of challenges between patients and providers, we conducted a series of semi-structured interviews with providers involved in the diagnosis and treatment of patients to augment our findings from the literature survey. These interviews provided us with a better understanding of the providers' work practices, approaches, and their perspectives on the difficulties they face when communicating with patients.

From both literature review and the interviews, we extracted seven overarching themes relating to patient-provider communication challenges. For each theme, we compare and contrast providers' and patients' perspectives about communication challenges. Our key observation is that although both providers and patients are clearly talking about the same communication challenges, at the micro-level their opinions and *attitudes* can be different. In addition, we discuss technological and non-technological tools that providers in our study use to address the challenges. We contribute a more holistic understanding of challenges in patient–provider communication, from which we draw directions for the design of future in-clinic communication technologies.

4.2 METHODOLOGY

Our intention is to expand our understanding of the communication challenges that occur during in-clinic visits when patients present their medical issues to providers. We first conducted a literature survey presented in Chapter 2. We found many studies interviewing patients and considerably fewer studies interviewing providers. While this may be due to factors such as difficulty in obtaining interview time with providers, it showed that a balanced view may need more provider input, because communication always involves both parties. Also, the provider interviews in the literature rarely consider day-to-day in-clinic visits and tend to be focused on specific medical situations such as when a provider needs to impart a difficult fact to a patient. To learn more about the communication challenges of day-to-day patient visits, we augmented our literature review with provider interviews about the communication issues experienced across many in-clinic visits. The literature survey and the provider interviews grant complementary insights. By combining these, we can offer more details about patient-provider communication and, in particular, discuss and contrast providers' and patients' perspectives.

4.2.1 *Provider Interviews*

We conducted semi-structured interviews with ten providers. We interviewed a range of providers (both specialists and primary care physicians) who are directly involved in understanding and diagnosing patients' conditions, and suggesting treatments, corresponding to our focus on a day-to-day visit. Similarly to 80% of the papers in our survey, we conducted interviews, in which we asked questions directly about communication challenges, since we are interested in the major challenges of which providers are aware.

Why Interviews? Observations and interviews are two important methods of gathering qualitative data. Observations lend a rich, at the moment, glimpse of reality. Their strength comes from the richness and the reality; however, in observational studies with no experimental interference, we cannot really choose to focus on a particular aspect of reality. In patient-provider relations, studies have shown that providers usually have trouble with 1 in 6 of their patients Giroldi et al. (2015). As for interviews, one of their strengths is that you can ask the questions you are interested in and do not have to wait until some unknown time in the future when some relevant instance may occur. However, the answers collected are of necessity those that the provider has thought of – or in some way is consciously aware of. Since we are trying to understand the broad spectrum of these challenges, and are particularly interested in the major issues and those issues that are difficult enough that the providers are thinking about them – interviews are very well suited to our purposes.

Participants. Finding a wide variety of healthcare provider expertise with a willing to give interview time was a challenge. We recruited ten providers (4 female, 6 male) from two different cities using snowball sampling. To maintain providers' requests for privacy, we do not explicitly report their length of practice but can say that we have a good range from junior to senior providers. We recruited two physician pain specialists from two separate pain clinics, an established physiotherapist, a physiotherapist trainee, a neurologist, a neurology resident, and a primary care physician, two diabetes specialists, and a chronic condition specialist.

Why a mix of providers? This set of providers give a good range of perspectives from the provider's point of view. Also, and importantly from our perspective, all these providers regularly do have day-to-day visits in their practice where they see patients in their office/clinic for diagnosis or treatment purposes. Therefore, we did not differentiate between primary care physicians, specialists, or physiotherapists.

Procedure and Analysis. We used semi-structured interviews to let the providers influence the conversation and deviate from our questions. Our interview questions were regarding the interaction between providers and patients and were not related to the providers' field of medicine. The questions covered four main topics: 1) providers' views on patients' difficulties describing their medical issues, 2) strategies providers employ to facilitate communication with the patients, 3) problems providers' face presenting information to patients, and 4) providers' approaches to simplify information for patients.

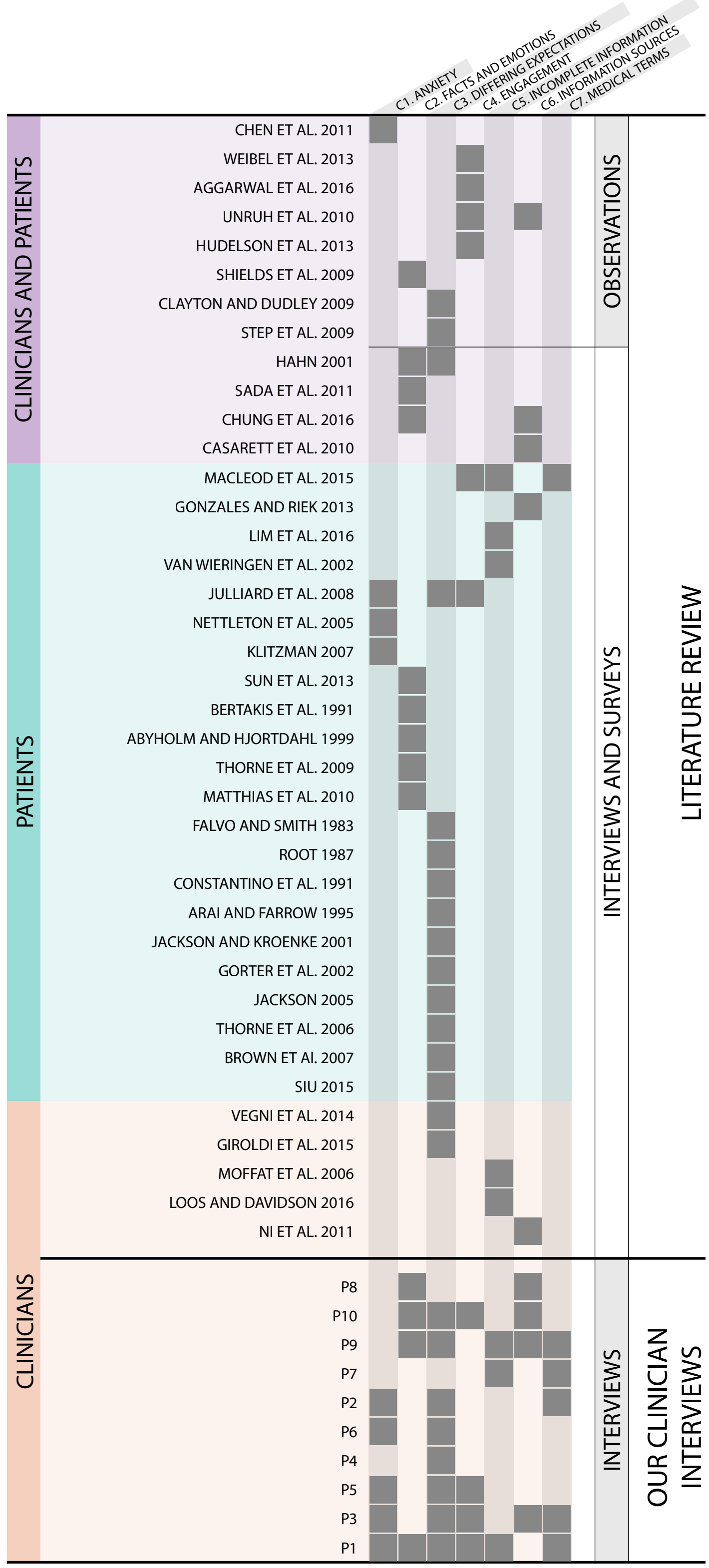
Given their busy schedules, we conducted the interviews at the providers' convenience. Eight interviews took place in the providers' offices/clinics, one in a public place, and one via Skype. According to the consent received, interviews were either audio or video recorded. The interviews lasted 30–60 minutes depending on provider availability and the interview process. We transcribed and analyzed the interviews using inductive qualitative methods Strauss and Corbin (1997). One researcher coded all the transcripts and another researcher independently coded a subset of transcripts. We then discussed, refined, and verified the codes. From this phase, we gathered 52 codes.

4.2.2 *Relating the Literature Review to the Interviews*

We coded both the selected literature and the interviews. We arrived at 21 codes from the literature and 52 from the interviews. We further split up the interview codes in two groups: 22 codes describing the *challenges* providers mentioned, and 24 codes about the *strategies* providers used to address these challenges. We kept the strategy codes separate. We use the strategy interview codes to inform our discussion on possible methods to address the communication challenges. The remaining 6 codes were not used. These consisted of three topics: treating patients with cognitive deficits, delivering bad news to patients, and the variation between different providers' performance. Given our focus on communication during day-to-day visits, we excluded the above codes.

To reveal the major issues from both the providers' and the patients' challenges, we created an affinity diagram (See Figure 5) from literature codes (21) and the interview codes regarding the challenges (22). Affinity diagram is commonly used method to group ideas. In here, we printed the interviews, cut the quotes from the interviews, coded them, and grouped them into themes Holtzblatt et al. (2004); Beyer and Holtzblatt (1998).

From this process, seven themes of challenges emerged: *C1. Anxiety*, *C2. Facts and Emotions*, *C3. Differing Expectations*, *C4. Engagement*, *C5. Incomplete Information*, *C6. Information Sources*, and *C7. Medical Terms*. This process is illustrated in Table 4, where columns are the seven themes and rows are the thirty nine selected papers and the ten interview participants, ordered by similarity Perin et al. (2014). Papers are grouped according to whether they consider patients and providers together, patients alone, or providers alone. The dark squares indicate which themes were mentioned in a paper or by a participant.



				C1. ANXIETY	C2. FACTS AND EMOTIONS	C3. DIFFERING EXPECTATIONS	C4. ENGAGEMENT	C5. INCOMPLETE INFORMATION	C6. INFORMATION SOURCES	C7. MEDICAL TERMS
CLINICIANS AND PATIENTS	OBSERVATIONS	LITERATURE REVIEW	CHEN ET AL. 2011	■						
			WEIBEL ET AL. 2013				■			
			AGGARWAL ET AL. 2016				■			
			UNRUH ET AL. 2010				■		■	
			HUDELSON ET AL. 2013				■			
			SHIELDS ET AL. 2009		■					
			CLAYTON AND DUDLEY 2009			■				
			STEP ET AL. 2009			■				
	INTERVIEWS AND SURVEYS		HAHN 2001		■	■				
			SADA ET AL. 2011		■					
			CHUNG ET AL. 2016		■				■	
			CASARETT ET AL. 2010						■	
PATIENTS			MACLEOD ET AL. 2015				■	■		■
			GONZALES AND RIEK 2013						■	
			LIM ET AL. 2016					■		
			VAN WIERINGEN ET AL. 2002					■		
			JULLIARD ET AL. 2008	■		■	■			
			NETTLETON ET AL. 2005	■						
			KLITZMAN 2007	■						
			SUN ET AL. 2013		■					
			BERTAKIS ET AL. 1991		■					
			ABYHOLM AND HJORTDAHL 1999		■					
			THORNE ET AL. 2009		■					
			MATTHIAS ET AL. 2010		■					
			FALVO AND SMITH 1983			■				
			ROOT 1987			■				
			CONSTANTINO ET AL. 1991			■				
			ARAI AND FARROW 1995			■				
			JACKSON AND KROENKE 2001			■				
			GORTER ET AL. 2002			■				
			JACKSON 2005			■				
			THORNE ET AL. 2006			■				
			BROWN ET Al. 2007			■				
			SIU 2015			■				
CLINICIANS			VEGNI ET AL. 2014			■				
			GIROLDI ET AL. 2015			■				
			MOFFAT ET AL. 2006					■		
			LOOS AND DAVIDSON 2016					■		
			NI ET AL. 2011						■	
	INTERVIEWS	OUR CLINICIAN INTERVIEWS	P8		■				■	
			P10		■	■	■		■	
			P9		■	■		■	■	■
			P7					■		■
			P2	■		■				■
			P6	■		■				
			P4			■				
			P5	■		■	■			
			P3	■		■	■		■	■
			P1	■	■	■	■	■		■

Figure 4: Summary of the literature review papers and our provider interviews.

Figure 5: Affinity Analysis of Patients' and Providers' interviews.

For each of the seven themes of challenges that we extracted (C1–C7), we use the following structure:

- For the patients' perspectives on communication challenges, we provide results from the literature review.
- For the providers' perspectives on communication challenges, we combine the results from our interviews with the providers' perspectives found in the literature review.
- We discuss, contrast, and identify similarities and subtle differences between both perspectives.
- We present technological and non-technological strategies that providers currently use to address the challenge.

4.3.1 *Communication Challenge (C1): Anxiety*

Patients' Perspectives: From the literature review, we found that *patients* sometimes find it stressful to present their medical issues to providers. They think stress interferes with establishing a smooth communication and sharing their necessary information with the providers Nettleton et al. (2005). Patients say that the lack of time is one of the factors that makes them anxious. As a result, they may not be able to share some of the information they have in mind Julliard et al. (2008). Patients also are not happy with the way providers usually structure the time. They think the waiting time to see providers enforces a feeling of hierarchy causing more anxiety Klitzman (2007). Patients expressed

ANXIETY	
PROVIDERS	PATIENTS
Notice the patient's anxiety and talk about the result of anxiety	Talk about the cause – about what they think makes them anxious
Mention how a patient's anxiety leads to: forgetting details; getting lost in words, and being confused	Think the environment might be the problem - the white coat, the time, the office, the computer

Table 1: providers' and patients' perspectives on anxiety.

their concerns about the physical set up of the room. For instance, the presence of computers can increase stress, especially when the display is not shared with the patients Chen et al. (2011); Asan et al. (2015). They are unsure what providers are doing behind the screen.

Providers' Perspectives: From our interviews, we found that *providers* are aware of patients' anxiety. They expressed concern about patients' confusion on how much and what type of information to share. Providers find it challenging to cut patients off when they are telling their story. They do not want to dismiss the provided information but at the same time not all the information that patients share is necessary useful for diagnosis. The providers observe that patients may not know how to describe their symptoms or may get lost in trying to use the right words, resulting in extra stress on the patients.

Providers added that stressed patients may misremember or forget incidents related to their health: *"there is that degree of information that the patient may be expected to have but does not have"* (P2). This is even harder when patients are experiencing a symptom for the first time. To mitigate this problem, the providers offer help by providing examples or giving patients adjectives to describe their symptom. However, they are careful in suggesting descriptions of symptoms in order to avoid leading patients or giving patients the feeling that they are looking for *the* right answer. They are also concerned about not contributing to the patient's feeling that providers are dominating the interaction: *"If they can't figure* *something by themselves, you give them a bunch of suggestions, being careful not to make someone feel frustrated or someone who has got low self-esteem, you have to be careful [to not] make them feel more inadequate"* (P3). Providers also feel that patients may think that the providers are not listening to them while they are looking at their computer: *"The electronic medical record is the third person in the room who seems to ask for more attention than the patient"* (P1). To mitigate this problem, P1 mentioned that to record a patient's history, he could use a mobile phone instead of a computer while he is talking to his patients. Since mobile phones are small and movable, patients get less distracted and providers can maintain a face-to-face conversation with patients.

Differences in Perspectives: Combining the literature review with our provider interviews, both patients and providers found patients' anxiety to be a problem for in-clinic communication (See Table 1). Providers are aware that their patients are anxious. They talk about how this anxiety affects patients. They think that patients' anxiety leads to forgetting details, getting lost in words, and being confused about what and how much information to share. Patients also state that they feel anxious when they visit their providers. However, patients do not talk about how their own anxiety might affect their behaviour. Instead, they indicate external causes for their anxiety, such as clinical environment Spruill et al. (2007), providers wearing a white coat Spruill et al. (2007), and the providers' use of computers Greatbatch et al. (1995, 1993); Chen et al. (2011).

4.3.2 *Communication Challenge (C2): Facts and Emotions*

Patients' Perspectives: In addition to medical help, patients seek the need to share their life situations with providers Sada et al. (2011); Thorne et al. (2009). They do not necessary expect much to be done by their providers rather they just need them to listen. Patients

FACTS AND EMOTIONS	
PROVIDERS	PATIENTS
Are mainly looking for medical information	Are looking for an emotional exchange
Feel they often get emotional information rather than factual details	Share emotions to get more attention and to make providers happy

Table 2: Providers' and patients' perspectives on the impact of emotions on communication.

sometimes think that they will get more attention from providers and that providers will take their conditions more seriously if they share their frustrations and emotional downs Chung et al. (2016). Patients also like to share their happiness with providers when they have progressed in their treatment or recovery with their disease. They think the good news will make their providers happy Sun et al. (2013).

Providers' Perspectives: Providers were aware that patients feel a need to share their emotional state with providers and the providers talked about trying to express their support for their patients to some extent Matthias et al. (2010); Hahn (2001). The providers in our study told us that they are willing to sympathize with patients to some degree. Providers were aware that it is important to hear about patients' emotions and that they may gain useful information from patients telling their story. The providers note that patient are often unable to articulate their symptoms because their thoughts are disorganized. Therefore, they try to narrow down patients' thoughts into a concise format, which in some cases might be complicated for patients. P1 gives the example of Twitter as a way to restrict a description since patients tend to be vague and disorganized: *"Twitter forces you to really think about what you are saying cause you only have 140 characters so you are not able to include unnecessary details"* (P1). Another participant, P10, encouraged her diabetes patients to email or text message their sugar level and blood pressure numbers to get advice on their insulin intake.

DIFFERING EXPECTATIONS	
PROVIDERS	PATIENTS
See patients who come with preconceived ideas and want quick fixes	Look for the providers to take patients' individual needs into consideration
Feel that patients should do the 'homework' they are given	Look for something they understand – medication they know, instructions that make sense to them

Table 3: Providers' and patients' perspectives on differing expectations.

Differences in Perspectives: Both patients and providers found patients' emotions to be a problem for communication (see Table 2). Patients have a different understanding of the information that they need to share with providers. Previous studies showed that patients seek emotional support and recognition when they visit their providers Chung et al. (2016); Sun et al. (2013). Patients think providers' emotional reaction to their complaints will give them more trust to share their medical issues Abyholm and Hjortdahl (1999). As a result, they feel more satisfied with their visit Shields et al. (2009); Bertakis et al. (1991) when they share their emotions. However, providers are trained to efficiently interpret medical history and establish diagnosis, based on precise factual information (e.g., frequency, severity). Providers in our study told us that they mainly look for specific information such as frequency, chronology of events, severity, and aggravating factors that will lead them towards diagnosis. They also told us that patients often share their emotions with them instead of describing their symptoms. This may cause difficulties for providers in understanding the patient's main problem. Therefore, there seems to be a conflict between providers thinking that patients share their emotions for "wrong" reasons and patients thinking that they share their emotions for "good" reasons.

4.3.3 *Communication Challenge (C3): Differing Expectations*

Patients' Perspectives: Sometimes patients and providers have different expectations from a medical visit that may cause issues in communication Clayton and Dudley (2009); Chung et al. (2016). Previous studies have shown that the most common expectations that patients have from a medical visit are: being informed about all processes Brown et al. (2007); Thorne et al. (2006), and having their providers taking into consideration their individual needs Clayton and Dudley (2009); Constantino et al. (1991); Jackson (2005); Vegni et al. (2014), age Step et al. (2009), gender Root (1987); Siu (2015), and culture Arai and Farrow (1995) when prescribing treatment.

For instance, elderly patients are more receptive to providers' treatment preferences than young patients, but they have more difficulty discussing sensitive subjects with their providers, such as their sexual activities Julliard et al. (2008). In addition, in some cultures people feel more comfortable and safe to be told what to do Arai and Farrow (1995). However, some patients prefer a more equal type of relationship with their providers Julliard et al. (2008); Arai and Farrow (1995); Gorter et al. (2002). Therefore, patients are expecting their providers to pay attention to their individual characteristics and treat them accordingly.

Providers' Perspectives: Providers think some patients have unrealistic expectations about receiving easy treatments Hahn (2001). The few studies that investigated providers' perspectives showed that providers sometimes think patients expect them to "do it all" and support patients in all aspects of their disease, even dealing with the patient's family Giroldi et al. (2015). The providers in our study observed varying expectations from patients, some of which can sometimes be unrealistic. For example, P3 said *"the patients tend to be a strange combination of more passive in their own health, at the same time feeling* *more entitled, they expect there will be a simple fix to everything and if a doctor can't provide [it], then he's not a good doctor."* Patients sometimes look for options that make sense to *them*; *"people want fancy scans where as physicians, we say all that will show you is more details about something that is irrelevant and confusing. And it is very hard, it takes 5 minutes to order a scan, but It takes 20 minutes to explain to someone why that won't be helpful , so that is a big barrier"* (P3). The providers noted that sometimes patients come with preconceived ideas from their cultural background and expect their providers to follow them: *"I have a sore throat, I need to get antibiotics and when you look at the culture, all want antibiotics no matter what, antibiotics is the cure because that is what the culture says. How do I explain it that they don't feel they were ripped off because they were waited 30 minutes to see me and they are leaving with salt water"*(P1).

Differences in Perspectives: The patients and providers have divergent expectations from a medical visit (See Table 3). Providers in our study and from the literature mentioned that some patients are looking for easy fixes instead of self-managing their condition or changing their life-style. In contrast, previous patients' studies revealed that patients have a different take on this problem. Patients want their providers to get to know them, and treat them based on their individual needs. They expect their providers to present them with more familiar and tailored information Falvo and Smith (1983) and failing to meet their expectations can negatively influence their treatment outcome Jackson and Kroenke (2001).

4.3.4 *Communication Challenge (C4): Engagement*

Patients' Perspectives: Patients want to be involved in their care, beyond their engagement in the clinical conversation. They show interest in collecting and organizing information related to their disease and life style that will help providers become more familiar with their condition and how it affects their everyday lives MacLeod et al. (2015).

Providers' Perspectives: Providers in our study mentioned that not all patients feel that their provider is a partner in their health. Rather they think they just need to follow what they have been instructed to do. They might feel that they are not invited and thus avoid engaging. Providers told us that they expect patients to take more responsibility in managing their condition, to collect and record data that do not require labs such as medical events, list of medications, possible symptoms, chronology of their symptoms, and side effects. To amplify patients' responsibilities, P5 used a specific email address for patients emailing their data to the pain clinic reminding them that they are supposed to be ready: *"The email is IamReadyToChange@... so the actual email address is already priming the way they think about their medical encounter."* In addition, three of the providers (P1, P3, P5) ask their patients to fill out electronic questionnaires before a visit to ensure patients' engagement and to save time during a clinical visit. Another way to engage patients in their care is to involve and inform them about the diagnosis process. For instance, P10 uses a risk calculation website to measure the risk of getting a heart attack for a diabetes patient: *" When you make the process more transparent to the patients, they realize I am not just looking at you saying OK "**I**" think you gonna have trouble with heart disease; therefore, "**I**" think you should get this pill. It is more of a this is how I am deciding. I have taken all of these into consideration"* (P10).

ENGAGEMENT	
PROVIDERS	PATIENTS
Think patients are not engaged cause they are intimidated or do not have the necessary information	Feel left out because of the speed of information exchange and potential language barriers
Want patients to collect information about medical events, medications, and symptoms	Want to collect information about their life style and habits

Table 4: Providers' and patients' perspectives on patients' engagement.

A simple solution providers use to address language barrier in communication is using translator applications. P1 uses Google Translate when dealing with patients who cannot speak his language. Some other providers do not find Google Translate always helpful since it is missing the translation for most of the medical terms. One provider (P7) uses a special app designed for interviewing patients. The app has pre-recorded sentences for medical interviews, and most of the questions require a simple yes/no answer or a node. The App contains questions such as such as "Are you experiencing any abdominal pain?", in different languages and would translate this sentence into the targeted language.

Differences in Perspectives: Both the providers and patients in previous studies are just as willing regarding patient involvement in the care plan. However, there are differences between their opinions on this matter (see Table 4).

Providers think patients avoid getting involved since they are intimidated by the hierarchy that exist between providers and patients Aggarwal et al. (2016) or do not have the information needed to get involved. However, patients see providers' high speed of speech, speaking in a different language, or irrelevance of the information as the main barriers Unruh et al. (2010); Julliard et al. (2008); Weibel et al. (2013).

Providers in our study showed interest in involving patients in creating and maintaining a care plan. This echoes results from previous patient studies, where patients showed early signs of interest in collecting a plan of care for their illnesses, and in keeping track of their vital signs, symptoms, exercise, and nutrition Choe et al. (2014); MacLeod et al. (2015); Milewski and Parra (2011). Providers also think that creating and maintaining a care plan will help patients to record and remember their symptoms, so that patients would feel more engaged and less frustrated when they come for a medical visit.

However, patients want to make providers understand their life situations and the impact of their condition on their life Aarhus and Ballegaard (2010). Patients think this will help them be more engaged with providers and in their care.

4.3.5 *Communication Challenge (C5): Incomplete Information*

Patients' Perspectives: Previous studies showed there are a number of reasons for why patients may withhold information from their providers. They may think it is not relevant to what providers need to know. Patients may also have different priorities, goals, or beliefs such as their career or family, rather than living a healthy long life or just simply *getting better* Van Wieringen et al. (2002); Lim et al. (2016). Prior negative experiences and mistrust of providers are other reasons patients may choose to withhold information Moffat et al. (2006). Another factor causing patients not to reveal information is thinking they are an expert on their disease after having dealt with it for a long time MacLeod et al. (2015). Therefore, they may not necessarily see the value of sharing all detailed information about their disease and may prefer to manage it themselves Lim et al. (2016); MacLeod et al. (2015).

INCOMPLETE INFORMATION	
PROVIDERS	PATIENTS
Think patients have unknown problems and want to investigate them	Do not mention information that they think is not relevant
Want patients to have a longer and healthier life	Want to be able to live a normal everyday life

Table 5: Providers' and patients' perspectives on incomplete information.

Providers' Perspectives: The providers in our study told us that they sometimes do not receive all the information they need from patients. They think patients are sometimes not even aware of their problem. Patients may visit them with a problem in mind, but there may be other problems. For example, P1 said: *"Depression can express itself as fatigue, as pain. [For example saying,] 'I have pain in my back' but it is really depression because you don't have a job and are feeling low self-esteem, the problem is often mental health but being manifested in a physical form."*

Providers are aware that they may not receive all the information they need from patients. Therefore, they order lab tests to confirm the information they received from patients and to investigate possible unknown problems Loos and Davidson (2016). For example, P9 said: *"Often what you are dealing with is a scenario where there are certain things that patients are aware of and there are certain things that physicians might find in an examination, on a x-ray or measures in a blood test that will lead physicians to have different concerns."*

Differences in Perspectives: Both patients and providers are aware that patients sometimes hide or fail to communicate certain information (See Table 5). Providers think that patients are sometimes not even aware of their medical problem. Patients, on the other hand, think that some information is not relevant to share with their providers. Patients and providers may sometimes have different goals. For instance, providers may want their patients to live longer and healthier lives Van Wieringen et al. (2002); Lim et al.

(2016) , but the patients may want to live a normal everyday life without constantly having to think about their illness.

4.3.6 *Communication Challenge (C6): Information Sources*

Patients' Perspectives: Evidently, patients see value in the information their providers give them during an in-clinic visit. Previous studies have shown that patients develop different information management strategies. These include taking notes on a piece of paper or bringing another person along to help them capture the information during a visit Unruh et al. (2010). Patients think that some of the information their providers present to them are generic information that providers tell to every patient with the same condition Seçkin (2010). However, patients are more interested in getting tailored information that matches with their everyday life Gonzales and Riek (2013b), causes of their symptoms, the reasons why they developed a disease Chung et al. (2016), and to verify the diagnosis or treatment that they received from their providers Attfield et al. (2006). As mentioned earlier in "*C3. Engagement*", patients are becoming more proactive in their care management. As a result, they seek out these information online Bowes et al. (2012). They mostly look online for information that can empower them with their personal needs Broom (2005); Wilcox et al. (2013, 2014).

Providers' Perspectives: Previous studies showed that using the internet as a source of information empowers patients in decision making and improves communication Broom (2005), our providers also confirmed that and supported patients' effort in gathering information from the internet. However, the providers stated their concerns on the negative effects of searching for information on the internet which may result in unnecessary stress on patients, a phenomena called *cyberchondria* White and Horvitz (2009); Starcevic and Berle (2013); Helft et al. (2005); Dedding et al. (2011). Previous studies also confirmed this phenomena and found that the internet that can potentially increase anxiety in patients who do not have medical training Bessière et al. (2010). In addition, providers in our study have doubts about the credibility of all the information that patients gather, and wonder if patients have access to the necessary information. The providers are concerned that patients do not always look for necessary information or may not fully understand what they find. As a result, the providers feel they still need to inform patients in order to ensure that they have the correct information. This led some online forums to employ health experts as moderators to help provide clinical knowledge and avoid misinforming patients Huh et al. (2013); Huh and Pratt (2014); Huh et al. (2012b,a).

Some providers think that patients are often overwhelmed with the amount of information they receive during their visit. To address this issue, one of the providers, P10, told us that she was keen to allow patients to record their conversation. However, she was concerned with the healthcare policies on recording a visit. In addition, both the providers in our study and previous studies that looked at the providers' point of view on educational materials agree that patients will have a higher incentive to get involved in their care if they have an understanding of their anatomy and of the mechanism of their disease Ni et al. (2011). One clinician used the following strategy: *"I was actually taking their own smart phone and filming them doing their exercises. Because then they have it on their phone and my voice talking through it and they can see their own body doing it"* (P6).

Differences in Perspectives: Both providers and patients see value in educating patients about their disease Ni et al. (2011). However, providers and patients disagree on the material that they find useful to discuss during a medical exam visit (see Table 6).

The providers are interested in educating patients about their conditions, anatomy, and mechanism of their disease and making sure patients understand all the necessary

INFORMATION SOURCES	
PROVIDERS	PATIENTS
Want to educate patients about the mechanisms of their disease	Want to know about the cause of their symptoms and the reasons why they developed a disease
Want to educate patients about their anatomy	Want information that is practical in their daily lives

Table 6: Providers' and patients' perspectives on information sources

information. Patients may not find all this information useful, and they need to know how to turn this knowledge into everyday practice Gonzales and Riek (2013b); Casarett et al. (2010). As a result, not only do patients need to learn and understand this information but they also have to make an extra effort in finding ways to apply this knowledge in their lives perhaps through searching for this information online.

4.3.7 *Communication Challenge (C7): Medical Terms*

Patients' Perspectives: Patients sometimes like to use medical terminology when talking to their providers. Previous studies showed that speaking in "surgeon-ese" MacLeod et al. (2015) is as much for the patients to feel proud of their own expertise and ability to use medical terms as it is for the sake of the providers MacLeod et al. (2015); Siek et al. (2006).

Providers' Perspectives: The providers in our study think patients sometimes use medical terminology when *describing their condition*, to help providers or to save time. However, problems can arise from an incorrect understanding of the medical terminology: *"Every time they use a medical term I have to stop them and ask what they mean. I want to hear their story, not their story filtered through someone else"* (P3). To address this issue, one provider tried to educate patients about medical terms and how to describe their condi-

MEDICAL TERMS	
PROVIDERS	PATIENTS
Think patients want to help providers by using medical terms	Want to appear more informed and feel proud of their ability to use medical terms
Do not trust patients' understanding of the medical terms	Want to feel that they are an expert on their own disease

Table 7: Providers' and patients' perspectives on use of medical terms.

tions: *"Sometimes I will say a fancy word then I will have later a term that might match that, to try to teach them as we are going along. Sometimes the language that is watered down loses some of its specificity and when that happens, there could be a danger of misinterpretation or misapplication"* (P2).

Differences in Perspectives: Using medical terms during an in-clinic visit by patients is a challenge. We found subtle differences between patients' and providers' perspectives regarding the reasons why patients use medical terms (see Table 7).

Some of the providers in our study are skeptical when patients use medical terms and do not fully trust that the patients understand the terms. They think that patients' understanding of a medical term may be different from their own understanding, which may result in misunderstanding and misinterpretation. This is in line with past studies that have shown that patients do not always use medical terms correctly Castro et al. (2007); Boyle (1970). In contrast, Providers and patients disagree on the reasons why patients use medical terms. The providers in our study think that patients are eager to use medical terms to help providers and to save time in the visit. However, patients like to use medical terminology to feel proud of their expertise and appear more knowledgeable and informed MacLeod et al. (2015); Siek et al. (2006).

4.4 DIRECTIONS FOR DESIGNING TECHNOLOGIES TO FACILITATE PATIENT–PROVIDER COMMUNICATION

In this section we discuss how the subtle differences we have unearthed can be useful in formulating design directions. Being aware of the subtle differences between providers' and patients' ideas about communication challenges can play an important role in designing communication technologies that benefit both providers and patients. Both providers and patients raised the same issues, talking about anxiety, emotions, differing expectations, challenges of engagement, incomplete information, information sources, and the use of medical terminology. While the topics are the same the details and thinking around these issues hold fundamental differences. These deep-seated differences pose a considerable challenge for designers who wish to develop technology that might help improve patient–provider communication.

4.4.1 *Considering a Holistic Approach to Technology Design*

Both the providers and patients were aware that the patients' anxiety was a problem that affected the communication. In fact, the patients' discussion about anxiety pointed directly to technology. At first glance, they consider technology to be a problem and discuss how the providers disappearing behind the computer screen adds to their anxiety. Screens can restrict movement and interfere with work practices Luff et al. (1992), and can impact communication between providers and patients Greatbatch et al. (1995, 1993). While one could interpret this as an indication the technology might not be a solution, it can also be taken as an invitation to change the way we think about technology use during the in-clinic visit Crampton et al. (2016). Interestingly, the providers suggested trying alternate technological form factors such as using a phone, which is smaller and forms less of a barrier between the patient and the provider. A useful design direction is to consider the set-up of the clinical consultation environment, i.e., how technology can be used more seamlessly to ensure that it does not form a barrier between the patient and provider.

4.4.2 *Involving Patients through Information Transparency*

It is possible that increasing information transparency may contribute to reducing anxiety, encouraging engagement and reducing the amount of missing information. Patients said that providers recording information on computer and not maintaining eye contact contributed to their anxiety Chung et al. (2016). They said they felt left out and not involved. Providers think that if patients could feel part of the process of data recording it might encourage them to be more involved. Providers suggested that allowing patients to view the screen and making it possible for the patients to follow the information that providers record may reduce patients' anxiety. Also it would give them another opportunity to add missing information or bring up what they initially forgot to say. However, the amount and the type of information that can be displayed would require careful consideration since providers may be concerned about sharing sensitive data that could make patients worry even more.

4.4.3 *Providing Alternate Ways of Exchanging Information*

Medical visits are almost exclusively a verbal exchange. To increase patients' comprehension, providers can use technology to include alternate modalities like written words and various visuals including images, charts, and even animations. In addition, patients can use various ways to exchange information that they collected with their providers. There is an increasing number of technologies to facilitate collecting and presenting self-generated data Nunes et al. (2015); Andersen et al. (2014). Designing technologies/visualizations that provide both patients and providers with alternative ways to look at patient-generated data could be a promising approach for future work in this area.

4.4.4 *Incorporating Motivational and Decision Support Tools*

Recently, expectations of both providers and patients have changed towards a model of more active patients Thomasma (1983); Bodenheimer et al. (2002). Providers expect patients to take more responsibilities in managing their condition instead of putting it all on the providers' shoulders. However, patients may not always see value to engage in their care. There is a need for new technological tools that assist providers in motivating patients to stay engaged in their care. The interviewed providers took various approaches to address this issue. One provider involved patients in the diagnosis process and in calculating health risks to motivate them to take their treatment more seriously. A promising research direction would be to investigate the design of technologies and tools that provide opportunities for patients and providers to collaboratively input and analyze information. These tools can encourage patients to get more involved in their treatment process. Another provider carefully named the email address she uses - Iam

ReadyToChange - to actively promote health-related goals when patients send their information to her. Developing motivational tools could be a promising direction when designing new communication technologies to encourage patients' engagement in care.

4.5 CONCLUSIONS

From our exploration, we describe how while patients and providers may agree on the topics of the challenges they face when communicating, they have different attitudes or reasons for these challenges. By combining a literature review with provider interviews, we note a series of subtle differences between patients' and providers' ideas about seven major in-clinic communication challenges: anxiety, emotions, differing expectations, engagement, incomplete information, information sources, and use of medical terms. In our investigation, we considered patients' perspectives in conjunction with providers' perspectives plus their current suggestions for possible technology solutions. In this manner, we contribute to the holistic understanding of patient–provider communication and offer design directions for technologies that more fully support patients and providers.

Part III

DESIGNING VISUALIZATIONS TO ENHANCE PATIENT-PROVIDER COMMUNICATION

In chapter 4, we compared patients' and providers' perspectives to gain a more in-depth understanding of the challenges patients and providers encounter when communicating during clinical visits. Next, as a group we ideate about possible technological solutions to address these communication challenges. We thought of possible technological solutions for three communication challenges: lack of information and support for patients, patients' and providers' different perspectives on how to discuss patient-generated data during visits, and patients' and providers' different goals.

We presented our proposed technological solutions to our healthcare provider collaborators. After extensive discussions, we decided to focus on designing possible visualizations for presenting patient-generated data collections during clinical visits. For convenience and for ease of reference, I include the citation for my relevant publication for this part as footnote [1].

We know collecting patient-generated data is becoming increasingly common in disease management. Patients use various tools to collect health and lifestyle data in disparate places. However, aggregation and effective use of this data remains a challenge. Both providers and patients agreed that this data could be used to make smarter decisions regarding patient disease or treatment options, to improve patients' quality of life, and to share patients' data with their providers to aid making decision about their ongoing care. However, most of these tracking tools also do not support collaborative data sharing between healthcare providers and patients, thereby exacerbating the challenges.

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[1] A version of this part was previously published at ISS Companion 16 (see Rajabiyazdi (2016)) and is distributed in ACM Digital Library. Excerpts included with permission from Rajabiyazdi, F. Designing and Developing Technologies to Facilitate Clinician-Patient Communication, Proceedings of the 2016 ACM Companion on Interactive Surfaces and Spaces, 2016.

In this part, we address Objective 2: Explore the reality of patients monitoring and recording their health data and consider the challenges providers and patients face when reviewing these data. For convenience and for ease of reference, I include the citation for my relevant publications for this past as footnote [2].

We leverage this understanding to map out a design space of potential targeted visualizations to improve the process of reviewing patient-generated health data [3].

To address this problem, we first *discover* the patients' and healthcare providers' needs to make sense of and to collaboratively discuss patient-generated data during clinical visits. We uncover eight patient stories and their approaches to tracking and sharing their health data (Chapter 5). Later, based on each patient story, we *design* possible visualizations to represent patient-generated data collections (Chapter 6).

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[2] A version of this part was previously published at PervasiveHealth 17 (see Rajabiyazdi et al. (2017a)) and is distributed in ACM Digital Library. Excerpts included with permission from Rajabiyazdi, F. and Perin, C. and Oehlberg, L. and Carpendale, S. The Challenges of Individuality to Technology Approaches to Personally Collected Health Data, Proceedings of the 11th EAI International Conference on Pervasive Computing Technologies for Healthcare, 2017.

[3] A version of this part was previously published at IEEE VIS Electronic Proceedings 2018 (see Rajabiyazdi et al. (2018)) and is distributed in ACM Digital Library. Excerpts included with permission from Rajabiyazdi, F. and Perin, C. and Oehlberg, L. and Carpendale, S. Personal Patient-Generated Data Visualizations for Diabetes Patients, Electronic Conference Proceedings of the IEEE VIS, 2018.

5

THE INDIVIDUALITIES AND COMPLEXITIES OF PATIENT PERSPECTIVE ON PATIENT-GENERATED DATA COLLECTIONS

5.1 INTRODUCTION

Healthcare providers think for some conditions (e.g., chronic conditions, cancer patients), they may be able to improve patients' quality of life if they had access to more details about the patient's health Patel et al. (2012); Smith et al. (2007). In this situation, a provider may ask the patient to collect data in a particular format to be able to retrieve the necessary information. However, providers sometimes receive data collections including both requested and unrequested data Rajabiyazdi et al. (2017a). The patients may provide unrequested data because they believe it to be relevant. However, it is hard to find the time to examine unrequested data during a short clinical visit Rajabiyazdi et al. (2017b). In addition, patients use different mediums and organization formats that work best for them to collect and present their health data. As a result, the patient-generated data collections become heavily personal and complex making it challenging for healthcare providers to understand and analyze them. Therefore, the providers may not find as much value reviewing patient-generated data during a clinical visit.

We were approached by a group of healthcare providers who were looking for potential technological solutions to enhance their experience analyzing patient-generated data. To explore this problem space, we conducted a focus group with a mixed group of healthcare providers from which we extracted their requirements for understanding and analyzing patient-generated data during a clinical visit.

Sharing and discussing patient-generated data is a two-sided problem involving both healthcare providers and patients. Patients play an important role in tracking the right data, recording their data in an organized manner, and presenting them to their providers. To gain a better understanding of the characteristics of patient-generated data collections, we interviewed eight patients with chronic conditions who actively track their health data. We unfold eight individual patients’ stories including the history of their conditions, their data collection routines, and their experiences sharing this data with the healthcare providers, if any.

Our findings confirmed the individuality and the complex nature of patient-generated data collections. Therefore, designing the right technological solutions or visualizations to represent these data requires a careful attention to the patients’ individualities.

Tracking and collecting personal health data is becoming more common among patients with chronic conditions Fox and Duggan (2013). Collecting health data can be useful for patients to increase self awareness of their conditions Heitkemper et al. (2004) and taking one step further to share and analyze these data (view any changes, patterns, and outliers) can be more beneficial. Although, patient-generated data can be more detailed than lab results, some healthcare providers may not trust the credibility of patient data collections Ferguson et al. (2015). Some self-tracking tools lack scientific rigor. These tools may present patient data in ways that implies associations between symptoms or shows patterns in data that may not be medically correct Ferguson et al. (2015).

Many patients share their health self-collected data with their healthcare providers during clinical visits seeking medical advice Zhu et al. (2016). Previous studies have shown that sharing patient-generated data with healthcare providers can improve patient-provider communication Patel et al. (2012); Smith et al. (2007). Sharing health data also empowers patients in taking control of the conversation during a clinical visit and helps healthcare providers build relationship with patients Ong et al. (1995).

While there are many benefits to sharing health data in a clinical visit, sharing patient-generated data is a real challenge in practice, both for patients and for healthcare providers Schroeder et al. (2017). The common clinical visits with family physicians usually last about 15 to 20 minutes. A recent studies showed that healthcare providers would spend less than 5 minutes of the visit to review patient-generated data Chung et al. (2015). *Patients* often feel that their healthcare providers do not engage with the data nor give usable advice Chiauzzi et al. (2015). *Healthcare providers*, on the other hand, are sometimes asked by their patients to deal with large amounts of complex and disorganized datasets that they cannot assimilate during a short clinical visit Ancker et al. (2015a).

One way of facilitating this communication would be to have standardized data collection and presentation processes Chung et al. (2015). But most self-tracking technology (e.g., Fitbit, phone application, notebook) have not been designed considering healthcare providers' or patients' needs Chiauzzi et al. (2015). Also, a standardized process is probably not a panacea, as every patient and provider may have individualized preferences and needs. In fact, patients take very different approaches to collecting their health data Rajabiyazdi et al. (2017a). Patients track various types of data depending on their chronic conditions, personal goals, hopes, and even fears. This makes patient-generated data collections very individualized and complex.

Designing a general solution that works for all patients and providers is not easily achievable. Thus, we need to move towards creating visualizations that are customizable, making an individualized visualization experience for each patient and provider.

5.3 METHODOLOGY

We were approached by a group of healthcare providers from a local hospital who are involved in the care of complex chronic patients to explore if and how technology can enhance the process of sharing and discussing patient-generated data during a clinical visit. During our initial investigation phase, our healthcare provider collaborators' voiced the challenges they face when reviewing patient-generated data.

To complete the healthcare providers' perspectives working with patient-generated data, we interviewed eight patients who were already collecting their health data. We formed our patient interview questions based on the results of our discussions and focus group with healthcare providers. We asked our patients participants about their experience collecting, analyzing, and sharing their data with healthcare providers.

5.3.1 *Healthcare Provider Focus Group*

To clarify, confirm, and gain a deeper understanding of the patient-generated data collection review process, we conducted a formal focus group with a mixed group of healthcare providers including the group of providers who initially approached us in addition to several other providers and researchers who were recruited through word of mouth in the same hospital. In our focus group, we shared and elaborated on the knowledge we gained from our initial discussions with the healthcare providers who initially approached us. We asked healthcare providers about their experiences reviewing the patient-generated data, analyzing and understanding the patient data, and giving advice to patients based on their data.

Our focus group included one diabetes specialist physician, one internal medicine specialist physician, and four health researchers who have been involved in direct interactions with patients for several years (Table 8). One researcher primarily posed the questions during the discussion and two other researchers took field notes. The focus group lasted around 60 minutes. We video-recorded, transcribed the focus group discussions, and later we used grounded theory Strauss and Corbin (1997) for analysis.

No.	Position	Sector
Ph01	Internal medicine specialists	Medicine
Ph02	Diabetes Specialist	Medicine
RS1	Program Manager	Operations
RS2	Senior Research Associate	Research
RS3	Project Coordinator	Research
RS4	Research Associate	Research

Table 8: Demographic Information of Focus Group Participants

5.3.2 *Healthcare Provider Focus Group Findings*

After analyzing the focus group, we extracted a series of requirements that healthcare providers wished to be supported while communicating patient-generated data with patients during a clinical visit. Below we go into details of three requests (R1-R3) commonly mentioned and emphasized by our participants.

R1-Presenting data: Patients sometimes come to clinical visits with a large collection of data and expect their healthcare providers to help them make sense of their data *"they clearly put in a lot of work, but you don't have time and you have nowhere to begin"* (Ph01). Healthcare providers want **tools with abilities to summarize, sort, and order patient**

data that allows for fast and powerful analysis to see trends, patterns, and anomalies. They want tools to confront patients with their data and start analyzing it with them.

R2-Sharing data: Healthcare providers need technological tools that open up communications with patients which may have not happened otherwise; **a tool that allows more focused discussion and that gives patients a greater presence in the conversation**. The tool should support both patients and healthcare providers to discuss areas of concern: *"[patient says] I have questions about [this] and the doctor says ok, great, that is what is going on there. But I am more concerned about this, I think that makes for a far more efficient conversation"* (Ph01). Furthermore, our healthcare providers told us how patients usually have different goals than providers which may cause conflicts, they wanted *"a platform that forces people to be explicit between stakeholders"* (Ph02), so they can clarify both the patients' and healthcare providers' goals.

R3-Analyzing data: Healthcare providers think patient data without context is not helpful; they need **tools that are able to integrate context with data**. *"you get the data in a 7 by 6 table with numbers and they are all over the place, and you are like, Ok. Without food information, stress information, activity information it does look like a bunch of noise. You don't see a pattern without being able to query on those other dimensions. Like your sugar is high, are you stressed?"* (Ph01).

The findings from the focus group helped us form our patient interview questions. We asked our patient participants to talk about their experience **presenting their data** to providers, **sharing their data** with providers, and the insights they gained from **analyzing their data**.

5.3.3 *Patient Interviews*

To understand patients' perspectives, we interviewed eight patients who suffer from one or multiple chronic conditions. We recruited these patients with the help of the healthcare professionals in the focus group study.

With collaboration of our healthcare provider colleagues, we used several methods of recruitment this study: emails from Foothills Medical Center Patient Care Networks directors, Patient Care Networks newsletter ads, targeted recruitment through the research team and existing network of contacts (reach out to potential participants through email, phone, in person, or a combination of these methods), and snowball sampling (researchers asked participants to reach out to their colleagues who may be interested in participating.

We conducted an hour long semi-structured interview with each patient. We asked our participants to bring a sample of their data to the interview session. We started the interviews with questions regarding our participants' health conditions, their diagnosis, and their current treatment plans if any, and goals and personal life styles. Then, our participants walked us through their data sample in detail.

We video-recorded and transcribed all interviews. It is not possible to reach saturation among patients with the unique needs and conditions. To analyze the interview results, we used open-coding a grounded theory method Strauss and Corbin (1997), analyzing each individual interview in a separate process. In this paper, our goal is to reach a deeper understanding of each patient story. We state proof of existence for each interview and do not try to generalize our findings across patients.

5.4 PATIENT INTERVIEW RESULTS

In this section, we present each patient's profile and give a short description of the patient's medical history and their data collection processes. Finally, we talk about the patient's hopes, goals, and fears.

Note that we allocated pseudonyms to confer anonymity of our patients.

5.4.1 *Patient #1: Maria Freeman*

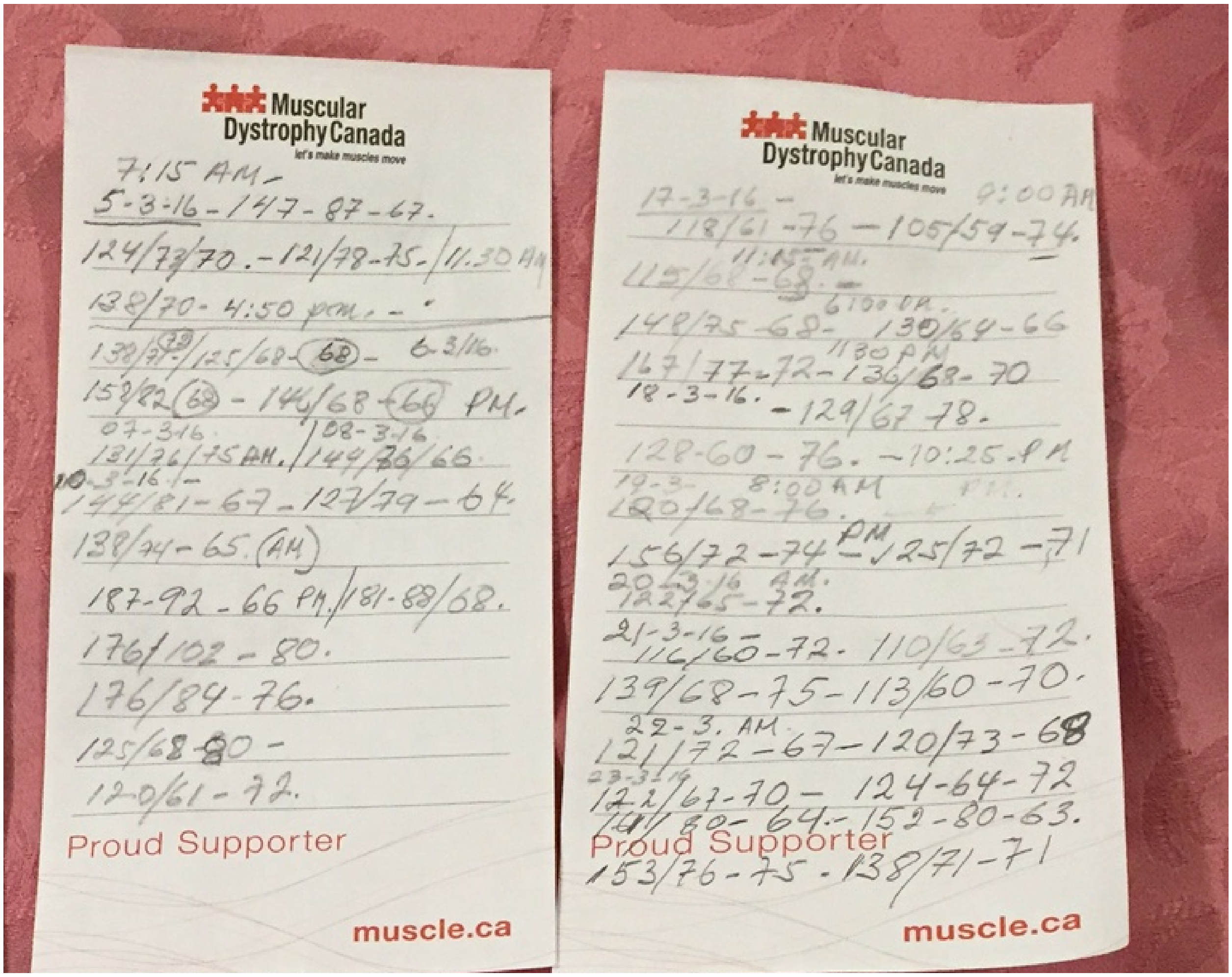
Patient Profile:

Age & Gender	67 years old, Female
Conditions	Hypertension, arthritides
Provider care team	Family physician, anesthesiologist, pain specialist
Data collection motivation	Advised by her family physician
Collected data item(s)	Blood Pressure, Heart Rate

Table 9: Patient #1 Profile

Patient History and Data Collection Routine: Maria is 67 years old and suffers from hypertension (Table 9). One day she experienced high blood pressure and visited the hospital emergency room. After that hospital visit, Maria constantly experienced high blood pressure. Later that year, she was diagnosed with hypertension and was advised to track her blood pressure and heart rate on a regular basis using a cuff machine (Figure 6).

Hopes, Goals, and Fears: Since March 2016, Maria has been tracking her blood pressure and heart rate three to four times per day. She uses a notebook to record her readings. She presented her notebook to her family physician saying, *"because of this [notebook], it will be easier for me to inform the doctor"* (P01). She hopes her providers can make sense



Muscular Dystrophy Canada
let's make muscles move
7:15 AM -
5-3-16 - 147-87-67.
124/73/70. - 121/78-75. / 11.30 AM
138/70 - 4:50 pm. -
138/74/125/68-68 - 6-3/16.
159/82 (68) - 146/68-66 PM.
07-3-16. / 08-3-16
131/76/75 AM. / 149/76/66.
10-3-16. -
144/81-67 - 127/79-64.
138/74-65. (AM)
187-92-66 PM. / 181-88/68.
176/102-80.
176/84-76.
125/68-80 -
120/61-72.
Proud Supporter
muscle.ca

Muscular Dystrophy Canada
let's make muscles move
17-3-16 - 9:00 AM
118/61-76 - 105/59-74.
11:15 AM.
115/68-68.
6:00 PM.
148/75-68 - 130/64-66
11:30 PM
167/77-72 - 136/68-70
18-3-16. - 129/67 78.
128-60-76. - 10:25 PM
19-3- 8:00 AM PM.
120/68-76.
156/72-74 PM - 125/72-71
20-3-16 AM.
122/65-72.
21-3-16 -
116/60-72. 110/63-72.
139/68-75-113/60-70.
22-3. AM
121/72-67-120/73-68
23-3-16
122/67-70 - 124-64-72
141/80-64. - 152-80-63.
Proud Supporter
153/76-75. 138/71-71
muscle.ca

Figure 6: (Patient #1) Maria's notebook: sample pages of her blood pressure recordings.

of the data for her and make adjustments to her treatment plans based on her data. Her ultimate goal for tracking her data is *"to feel better ... make my blood pressure go down"* (P01). After her diagnosis, she changed her life style to reach her goals. She is drinking more fluids and has reduced the amount of salt in her diet. She is hopeful that she can reach her goal saying, *"I'm on my way. I need more time"* (P01).

5.4.2 *Patient #2: Andrew Gellar*

Patient Profile:

Age & Gender	52 years old, Male
Conditions	Type 1 diabetes
Provider care team	Endocrinologist in a diabetic clinic, nurse educator, foot care clinic
Data collection motivation	Advised by his endocrinologist and nurse educator
Collected data item(s)	Basal insulin, blood glucose, exercise

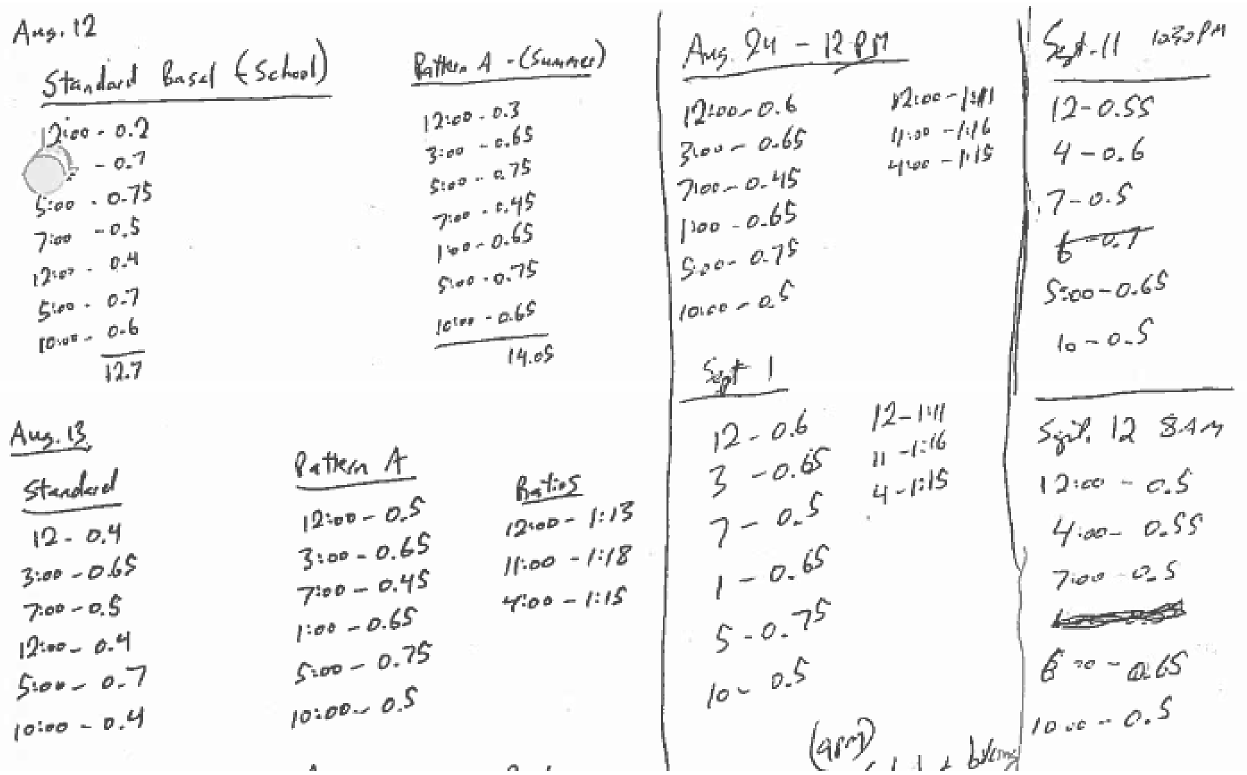
Table 10: Patient #2 Profile

Patient History and Data Collection Routine: Andrew is 52 years old and was diagnosed with type 1 diabetes about 16 years ago (Table 10). Because of his age, he was first misdiagnosed with type 2 diabetes. Andrew thinks there is less support available for adults with type 1 diabetes since it typically affects younger individuals. After his diagnosis, Andrew's interaction with the healthcare system changed from visiting his family physicians once a year to getting an A1C test every three months. Andrew has been in direct interaction with a nurse educator, a foot care clinic, and an endocrinologist in a diabetic neuropathology clinic.

Andrew measures his blood glucose and basal rate as advised by his nurse educator and endocrinologist (Figure 7). He uses a glucose meter to measure the concentration of glucose in his blood and an insulin pump to calculate the amount of insulin required. Before each meal, he measures his blood glucose using the glucose meter and enters his readings into the insulin pump. The insulin pump calculates the amount of insulin he needs to give himself. The pump automatically send Andrew's insulin intake to his nurse educator. Besides that, Andrew keeps track of his basal rates that he measures using the glucose meter, in a notebook to share with his nurse educator later in his visits. Every time Andrew visits his healthcare providers to check on his conditions, he shares the recorded data he collected over the past few months with his healthcare providers. He has a hard time analyzing and finding trends in his data to adjust his lifestyle saying, *"Data management is very complex for diabetics. There's so many factors that come to play with your blood sugars and trying to get everything in the right spot"* (P02). He expects his healthcare providers to make sense of his data for him and give him direct instructions on how to better manage his conditions.

Andrew sometimes rides his bike to work which takes him about 15 minutes. After biking, he usually experiences two days of low glucose levels that he needs to manage to get back to normal range. He thinks routine exercise can help him have a more balanced reaction to the amount of insulin he takes. Andrew found his nurse educator very helpful supporting him in reading and analyzing his data, and giving him advice based on his numbers. However, he does not think his nurse educator is knowledgeable enough about the effect of exercise and he does not have access to an exercise specialist.

Hopes, Goals, and Fears: Andrew lives a good life, eats healthy, gets enough sleep, and has a balanced work-life. He has had diabetes for 16 years and recently got some complications, *"so it's been a wake-up call for me"* (P02). After experiencing the complications, he is hoping to start an exercise routine, *"to stay healthy until they come up with a cure. That's really what I want. I want to live a good life. I want to be able to do stuff as I'm getting older, and with my kids and my grandkids"* (P02).



Aug. 12

Standard Basal (School)

12:00 - 0.2
[illegible] - 0.7
5:00 - 0.75
7:00 - 0.5
12:00 - 0.4
5:00 - 0.7
10:00 - 0.6
12.7

Pattern A - (Summer)

12:00 - 0.3
3:00 - 0.65
5:00 - 0.75
7:00 - 0.45
1:00 - 0.65
5:00 - 0.75
10:00 - 0.65
14.05

Aug. 13

Standard

12 - 0.4
3:00 - 0.65
7:00 - 0.5
12:00 - 0.4
5:00 - 0.7
10:00 - 0.4

Pattern A

12:00 - 0.5
3:00 - 0.65
7:00 - 0.45
1:00 - 0.65
5:00 - 0.75
10:00 - 0.5

Ratios

12:00 - 1:13
11:00 - 1:18
4:00 - 1:15

Aug. 24 - 12 PM

12:00 - 0.6
3:00 - 0.65
7:00 - 0.45
1:00 - 0.65
5:00 - 0.75
10:00 - 0.5

12:00 - 1:11
11:00 - 1:16
4:00 - 1:15

Sept 1

12 - 0.6
3 - 0.65
7 - 0.5
1 - 0.65
5 - 0.75
10 - 0.5

12 - 1:11
11 - 1:16
4 - 1:15

(9pm)

Sept. 11 1030PM

12 - 0.55
4 - 0.6
7 - 0.5
~~6 - 0.7~~
5:00 - 0.65
10 - 0.5

Sept. 12 8AM

12:00 - 0.5
4:00 - 0.55
7:00 - 0.5
[illegible]
6:00 - 0.65
10:00 - 0.5

Figure 7: (Patient #2) Andrew's notebook: sample pages of his blood glucose recordings.

5.4.3 *Patient #3: Jen Adams*

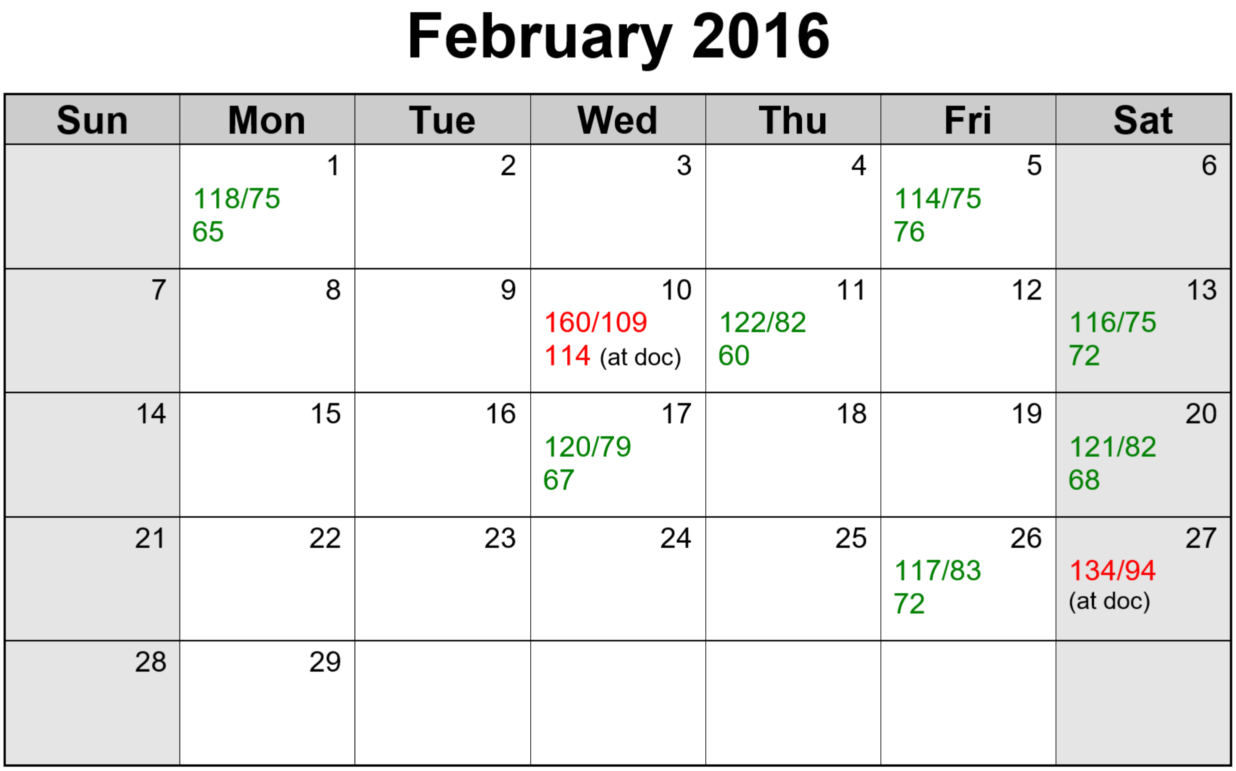
Patient Profile:

Age and Gender	34 years old, Female
Conditions	Hypertension
Provider care team	Family physician, cardiologist
Data collection motivation	Helping with her diagnosis and avoiding unnecessarily medication
Collected data item(s)	Blood pressure, heart rate

Table 11: Patient #3 Profile

Patient History and Data Collection Routine: Jen is 34 years old and was diagnosed with hypertension when she was 18 years old and was medicated for a few months (Table 11). After she got off her medication, she started monitoring her diet and adjusted her life style to control her condition. Last year, she had a visit with her family physician to get treatment for an infection and her blood pressure reading was high at the clinic. She checked her blood pressure at home and noticed that her reading was much closer to normal readings than in the clinic. She thinks having high blood pressure during a medical visit was due to anxiety of being in a clinical environment and interacting with physicians saying, *"anytime I go to the doctor it's still high, because I get quite anxious going to see them, so it's hard for them to know if it's actually high all the time or not"* (P03).

Since her last clinical visit, Jen monitors her numbers to prevent any complications or developing hypertension for the second time. A few times a week, she tracks her blood pressure and heart rate (Figure 8). She is hoping by showing the numbers she tracked at home to her healthcare providers, she can tell them, *"No, it's usually right around 120/80. It's not always this high"* (P03). She also writes notes next to her readings keeping track of any triggering factors such as an intense exercise session. Jen does not own any activity monitoring device such as Fitbit since she does not want to track too many numbers which can make her anxious and it may become an obsession.



February 2016

Sun	Mon	Tue	Wed	Thu	Fri	Sat
	1 118/75 65	2	3	4	5 114/75 76	6
7	8	9	10 160/109 114 (at doc)	11 122/82 60	12	13 116/75 72
14	15	16	17 120/79 67	18	19	20 121/82 68
21	22	23	24	25	26 117/83 72	27 134/94 (at doc)
28	29					

Figure 8: (Patient #3) Jen's Excel file: sample sheet of her blood pressure recordings.

Hopes, Goals, and Fears: Jen usually does light exercises, gardening, or short walks to stay healthy. To stay under 1500 mg sodium per day she plans her weekly meals with her husband every weekend saying, *"sometimes we have a dinner meeting out or something and I'm sure that those days it's not under 1500 but for those days I plan ahead and try to make sure the sodium stays low the rest of days, so that I'm not completely over doing it"* (P03). Last time she was taking medication for her hypertension, she experienced many side effects from her medications, so she fears that her healthcare providers may medicate her again: *"I've been borderline and they've talked about medicating me for it, but I would rather not be if I* *can avoid it. So, I am just trying to manage it other ways before getting to that point"* (P03). She expressed her concerns to her physicians that she only has high blood pressure when she is at the clinic, visiting her providers getting anxious and stressed, *"and they often don't believe that, because they're like 'well you're sitting here and it's 160/100. That's not good!' So, I kind of wanted to be able to actually show them that I'm not just making this up"* (P03). So far, Jen has been measuring her blood pressure for a year and believes her condition is under control with steady normal blood pressure readings: *"Lately, it's been quite good for the last several months. So, kind of since January I check it maybe once a week now as opposed to every day"*(P03).

5.4.4 *Patient #4: Lucas Ford*

Patient Profile:

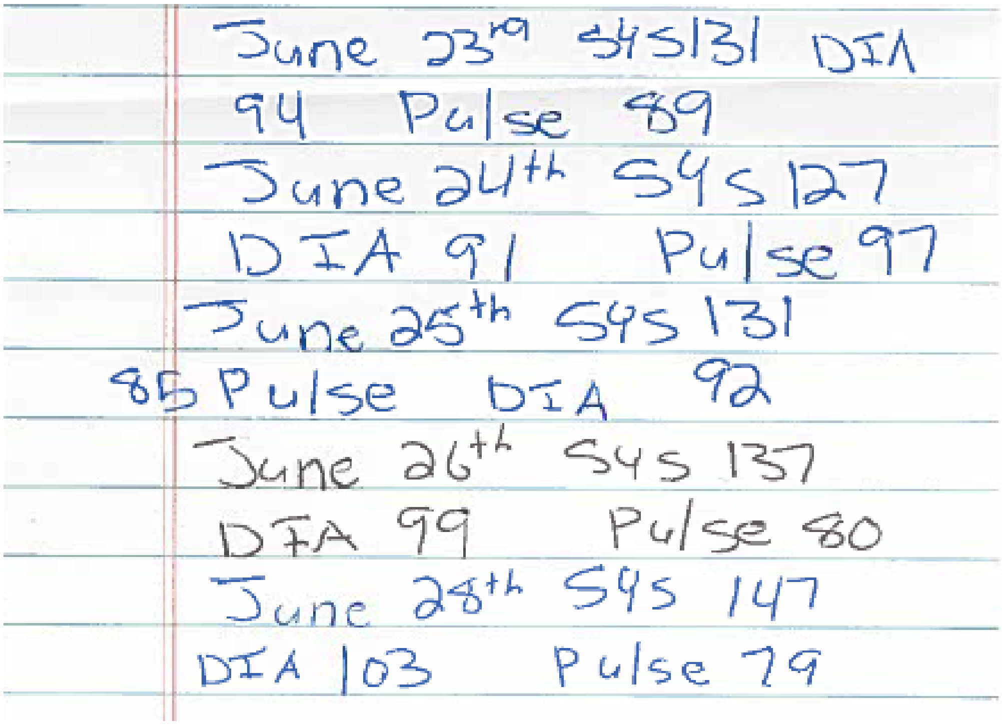
Age and Gender	43 years old, Male
Conditions	Hypertension, type 2 diabetes, depression
Provider care team	Family physician, nutritionist, pharmacist, counselor, and case manager
Data collection motivation	Advised by family physician to track his numbers and wants to find relation between his conditions
Collected data item(s)	Blood pressure, blood glucose, heart rate, medications

Table 12: Patient #4 Profile

Patient History and Data Collection Routine: Lucas is 43 years old and suffers from hypertension, type 2 diabetes, and depression (Table 12). He collects his glucose (Figure 10), blood pressure, and heart rate (Figure 9) in two different notebooks. He was advised by his healthcare providers to track his glucose five times per day. However, he only manages to measure his glucose once a day. Lucas thinks his busy schedule and depression are the major reasons he falls behind on tracking his data on a regular basis. Every time he has a clinical visit, he makes copies of his notebook pages and hands them to his family physician. He has difficulty making sense of his data and expects his healthcare providers to understand his data and give him advice based on them. For instance, he was hoping to find relations between his blood pressure readings and glucose level, but could not find any correlation.

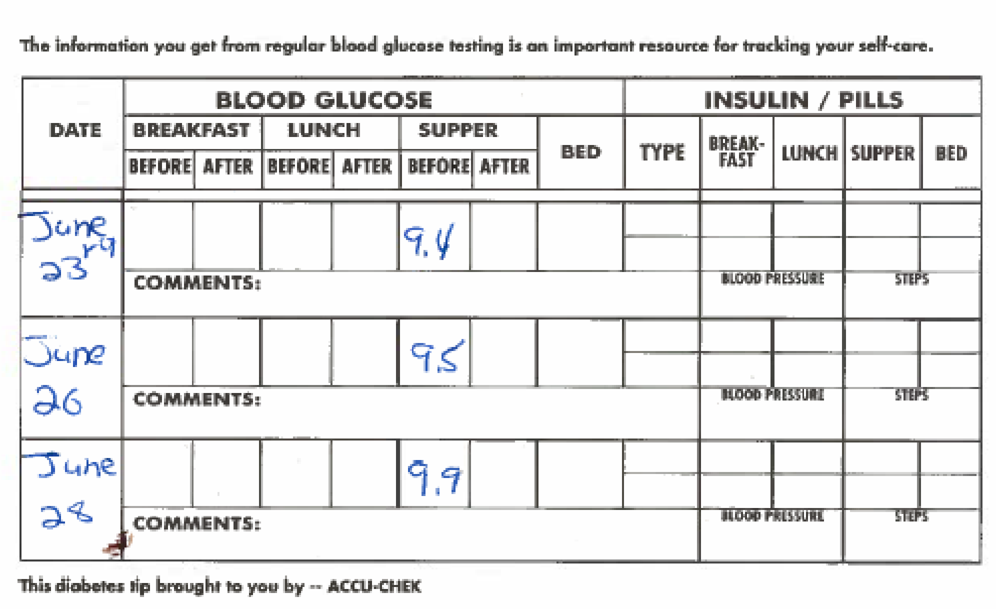
Lucas needs to inject insulin three times a day; he learned self-injection technique from his uncle who is also a diabetic. However, he feels that he does not have enough family support and his family lacks compassion and doesn't understand the seriousness of his conditions. He is prescribed 8-9 medications per day to keep his conditions under control. Since he is overweight, his aunt advised him to stop his hypertension medications otherwise he will gain more weight. After a clinical visit, his family physician convinced him to stick with his medications, despite what others may say.

Lucas was hospitalized a few times with suicidal thoughts and high blood glucose. His depression caused him extra challenges, making it difficult for him to focus on his job, which got him fired. Although tracking his blood pressure and glucose level helps him get his conditions under control, sometimes he experiences an emotional break down when his readings are higher than the normal range advised by his providers.



June 23rd Sys 131 DIA
94 Pulse 89
June 24th Sys 127
DIA 91 Pulse 97
June 25th Sys 131
85 Pulse DIA 92
June 26th Sys 137
DIA 99 Pulse 80
June 28th Sys 147
DIA 103 Pulse 79

Figure 9: (Patient #4) Lucas's notebook provided by the clinic: a page sample of his blood pressure and heart rate recordings.



The information you get from regular blood glucose testing is an important resource for tracking your self-care.

DATE	BLOOD GLUCOSE							INSULIN / PILLS				
	BREAKFAST		LUNCH		SUPPER		BED	TYPE	BREAK-FAST	LUNCH	SUPPER	BED
	BEFORE	AFTER	BEFORE	AFTER	BEFORE	AFTER						
June 23rd					9.4							
	COMMENTS:								BLOOD PRESSURE		STEPS	
June 26					9.5							
	COMMENTS:								BLOOD PRESSURE		STEPS	
June 28					9.9							
	COMMENTS:								BLOOD PRESSURE		STEPS	

This diabetes tip brought to you by -- ACCU-CHEK

Figure 10: (Patient #4) Lucas's Excel file: a sample sheet of his blood glucose recordings.

Hopes, Goals, and Fears: Lucas's mom died from cancer and his dad died of a heart attack. He is scared, thinking the same conditions may happen to him and does not know what to do for prevention. He feels frustrated and upset with himself for not having his conditions under control. Lucas hopes to get support that motivates him to track his data, but does not want to be pushed. He wants to exercise regularly, as it can help him stabilize his blood pressure and glucose level; however, his busy schedule does not allow for exercise. Instead, he tries to go for short walks to lower his blood pressure when he experiences high blood pressure. His ultimate goal is to get off the insulin by next year. *"I've just been dealing with way too many things, work, family, and just different barriers in my life, so it's been up and down"* (P04).

5.4.5 *Patient #5: Ken Smith*

Patient Profile:

Age and Gender	37 years old, Male
Conditions	Memory problems, paranoia, learning difficulties, asperger syndrome, behavioral disorder
Provider care team	Family physician, primary care network nurse, nutritionist, psychologist
Data collection motivation	Help with diagnosis and take control of his conditions
Collected data item(s)	Pain, bowel movements, moods, nutrition

Table 13: Patient #5 Profile

Patient History and Data Collection Routine: Ken is 37 years old and suffers from multiple conditions. He had memory problems, paranoia, and learning difficulties since childhood (1986). He was diagnosed with behavioural disorder in 2005, mental health problems in 2009, and asperger syndrome in 2011 (Table 13). Ken has five to six different apps installed on his Android tablet each recording one or two health data items (Figure 11). He has tracked his nutrition data since May 2016. He uses the MySymptoms app to track his nutrition data and his symptoms related to his stomach pain and bowel movements such as nausea, vomiting, diarrhea, stomach pain, bloating, heartburn, and gas. Due to his mental health problems, Ken has difficulty collecting his data on a regular basis. To understand the effects of his mental state on his conditions, he also tracks his mood. In addition, Ken is experiencing pain in different parts of his body (neck, back, shoulder, ankle, etc.), which has not been diagnosed yet. Thus, he tries to track his pain to help with diagnosing the source of his pain.

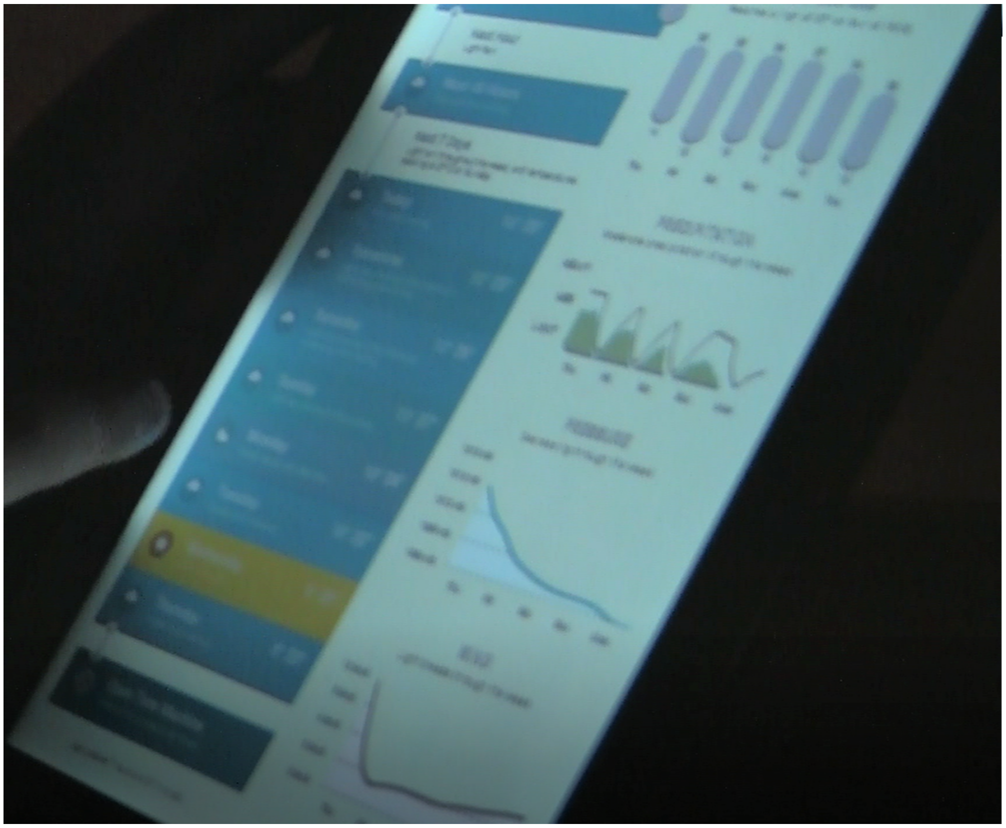


Figure 11: (Patient #5) Ken's sample of mood and nutrition data on his tablet.

Hopes, Goals, and Fears: Ken has been tracking several symptoms and factors that he thinks may be helpful for improving his health, but his healthcare providers do not always find his collected data useful. He recalls sharing his data with his family physician: *"I gave all my symptoms to her, all recorded on a sheet and then she came back and said, 'Oh, we're just looking at the gut issues.' I'm like, What about the rest?"* (P05). He is confused about which data items he needs to collect that are useful saying, *"[it's] a waste of time, maybe a little bit stupid, she [his physician] could have been more clear"* (P05). Ken uses another app on his tablet to help him set goals. His goal is to eat healthier, get more physically active, and lose weight, *" [my extra weight] puts a lot of pressure on everything else, increases my arthritis, all my spine issues, which I already have, like spinal stenosis"* (P05). He visits a complex care clinic regularly. He is hoping to get more involved in his care; however, he sometimes feels left out saying, *"[The provider team] met without me, and they decided some stuff without me. I don't think this is patient-centered. I ask many questions, I want the information, and then they don't have the time"*(P05).

5.4.6 *Patient #6: Sarah Green*

Patient Profile:

Age and Gender	49 years old, Female
Conditions	Type 1 diabetes, meningitis, gastroparesis, diabetic retinopathy
Provider care team	Endocrinologist, diabetic nurse, neurologist, optometrist
Data collection motivation	Manages her gastroparesis to avoid severe situations like getting fed by tube, tracks her glucose to manage her diabetes
Collected data item(s)	Glucose level

Table 14: Patient #6 Profile

Patient History and Data Collection Routine: Sarah is 49 years old and was diagnosed with type 1 diabetes in 1984 (Table 14). She uses an insulin pump to manage her diabetes. The pump automatically tracks her blood glucose level in different time intervals and lets her program her insulin (Figure 12). Her diabetes nurse monitors Sarah's glucose level regularly. On the occasion that Sarah feels sick or in need of help, she calls her nurse and asks her nurse to log into her pump results remotely. Based on her pump results, the nurse will give her advice on how to normalize her glucose level.

In 2013, Sarah was hospitalized experiencing severe gastroparesis symptoms. After her gastroparesis diagnosis, she has started watching her diet. It is important for her to see the relation between her food intake and her blood glucose. Sometimes she gets low glucose because of a certain food that she had a few days ago saying, *"[I'm] trying to keep the diabetes under control, and changing my whole diet because I can't eat meat any more. My stomach just won't digest, with the gastro, I just can't process"* (P06). Sarah does not regularly record her food intake, but when she feels sick, she takes notes in her phone of what she ate and her activities that may have affected her glucose: *"But there's really no answer, I've been dealing with this for about two or three years now. And I'll be really good, something will work for a little bit, and then it just stops, so, it's trial and error with the diet, that's all it is"* (P06). Sarah was in stable condition until 6 months ago, but now she is struggling, for instance experiencing a low glucose level of 3.4 mmol/L and a high of 20.9 mmol/L.

Sarah is going through perimenopause that affects her metabolism. She started tracking her menstrual cycles since she thought the hormonal changes in her body may affect her glucose levels. After consulting with her endocrinologists, she started to take birth control pills which helped stabilize her glucose levels. Sarah developed arthritis in her hand and gets cortisone shots, which caused her glucose levels to go up after each shot. However, after a few years of cortisone shots, they are no longer effective and she is waiting to get hand surgery.

Hopes, Goals, and Fears: Sarah has changed her lifestyle especially after her diagnosis with gastroparesis: *"I've totally adapted, because before I could just plan anything, and go anywhere, and do anything, but the last three years have just been really really, really hard"* (P06). Sarah takes an active role in managing her conditions. She says *"with gastroparesis there's no medication, there's no cure . . . it's a matter of just doing a lot of research and reading in different avenues* (P06). She feels fortunate to have a provider care team who welcome her opinions and her research. Sarah has a fear of getting sick to the extent that she needs hospitalization, *"I'm so sick, my husband and my son just freak right out. My trick is just to*

Figure 12: (Patient #6) Sarah's glucose meter

stay hydrated enough that I don't go into ketoacidosis and stay out of the hospital, and that's my big thing" (P06). She does not trust nurses in the hospital saying, *"Don't you dare get sick in a hospital because they don't know how to use [insulin] pumps"* (P06).

5.4.7 *Patient #7: Tim Muller*

Patient Profile:

Age and Gender	56 years old, Male
Conditions	Type 2 diabetes, Hypertension, Hereditary Hemorrhagic Telangiectasia (HHT)
Provider care team	Family physician, diabetes nurse
Data collection motivation	To keep his numbers under control
Collected data item(s)	Glucose level, blood pressure, medications

Table 15: Patient #7 Profile

Patient History and Data Collection Routine: Tim is 56 years old and was diagnosed with type 2 diabetes about 8-10 years ago (Table 15). His condition has gotten worse in the past two years. Six months ago, he started tracking his blood glucose once or twice a day using his glucose meter and recording his readings in an app on his phone (Figure 13). Whenever his glucose level goes too high, he takes a short walk in an indoor shopping mall to drop his glucose immediately.

Tim has been also dealing with hypertension for a long time. He uses a blood pressure cuff machine to measure his blood pressure at different times of the day. He then manually enters his blood pressure readings into two different apps on his phone since he is afraid one app will wipe out his recorded data. He prefers to collect his data on his phone rather than the booklet he was given by the nurse saying, *"I can't even read my own handwriting . . . you forget the booklet, and you can't record it"*(P07). Despite having his phone handy, he does not track his numbers when he goes on vacations. However, not tracking his data during his last vacation caused an abnormality in his data: *"I was good for a while. Then took a vacation and, whoaa!"*(P07). Beside diabetes and hypertension, he has a genetic disorder, Hereditary Hemorrhagic Telangiectasia (HHT) that can cause abnormality in blood vessel formation. However, HHT does not affect his chronic conditions and he is taking medications to control his HHT.

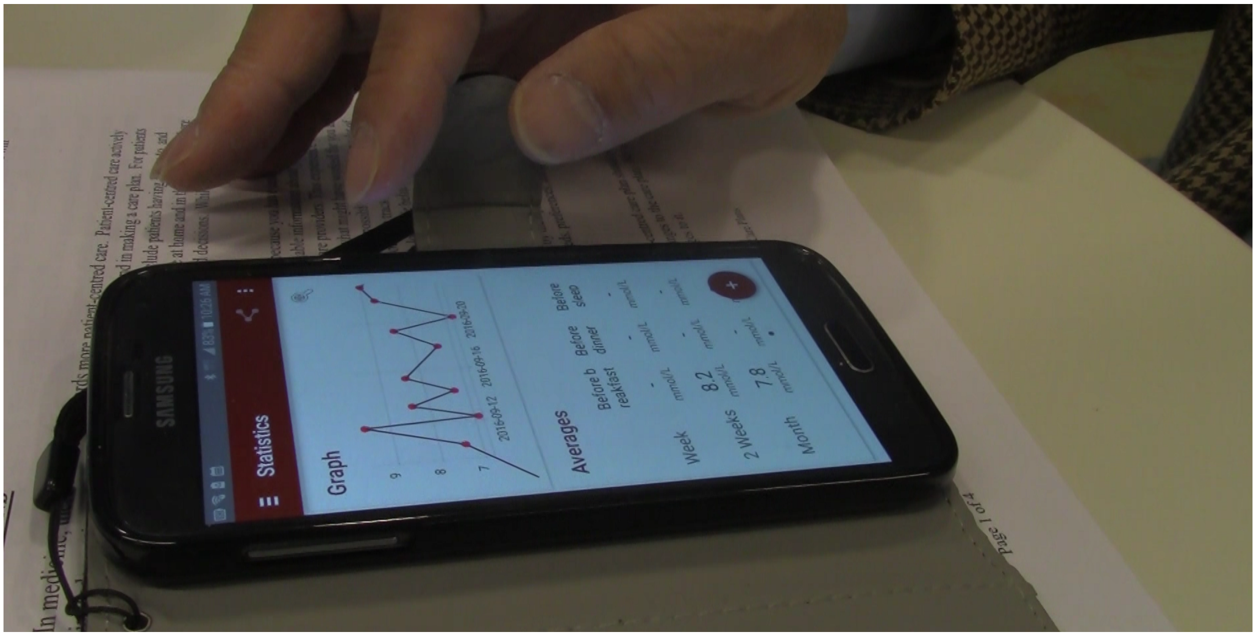


Figure 13: (Patient #7) Tim's glucose and blood pressure data on his phone

Hopes, Goals, and Fears: Tim keeps a record of all his medications over the years. He used to take an older medication which was not controlling his blood pressure very well. After visiting a new physician, the physician changed his hypertension medication to a more recently developed medication. Since the change of his medication, his blood pressure has been generally stable and he got motivated to start tracking it, *"I kicked myself, I should have tracked it longer"*(P07). He is hoping to become more active in his care. Tim has a standing order from his diabetes nurse to get A1C test every three months. His diabetes nurse and his family physician receive the results of his test. He is hoping his glucose level goes below 6.5: *"six months ago, it was 8.1. Now it's 7.1, so pretty good"*(P07).

5.4.8 *Patient #8: Katy Mok*

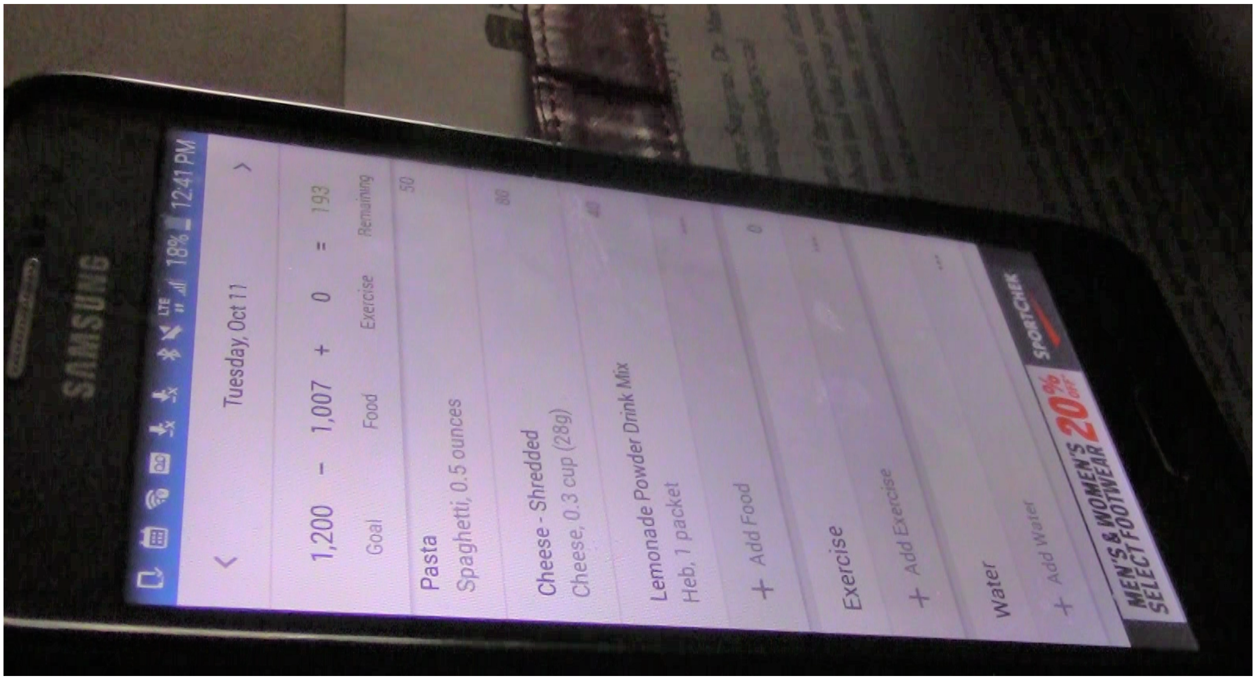
Patient Profile:

Age and Gender	52 years old, Female
Conditions	Asthma, rheumatoid arthritis, hypertension, chronic pain, depression
Provider care team	Family physician, gynecologist, dietitian, psychiatrist
Data collection motivation	To help healthcare providers with pain diagnosis
Collected data item(s)	Pain level, food and water intake

Table 16: Patient #8 Profile

Patient History and Data Collection Routine: Katy is 52 years old and she suffers from hypertension, asthma, arthritis, chronic pain, and depression (Table 16). She was diagnosed with asthma 21 years ago which is mostly under control with medications. In 2004, she gave birth to a premature baby and had a sudden death in her family. Later that year, she was diagnosed with severe depression and was hospitalized in the psychiatric ward a few times. As a result of her depression, she gained 150 pounds. Three years ago, she joined a weight management group and was advised by her dietitian to track her food intake and she lost 125 pounds. Katy does not like to share her collected data with anyone: *"you are doing it for yourself, so you gotta be honest even if you are totally off the rack, but I don't necessary want to share that honesty with everybody"* (P08). She uses the MyFitnessPal app (Figure 14) on her phone to record her food intake, occasionally her water intake, and free-styled notes: *"Under the food note I actually write down the emotional stuff, and I constantly do that"* (P08).

A few years ago, Katy started to experience pain in certain areas of her upper body; however, her physician did not believe her pain was real and was dismissive to her condition. After struggling with pain for a while, she decided to look for another pain specialist. She created an Excel sheet with body part names and each day she would put in a number corresponding to her pain level in addition to the type of pain (stabbing, stinging, and shooting). While Katy has hesitations to share her food diary with anyone, she shared her pain diary with her new pain specialist. She took her data to a specialist to see if there is any relationship between the time of the day, her activities, and her pain level; Katy told us her specialist said: *"This is great, there is no relationship to anything which just tells me it is probably a nerve or something. This is fabulous and I want to keep this!"*(P08). Later, her specialist ordered an MRI and she was diagnosed with a brain tumor.



Tuesday, Oct 11

1,200	−	1,007	+	0	=	193
Goal		Food		Exercise		Remaining

Pasta
Spaghetti, 0.5 ounces 50

Cheese - Shredded
Cheese, 0.3 cup (28g) 86

Lemonade Powder Drink Mix
Heb, 1 packet

+ Add Food 0

Exercise

+ Add Exercise

Water

+ Add Water

Figure 14: (Patient #8) Katy's data sample on her phone

Hopes, Goals, and Fears: Katy hoped to receive more tailored care by sharing her self-collected health data with her healthcare providers. She sees value in tracking her health data and sharing them with her healthcare providers. However, she had different experiences in sharing her data with different providers: *"the different doctors that I see, I will share with some of them some of the stuff . . . what I found is that, some doctors are really open to it, so you share, others are not at all"*(P08).

5.5 DISCUSSION

The results of patient interview studies confirms the complexity and the individuality of patient-generated data collection. Each patient may have a different approach to tracking, presenting, and sharing their health data with the healthcare providers.

Also, patients may have different goals for collecting their data, such as preventing more complications, having more control in their health outcomes, improving management of their conditions, and preventing their health conditions from getting worse.

Since all factors (the type and number of medical conditions, the circumstances of the patient, the collection practices and accuracy) about personal health collection vary significantly from patient to patient as a result, patient-generated data collections are all shaped differently and individualized. This complexity and individuality make it difficult for healthcare providers to understand and analyze patient-generated data collections in short clinical visits. Looking for a solution where this intense individuality may be generalized is unlikely.

Visualizations, which have the potential to summarize data and clarify its presentation, may be a research direction. Careful visualization of patient-generated data collections has the potential to support both patients and healthcare providers in understanding patient data and making better sense of their data. However, designing visualizations and technologies for patient-provider communication is a complex problem.

Perhaps one approach is to initially start with designing individualized visualizations based on each patient's characteristics, preferences, goals, etc. and work our way to design visualizations that are easily customizable.

5.6 CONCLUSION

Tracking and collecting personal health data is becoming more common among patients Choe et al. (2014). Healthcare providers also are showing interests in having access and reviewing these patient-generated data. Yet it is unclear how to efficiently present, make sense, and make decisions based on this data. Perhaps the first step is to study patients' stories and their data collections.

To unveil some of the characteristics of the patient-generated data collections, we interviewed eight chronic patients and illustrated their stories, including their conditions, data collection practices, goals, fears, and lifestyles. Our results revealed the complexity and individuality of these patient-generated data collections and how each patient-generated data collection vary from another patient's health data.

We offered eight unique perspectives as a starting point for researchers to develop new visualizations and technological tools for patients and healthcare providers for presenting and making sense of patient-generated data collections. We hope that future researchers and designers will contribute more patient stories to the research literature, and that the individualities and complexities from these stories will inspire new development of more visualizations and healthcare technologies.

6

DESIGN SPACE OF PATIENT-GENERATED DATA VISUALIZATIONS

6.1 INTRODUCTION

We designed various personal visualizations to represent patient-generated data collections considering the patient's lifestyle, their relationship with the healthcare providers, their health conditions, and their data.

Tracking and collecting personal health data is becoming more common among patients with chronic conditions Choe et al. (2014). These patients have a high incentive to track their health data due to the nature of their conditions that requires close self-monitoring. Each patient may have different goals and motivations for collecting their health data. These goals can range from preventing more complications, having more control over their health outcomes, improving their conditions, to sharing these self-collected data with their providers hoping to receive more tailored medical advices and to help the providers make more personalized medical decisions Chung et al. (2016).

Healthcare providers also think they can provide patients with more tailored care and make data-informed decisions when they have access to patient-generated data collections Chung et al. (2016). However, due to a shortage of time, providers may not be able to glean all the important information collected by the patients and give useful advice. Providers do their best with the data they receive, but often such data has missing parts or is difficult to read all at once. By working within the constraints of the clinical visits, the healthcare providers may not derive as much benefit from patient-generated data collections as is possible. We think visualizations, which have the potential to summarize data and to clarify its presentation, may be a promising direction to represent patient-generated data collections.

To visualize this data, we first needed to gain a better understanding of patients' perspectives on why and how they track, collect, and share their data with their providers during clinical visits. Hence, we interviewed eight patients with one or multiple chronic conditions and presented the results of these interview in the previous Chapter 5.

We gathered a list of requirements for each patient based on the patient's *data*, *motivation*, *time commitment*, and *support circle*. From these lists of requirements, we sketched possible visualization designs representing the patient-generated data collections. We designed multiple possible visualizations of patient-generated data tailored to specific patient's medical conditions, gathered data, and provider-patient relationships instead of immediately pursuing a single generalized design.

6.2 RELATED WORK

In the last decade, many technological tools have become available to support people with tracking personal data such as sleep hours, number of steps, weight loss, etc. Tracking and visualizing personal health data is becoming more common among patients with chronic conditions Fox and Duggan (2013). These patients collect their health data aiming to better understand their conditions, communicate their data, and improve their health. While many tools are available that help people record and visualize their personal health data, most tracking technologies and health data visualizations are not designed specifically to meet patients' and providers' needs.

6.2.1 *Patients Tracking Health Data*

Patients with chronic conditions often need daily self-management. As part of self-managing practice, patients track various types of data depending on their chronic conditions, personal goals, hopes, and even fears. Previous research investigated patients' goals for tracking and monitoring their health data such as 1) tracking for action to immediately adjust factors such as diet or medication, 2) tracking for goal-checking, 3) tracking to make sense of their disease, and 4) tracking upon the provider request Ancker et al. (2015b); Patel et al. (2013).

However, tracking health data does not always have a positive outcome. Sometimes patients feel strong negative emotions reminding them about their illness, or they may feel out of control over their conditions Ancker et al. (2015b); Peel et al. (2007). Moreover, patients may not have the medical expertise to understand their health data, or the reasons behind the fluctuations in their numbers which can lead to frustrations. For instance, Peel and his colleagues found a consistent theme among diabetic patients who did not know how to respond to high blood glucose readings or were unsure how often to track their glucose levels Peel et al. (2007). Some patients may look for temporary solutions to lower their blood glucose level without realizing that permanent lifestyle or behavior changes are required to bring their conditions under control Peel et al. (2007).

Patients collect health data partly to better inform themselves and partly to share their self-collected health data with the providers Patel et al. (2013). However, patients noticed that providers may not be inclined to trust patient-generated data for making medical decisions and dismiss this data. This negative experience can frustrate patients and discourage them in closely monitoring their conditions Ancker et al. (2015a).

In addition to providing more detailed information to the providers, patients track their health data to set goals Ancker et al. (2015b). Patients think that by sharing their goals with healthcare providers, they can all reach a mutual understanding of their expectations and their abilities van der Weegen et al. (2013).

6.2.2 *Patient Data Visualization*

Patient medical records are usually large, complex, and difficult to present. These patient data collections vary from patient clinical records including allergies, diagnosis, lab results etc., to patient self-collected data at home. Visualization literature has offered some different ways to visualize patient medical data that provide some visualization activities such as summarizing, filtering, and navigating through data.

One common approach to visualize patient health data is use temporal visualization representations. For instance, Powsner and Tufte (1994) proposed a visualization to summarize patient status and show the relation of medical findings and patient treatment over time. A large body of work in the context of visualizing patient clinical records and medical events has been done Plaisant et al. (1996); Wongsuphasawat et al. (2011); Monroe et al. (2013). Other examples include Factor et al. (1991)'s work where they proposed a real-time visualizations of patient health status during intensive care hospitalization. VisuExplore visualization was designed with interactive abilities to support exploring and analyzing chronic patient data gathered over a large period of time Rind et al. (2011). TimeSpan visualization was designed to represent stroke patient treatment process data to support stroke healthcare providers with analyzing their patient care processes Loorak et al. (2016).

While the design of these visualizations made significant contributions, there has been less attention to designing effective visualizations for representing patient health data gathered at home Zhu et al. (2016). Perhaps one approach to design patient-generated data visualization is to get inspirations and build upon personal visualizations literature.

6.2.3 *Personalized Data Visualization*

People's interest in collecting and exploring personal data to improve their everyday lives has increased. One way to gain insights on personal data is to visualize it. *Personal visualization* empowers people in being engaged and get inspired by their data Tory and Carpendale (2015). Today, there are many examples of personal visualizations built for different purposes; empowering memory constructions, changing behavior and improving lifestyle Bartram (2015), and reducing energy consumption. For instance, McDuff et al. (2012) designed a multimodal sensor system to log audio, visual, physiological and contextual data and visualized them to help people construct stories about their daily experiences. On a similar note, Wood (2015) designed a visualization representing cyclists' progress through long distance cycling events. The goal of this visualization is to help cyclists construct personal stories from their journey. Additionally, to help people understand their energy consumptions at home, Makonin et al. (2014) designed four eco-visualizations representing residential electricity use. They designed the visualization to reflect the people's household lifestyles.

There are already technological tools for tracking and visualizing health data; sleep, number of steps taken, variations in weight, and blood sugar levels. Many tools have been designed to raise self-awareness through visualizations. For instance, UbiFit Garden is designed to increase people's awareness about their current state of physical activity and encourage them to increase their activity levels Consolvo et al. (2008). Personal data visualizations have also been designed for reminiscing and creating memories Thudt et al. (2017); McDuff et al. (2012); Wood (2015). Since patients sometimes forget or mistakenly misremember details about their health, visualizing their data can help patients remember the events and symptoms correctly Rajabiyazdi et al. (2017a).

However, most tools do not allow self-experimentations and lack data integration among different data sources Choe et al. (2014). To cope with current technological challenges, some people take initiatives, get creative and build their own personal tracking and visualizing tools. For instance, "Quantified Selfers" [1] are a group of people who build their own platforms or technological tools tailored to their specific needs to collect and visualize their personal data. However, while most Quantified Selfers have technological skills or professions that involve working with technology (e.g., programmer, data analyst, or engineer, etc.) Choe et al. (2014), they are rarely visualization experts. Consequently, they may visualize their data in ways that convey non scientifically valid correlations which can be problematic Choe et al. (2014).

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[1] http://quantifiedself.com/

6.2.4 *Summary*

There is evidence that technology can support providers and patients in improving the quality of communicating patient data Sullivan and Wyatt (2005). While previous work investigated the challenges and opportunities for designing supportive technologies for reviewing patient-generated data, they raised questions about how visualization can assist in this manner Zhu et al. (2016). Visualizing patient-generated data can help providers summarize large datasets and can help patients engage in their data and develop self-awareness and self-reflection Tory and Carpendale (2015); Thudt et al. (2017). Although visualizing patient-generated data can benefit both patients and providers, it needs to be carefully designed so that it seamlessly integrates both perspectives into patient care planning Rajabiyazdi et al. (2017b,a). Therefore, we incorporated both providers' and patients' perspectives through the entire process of design.

As discussed earlier (Chapter 5), the results of our interviews with eight patients showed us how each patient's story is different from another patient. We used open coding, a method of grounded theory Strauss and Corbin (1997), to identify and categorize patients' requirement when making sense of their self-generated data collections and when sharing these data with their healthcare providers.

From this analysis process, we distinguished four main categorizes that shaped these patient-generated data collections: patient's *data*, *motivation*, *time commitment*, and *support circle*. However, within each category each patient had different sets of requirements. We mapped out patients' requirements in the categories we identified.

Next, based on each individual patients' requirements, we sketched various visualization alternatives representing patient-generated data collections for each patient. As discussed in our methodology chapter (Chapter 3), this is a wicked problem. Thus, there is no right design solution for this problem, but there are better and worse solutions. Drawing upon the same approach, we designed various visualizations for presenting one patient's data collections. In total we generated 21 preliminary visualization designs for eight patients. We laid out these designs on a design space board (Figure 15). Each column in the design space contains the variation of visualizations for a patient.

As a group, we discussed the visualizations and how they meet the patients' needs and selected one or multiple alternative designs that best matched the patient's requirements. In the following section, we first unfold patients' requirements and second, we discuss how our design meet the requirements.

Figure 15: Design Space: Visualization designs representing patient-generated data collections

6.4 DESIGN DESCRIPTION

In this section, we describe each patient's requirements that we identified from our interviews with the patient (Chapter 5) and how our design(s) satisfy these needs. After carefully analyzing patients' profiles, we came up with four main dimensions: patient *data*, *motivation*, *time commitment*, and *support circle* that shape patient-generated data collections. For each patient, we mapped out the patient requirements to these dimensions. We explain how we took the patients' requirements into considerations when exploring visualization design opportunities to represent their patient-generated data collections.

The first dimension we identified that plays a major role in shaping patient-generated data collections is the different aspects and ways of gathering *data*. Depending on the medium patient use to track their data, their data collections form differently. For instance, some patients measure and record their data manually and some use technological tools that partially or fully automatically track their data. All these factors have impacts on patient data including data items, data focus, and data context. Thus, they also impact design.

Patient *motivation* also has an impact on tracking and sharing the patient-generated data collections. The results of our interviews showed a difference among patients in their engagement levels depending on their goal when tracking their data.

Collecting and analyzing health data are time consuming tasks and patients invest different time periods for tracking their data. Patient *time commitment* differs depending on the frequency of measuring number of data items they collect, and how long they have been collecting data.

In our interviews, we asked the patients whether they shared their data with their healthcare providers or their caregivers at home and how was their experience sharing their data. Patients received different *support circle* from their healthcare providers and their family members that impacted their data collections.

Depending on the patient's conditions, needs, and challenges, we ideate and designed one or multiple visualizations. We did not restrict ourself to design a certain number of visualization representations, we sketched as many design possibilities as we could think of to carefully present patient data. We acknowledge that these designs are not the only possible visualizations and other designers/researchers may come up with variations to these designs. Here, we present our designs and we hope this will be a starting point for other researchers to contribute to this space. Note that we allocated pseudonyms to confer anonymity of our patients. The name of the patients in this chapter are the same as patient name in Chapter 5

6.4.1 *Design Description Patient #1: Maria Freeman*

Considering Maria's conditions, challenges, and needs (Table 17), we sketched a visualization representing her self-collected health data (Figure 16).

17.1 (Data Item): Maria tracks her blood pressure and heart rate data. Thus, we designed a visualization representing both her blood pressure and heart rate readings.

17.2 (Data Focus): In this visualization, we display blood pressure readings in the form of bars and show the patient's heart rate on demand. Each bar represents one blood pressure reading, we associate the bottom border of the bar to diastolic and the top border of the bar to systolic. The two horizontal lines in the background show the normal blood pressure reading range (120 over 80). Therefore, any bar with a height over or under the lines is immediately distinguishable for further investigation. In addition, we added colour to each bar showing a normal (green), an abnormal (yellow), or a

Table 17: Design Descriptions for Patient #1

Number	Category	Requirement	Design Description
17.1	Data (Item)	She tracks blood pressure and heart rate.	We represent both data items in the visualization.
17.2	Data (Focus)	She monitors her blood pressure but has a steady heart rate.	We display blood pressure data at the first view and heart rate data on demand and we added colours to the data points for easier focus.
17.3	Data (Context)	She tracks aggregating factors and relevant context.	We added the ability to add notes to data points.
17.4	Motivation	She follows her providers advice on collecting her data to find patterns and trends.	We have an overview of data points.
17.5	Time Commitment	She tracks blood pressure and heart rate 3 or 4 times a day.	We show each blood pressure reading with a bar in a day.
17.6	Support Circle	She asks for healthcare provider's help for her data analysis.	We have an overview of data points in a month.

dangerous (red) blood pressure reading. This can help her make immediate decisions to drink water, do mild exercises, or even see medical care. We added an on demand option that lets patients hover over each bar to see her heart rate readings. For instance, on day three Maria's heart rate was measured at 98 beats per minute.

17.3 (Data Context): Tracking the relevant context to the data point can help both patients and healthcare providers. The patient can think about the possible trigger factors when experiencing abnormal blood pressure or heart rate readings. Maria keeps a record of events or activities she thinks may be relevant to her blood pressure, so later during a medical visit, she can bring them up for discussion with her healthcare providers. Thus, in our design we also added an option for her to add notes associated with her blood pressure. For instance in Figure 16, we show "lack of sleep" to her high blood pressure reading on day three as a possible trigger factor.

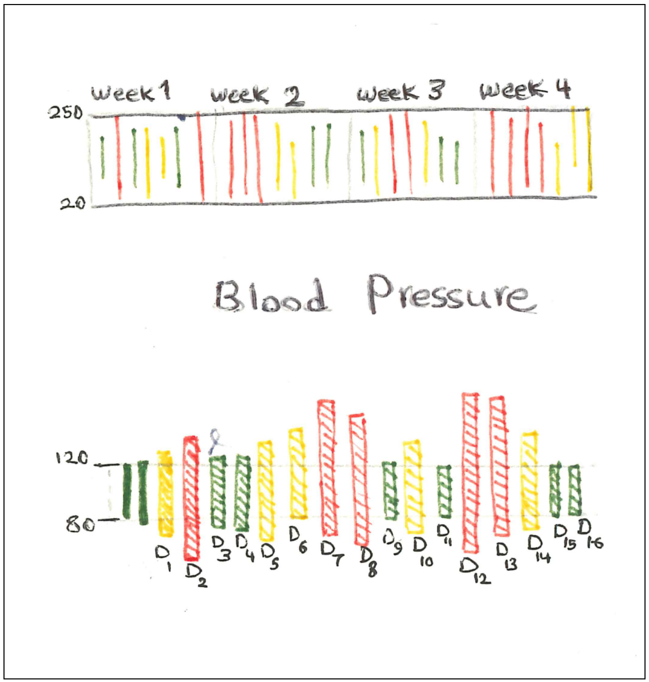

Figure 16: Preliminary visualization sketch for Patient #1.

17.4, 17.6 (Motivation & Support Circle): Maria is motivated to lower her blood pressure readings and she tracks her data to reach her goal. However, she is mostly relying on her healthcare providers to analyze her data. This representation has the capacity to show an overview of patient blood pressure readings over a period of months as well as detailed numbers on demand for providers to quickly check the patient status in the past month. The top view is an overview of a month of blood pressure readings divided by weeks. An overview look can be useful when patients or their providers are investigating an overall trend in the patient data. This view can help both patients and healthcare providers to find out if Maria had more high or low blood pressure readings in a month and look for possible patterns in her data.

17.5 (Time Commitment): Maria measures and records her blood pressure and heart rate readings three to four times a day. Thus in our design each bar in the visualization shows one reading in a day with the time of recording.

6.4.2 *Design Description Patient #2: Andrew Gellar*

Considering Andrew's conditions, challenges, and needs (Table 18), we sketched two alternative visualizations representing his self-collected health data (Figure 17).

Table 18: Design Descriptions for Patient #2

Number	Category	Requirement	Design Description
18.1	Data (Item)	Tracks blood glucose and basal insulin	We represent glucose readings in the visualizations
18.2	Data (Focus)	Focuses on sharing blood glucose readings and tracks basal insulin for his own record not for analysis purpose	We only present glucose level in the visualization view
18.3	Data (Context)	Wants to track his exercise to see the effects of his activities on his numbers	We added the ability to add notes to data points
18.4	Motivation	Wants to share his blood glucose readings with providers	We show an overview of the data with an ability to look for details on demand
18.5	Time Commitment	Tracks glucose level a few times a day	We show each glucose reading with a point/bar at a time
18.6	Support Circle	Expects his healthcare providers to review and make sense of his data	We show an overview of the data with an ability to look for details on demand

18.1 (Data Item): We represent Andrew's blood glucose data in two different visualization designs 17. In the (Figure 17 - A) view, each circular point shows one glucose reading. In the (Figure 17 - B) view, each bar shows one glucose reading.

18.2 (Data Focus): Andrew focuses on sharing his blood glucose readings and tracks basal insulin for his own daily record not for analysis purpose.

In the (Figure 17 - A) view, the top view is a detailed view of one day of patient's glucose level. The circle is a 24-hour clock. Each time Andrew measures his glucose, we show his reading on that time on the clock with a bar. The height of the bar represents

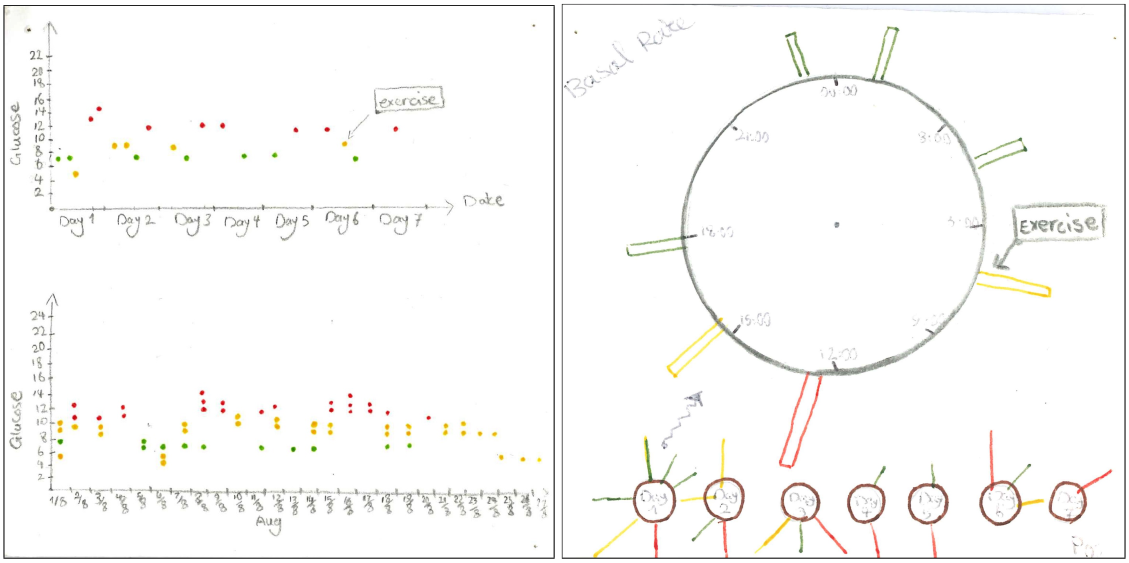

Figure 17: Preliminary visualization sketches, left (A) and right (B) for Patient #2.

the glucose number and the color of the bar represents the normality of the glucose number. For instance at 15:00, Andrew's glucose was at 0.7 and was in a borderline range (yellow). In the (Figure 17 - B) view, the top view shows a detailed view of one month blood glucose readings. Each day in a month has a few readings that we display with a circular point. The location of each data point on the chart is associated with the glucose number. We also double coded each data point with colours; if the glucose reading is too low (red), low (yellow), normal (green), high (yellow), or too high (red).

18.3 (Data Context): Andrew tracks his exercise on the side to understand the effect of his physical activities on his blood glucose. In addition, having these notes can help Andrew to share his notes with his healthcare providers to find trends or patterns that can contribute to making further medical decisions or treatment planning. Thus, we added an option for the patient to add a free style note on his data point to appear on demand when hovering over the data point in the visualizations.

18.4, 18.6 (Motivation & Support Circle): Andrew has trouble analyzing his data and needs support from his healthcare providers to make sense of his data. Thus, we included an overview of the data in our designs. In the (Figure 17 - B) view, the bottom view shows one months of data (glucose readings). The y-axis represents the glucose level, the x-axis shows the date. Each dot shows one data entry positioned. In the (Figure 17 - A) view, beside the detailed view on the clock, we added a weekly view at the bottom of this visualization. Each mini clock at the bottom shows one day of glucose data. This view gives the patient and his healthcare providers an overall look on a week of data then by choosing a day, they can see a more detailed view at the top.

18.5 (Time Commitment): Andrew tracks his glucose level a few times a day. Thus, in our visualization designs, we display each data point with a point or a bar in a day.

6.4.3 *Design Description Patient #3: Jen Adams*

Considering Jen's conditions, challenges, and needs (Table 19), we sketched two visualization alternatives representing her self-collected health data (Figure 18).

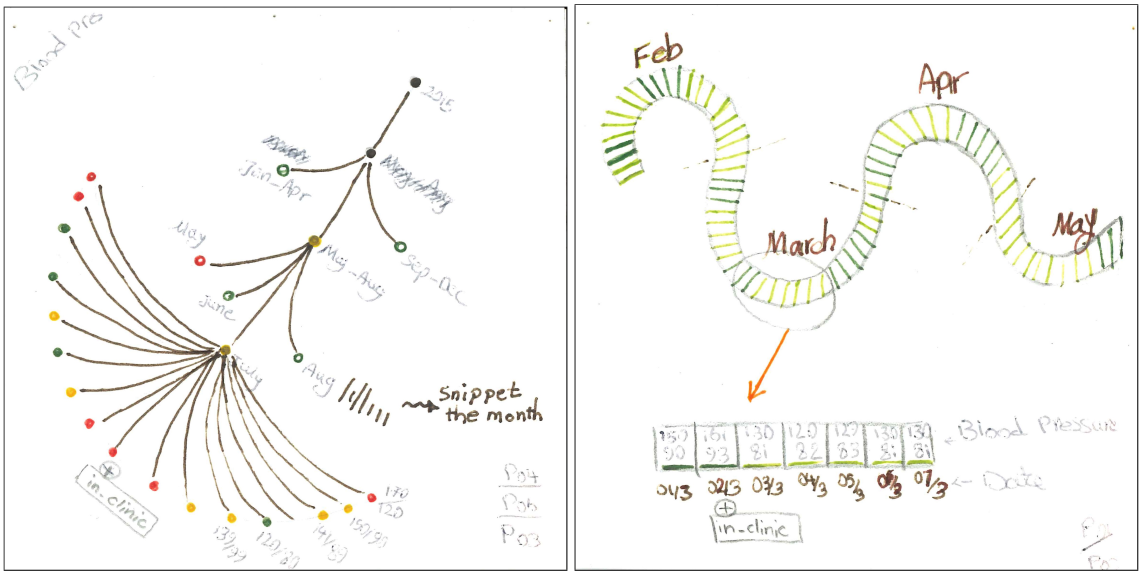

Figure 18: Preliminary visualization sketches, left (A) and right (B) for Patient #3.

Table 19: Design Descriptions for Patient #3

Number	Category	Requirement	Design Description
19.1	Data (Item)	Tracks blood pressure and heart rate	We only represent her blood pressure readings in the visualization
19.2	Data (Focus)	Monitors her blood pressure but has a steady heart rate	We present averaged blood pressure readings in the visualization
19.3	Data (Context)	Tracks her clinical visits	We added the ability to mark the blood pressure readings taken in the clinic
19.4	Motivation	Avoid developing hypertension for the second time	We display an overview of her average blood pressure readings with an ability to select data on demand
19.5	Time Commitment	Tracks blood pressure and heart rate a few times a week	Each bar/point shows one blood pressure reading in a day
19.6	Support Circle	Shares data with her spouse	We have an overview to her averaged blood pressure

19.1 (Data Item): Jen tracks her blood pressure and heart rate data. However, since she is experiencing a steady heart rate, we only display her blood pressure data in two different visualization alternatives.

19.2 (Data Focus): Jen's main focus is on monitoring her blood pressure and is not focused on her heart rate data. Thus, in both our designs, we focused the visualizations on representing blood pressure readings (Figure 18 - A and B). Both these visualizations represent the same data (blood pressure readings), but in different forms.

19.3 (Data Context): We saw in Jen's data that she was taking notes of her clinical visits beside her blood pressure readings. Jen thinks she experiences high blood pressure whenever she visits a clinic. Therefore, in our design, we have an option for Jen to mark the blood pressure readings measured during her clinical visits.

19.4, 19.6 (Motivation & Support Circle): Jen was previously diagnosed with hypertension and now only monitors her blood pressure to not develop hypertension again. She loosely tracks her data and is more interested in looking into an overview of her data and sharing this overview with her spouse. Thus, we designed two visualizations both displaying an average of her blood pressure data (Figure 18 - A and B). In the (Figure 18 - A) view, we have designed a tree based visualization with the ability to expand on demand. The top root represent the average blood pressure readings of the patient over one year. The next level shows the seasons, then months, and lastly the daily blood pressure reading. Jen uses three different colors to distinguish her readings into normal, borderline, and abnormal. With colour coding her numbers, she can quickly glance over her data. We have used the same idea in our visualization design and color coded her blood pressure readings. For instance looking at the month of May-Aug branch, we can see that she was experiencing high blood pressure readings in these months. In the (Figure 18 - B) view, each bar shows one day of blood pressure readings, with dark green indicating high blood pressure readings, green indicating a normal blood pressure readings, and light green indicating low blood pressure readings. Looking at this view, she can decide if she is having more dark or light colors in a period of time. Whenever she decides to focus on a certain period of time, she can select that section and a table view appears underneath with the blood pressure readings displayed for each day.

19.5 (Time Commitment): After months of tracking her blood pressure readings a few times per day, Jen ensured her blood pressure is steady. Currently, she only tracked her blood pressure a few times a week. Thus, in our design we also only display maximum one reading per day.

6.4.4 *Design Description Patient #4: Lucas Ford*

Considering Lucas's conditions, challenges, and needs (Table 20), we sketched two different visualizations representing his self-collected health data (Figure 19).

Table 20: Design Descriptions for Patient #4

Number	Category	Requirement	Design Description
20.1	Data (Item)	Tracking blood pressure, heart rate, glucose without time stamp	The visualization represents all the three data items
20.2	Data (Focus)	Does not focus on any data item in particular	We display all three items in the visualizations
20.3	Data (Context)	Does not tracks any notes	-
20.4	Motivation	Shares his data with his providers and wants to find relation between blood glucose and blood pressure	We show all three data items in one view to better find relation between them
20.5	Time Commitment	Advised by his healthcare providers to track his glucose five times per day; however, he only manages to measure his glucose once a day	We show only one reading per day without time stamp
20.6	Support Circle	Has not shared his data with his healthcare providers	-

20.1 (Data Item): We designed two visualizations displaying all three items Lucas is tracking, blood glucose, blood pressure, and heart rate in one view (Figure 19).

20.2 (Data Focus): Lucas does not necessarily focus on any data item but wants to look at all three collected data at once. Thus, we display all his data in one view without focusing on a data item. Each data point is color coded in both visualizations (Figure 19 - A and B) based on the ranges defined for Lucas's conditions. Green indicates normal, yellow shows borderline numbers, and the out of range readings are colored in red. For example, a normal glucose level for a patient with diabetes should stand between 0.5 to

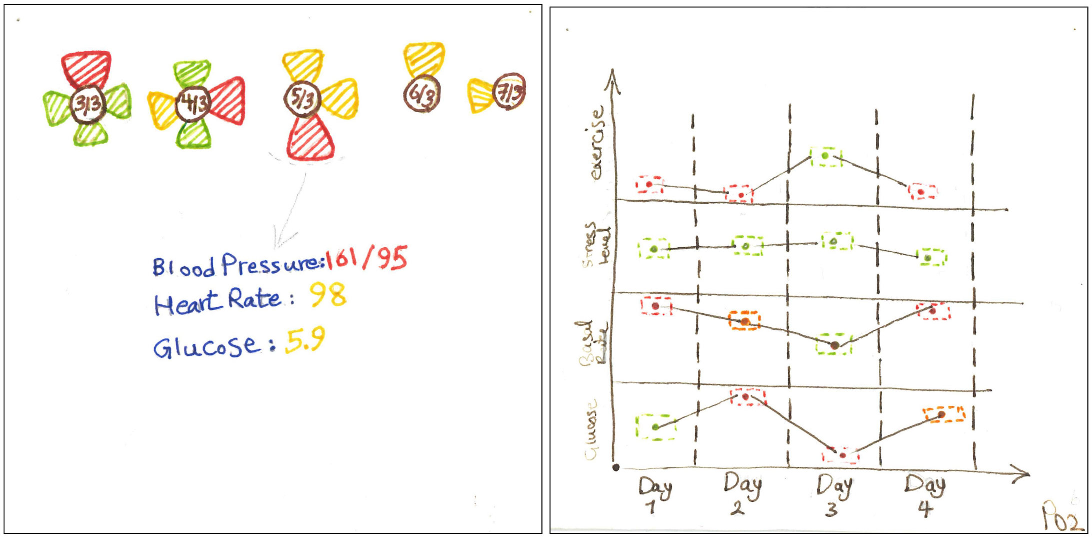

Figure 19: Preliminary visualization sketches, left (A) and right (B) for Patient #4.

0.6, this norm is colored with green. Ranges between 0.4 to 0.5 and 0.6 to 0.7 are in the yellow range that gives patient a warning. Any range beyond that will be risky and are represented by red.

20.3 (Data Context): Lucas feels overwhelmed with managing his conditions, so he avoids tracking any additional data other than what he was advised to collect. Thus, we do not have any option for him to track notes relevant to his data. This will ease the process of data tracking for him.

20.4 (Motivation): Lucas was advised to track his health data. Personally, he is also interested in finding possible relations between his data items (blood pressure, blood glucose, and heart rate). We designed two potential visualization views that can help Lucas with finding patterns or relations. In the (Figure 19 - A) visualization view, we display his heart rate data as the top petal, the blood glucose data as the right petal, and the blood pressure data as the bottom petal. Displaying the data items at the same position makes it easier for comparison. In the (Figure 19 - B) visualization view, each vertical division shows one data item. However, the dates are aligned across all three data items for easier comparison.

20.5 (Time Commitment): Lucas was advised by his healthcare providers to record his data five times a day. However, he is dealing with a lot of pressure due to his conditions and his personal problems, so he only manages to track his data once a day. In the (Figure 19 - A), we show each day of data readings in a flower shape visualization, each petal representing one data item: blood pressure, blood glucose, and heart rate. In the (Figure 19 - B), we display all three data items in one chart. Each vertical division in the chart shows one data item: blood pressure, blood glucose, and heart rate.

20.6 (Support Circle): Lucas has not shared his data with any of his healthcare providers before, so we do not have a clear understanding of his expectations.

6.4.5 *Design Description Patient #5: Ken Smith*

Considering Ken's conditions, challenges, and needs (Table 21), we sketched two visualizations representing his self-collected health data (Figure 20).

21.1 (Data Item): Ken tracks his pain, mood, bowel movements and nutrition data. He uses MySymptoms app to track his bowel movements and nutrition data and is happy with the functionalities of this app. However, Ken is lost in tracking his moods and pain data. Thus, we decided to focus on designing visualization to display these two data items. We designed two visualizations each representing one data item. A calendar based view to display mood and a body mock-up visualization to show his pain data. Ken prefers using multiple apps on his tablet to record different health data items. These apps are all disparate and disconnected, thus we also visualized his data in separate visualization forms.

Table 21: Design Descriptions for Patient #5

Number	Category	Requirement	Design Description
21.1	Data (Item)	Tracks pain and mood	We designed two visualizations each representing one item, pain and mood
21.2	Data (Focus)	Wants to control his mood and pain	We designed two focused visualizations for tracking mood and pain
21.3	Data (Context)	Writes notes about relevant context	We added the ability to add notes to data points
21.4	Motivation	Takes his mental health problems under control and help with diagnosing his pain	We represent an overview of his mood data and show his pain data
21.5	Time Commitment	Tracks his mood once a day and pain whenever occurs	We show mood data on a calendar visualization and date of recorded pain
21.6	Support Circle	Does not know what types of data to share with providers	-

21.2 (Data Focus): Ken has mental health problems that are effecting his other conditions. To display his mood in a month, we used a calendar view visualization colour coding the dates on the calendar depending on his mood of the day with (Figure 20 - A). The calendar view allows him to enter his mood by choosing a colour that later appears on the calendar. The colours are as following; green for happy, yellow for normal, red for unhappy, gray for a self-defined mood. The gray color will give patient an option to self-define a mood that is not listed. He is also experiencing pain in different parts of his body. We designed a simple body mock-up visualization for him to help him with focusing on tracking his pain (Figure 20 - B).

21.3 (Data Context): Ken records relevant context as notes that he thinks may trigger his mood. Thus, we added an option for him to add free style notes to keep track of

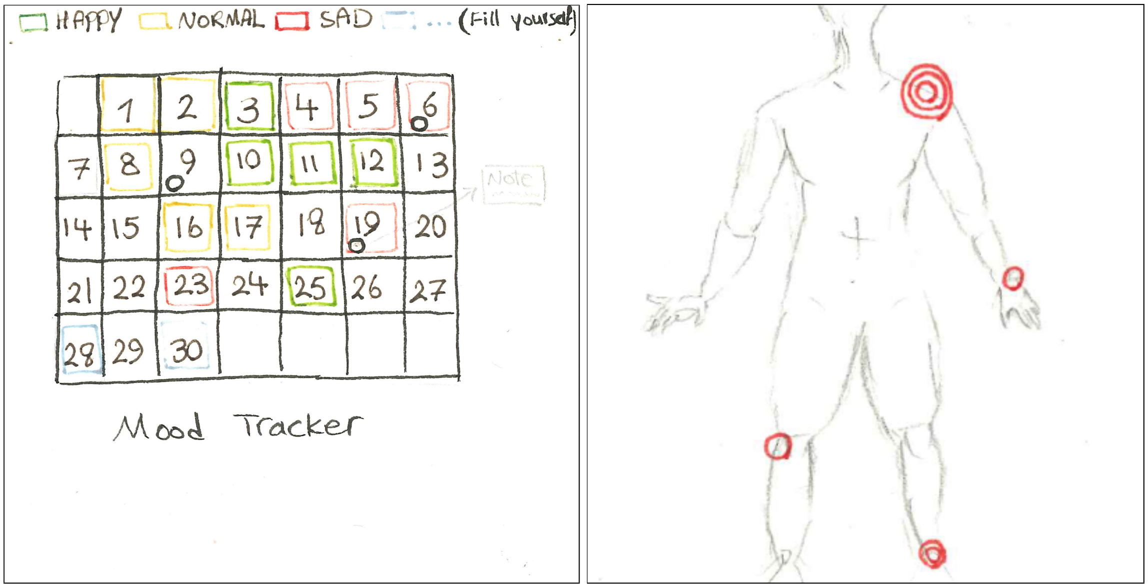

Figure 20: Preliminary visualization sketches, left (A) and right (B) for Patient #5.

the context associated with each day in the calendar view visualization. Once a note has been added, a pen symbol will appear on the right corner of that day on the calendar.

21.4 (Motivation): To help this patient get his mental health problem under control, we designed a calendar visualization displaying his moods in a month (Figure 20 - A). This visualization will give him an overview of his moods for a month helping him to make decisions regarding his mental health problems.

To help Ken with tracking his pain, we designed a body-mock up visualization allowing him to mark the location and intensity of his pain (Figure 20 - B). Ken experiences pain in different parts of his body and is unsure about the source of his pain. In this visualization, we allow for marking the location of pain in the body-mock up. Every time Ken experiences pain, he marks that part of his body. For instance, three rings on the shoulder area in this visualization means he had pain in his shoulder three times.

21.5 (Time Commitment): The calendar visualization allow for mood entry once a day. The body mock-up visualization does not record the time and lets patient to record as many pain occurrences as he experience them. Each ring in this visualization represent one time pain experience in that location of body.

21.6 (Support Circle): This patient has not shared mood and pain data with any of his healthcare providers.

6.4.6 *Design Description Patient #6: Sarah Green*

Considering Sarah's conditions, challenges, and needs (Table 22), we sketched alternative visualizations representing her self-collected health data (Figure 21).

Table 22: Design Descriptions for Patient #6

Number	**Category**	**Requirement**	**Design Description**
22.1	Data (Item)	Tracks blood glucose	We represent glucose data in the visualization designs
22.2	Data (Focus)	Automatically tracks blood glucose	We focus the visualization designs on displaying all glucose data in one view
22.3	Data (Context)	Does not record any context but tries to memorize them	-
22.4	Motivation	Keep her glucose in the normal range or take immediate action to balance her glucose	We colour coded the data points to ease the decision making for immediate actions
22.5	Time Commitment	Uses an insulin pump that automatically tracks her blood glucose many times a day	We show all her data points in one view in the visualization.
22.6	Support Circle	Asks her diabetes nurse to give her advice based on her insulin pump data	We show an overview of a week of patient glucose data

22.1 (Data Item): Sarah tracks her blood glucose level on a regular basis. Thus, in our visualization, we represent the patient's blood glucose data automatically measured via an insulin pump.

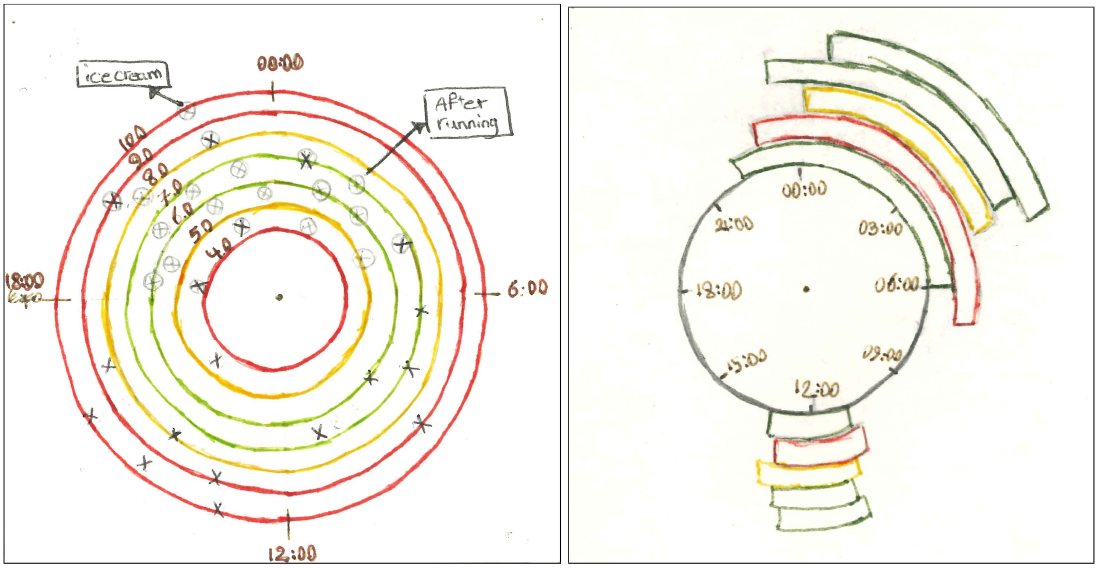

Figure 21: Preliminary visualization sketches, left (A) and right (B) for Patient #6.

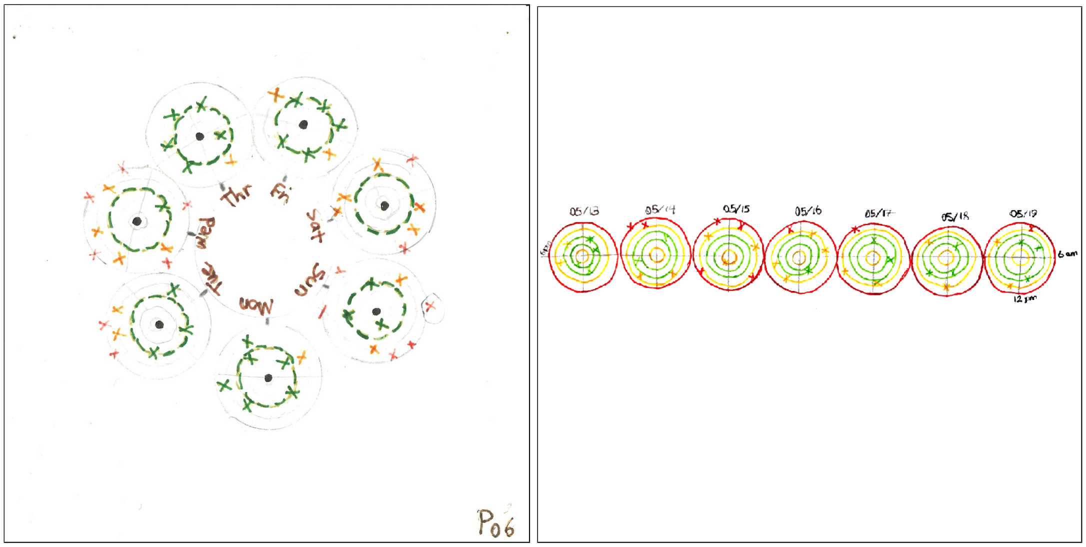

Figure 22: Preliminary overview visualization sketches, left (A) and right (B) for Patient #6.

22.2 (Data Focus): Since Sarah has an insulin pump, the device automatically tracks her blood glucose many times in a day. Thus, to visually show all the data points measured by her insulin pump in a day, we designed a clock visualization. The clock view can show all the data readings in one view with their timestamp.

22.3 (Data Context): Sarah does not record any notes relevant to her data points and prefers to memorize them in her mind. Thus, we did not add any option in our design to accommodate for recording notes.

22.4 (Motivation): Sarah's healthcare providers predefined a normal range of glucose level for her based on her conditions. In the (Figure 22 - A) visualization, the blood glucose reading is marked with an X inside each ring.

For example, a normal glucose level for a patient with diabetes should stand between 0.5 to 0.6, this norm is coloured with green. Ranges between 0.4 to 0.5 and 0.6 to 0.7 are in the yellow range that gives patient a warning. Any range beyond that will be risky and are represented by red. In the (right) visualization, we displayed each glucose reading with a bar on the clock circle. The colour of the bar shows if the glucose reading was normal, in warning zone, or dangerous. The length of the bar is associated with the glucose level. For example, a glucose reading of 9.2 is displayed with red and is longer in length than a glucose reading of 6.6 that is normal and in green. For each bar, we set the starting point of the bar from the time on the clock that the glucose level was measured.

22.5 (Time Commitment): Sarah uses an insulin pump for managing her diabetes. The pump automatically tracks her blood glucose level in different hour intervals. It is crucial for her to track her glucose level a few times per day for instance, when she wakes up, after and before each meal, and before going to sleep. Thus, we display all the data points gathered via her insulin pump in one clock visualization.

22.6 (Support Circle): Figure 21 shows all the glucose measurements in a day. To display the patient's readings over a week, we displayed seven rings in a circular shape (Figure 22 - A). Since the calendar view is linear shaped, we also designed a second overall view, placing rings next to each other in a line (Figure 22 - B).

6.4.7 *Design Description Patient #7: Tim Muller*

Considering Tim's conditions, challenges, and needs (Table 23), we sketched a visualization representing his self-collected health data (Figure 23).

Table 23: Design Descriptions for Patient #7

Number	Category	Requirement	Design Description
23.1	Data (Item)	Tracking glucose, blood pressure reading, and heart rate	We display blood pressure, heart rate, and blood glucose in the design
23.2	Data (Focus)	Focuses on blood pressure and glucose	We only display blood pressure and glucose in the visualization and we show heart rate data on demand
23.3	Data (Context)	Tracks the relevant context to his data	We added the ability to add notes to data points
23.4	Motivation	Keeps his numbers under control	We show his data in a colour coded format to ease the process of pattern finding
23.5	Time Commitment	Track his data once or twice a day and normally skips during vacation times	We show the dates with/without data to show the effect of not tracking data
23.6	Support Circle	Has not shared his data with anyone	-

23.1 (Data Item): Tim tracks his blood pressure, blood glucose, and heart rate data. Thus, we represent all his health data items in our visualization design.

23.2 (Data Focus): Tim's main focus is on controlling his blood pressure and blood glucose. Thus, we focused our visualization design on displaying blood pressure and blood glucose data.

23.3 (Data Context): Tim takes notes keeping track of events and special occasions such as holidays, birthday parties etc. Thus, to accommodate recording these notes, we added an option in our design to track and later display the notes.

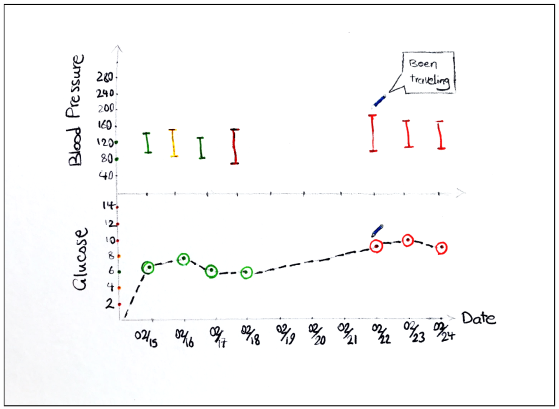

Figure 23: Preliminary visualization sketch for Patient #7.

23.4 (Motivation): Tim's main goal is to keep his numbers under control and to not go over or under the normal data range defined for his conditions. To make it easier for him to check if his numbers are normal, we colour coded the data points. We associated green colours to normal range, yellow or borderline, and red for dangerous readings.

23.5 (Time Commitment): Tim tracks his data once or twice a day without recording the time of the day he measured his numbers. Thus, we show one or two data readings on the chart per day. In addition, he normally skips tracking his data during vacation times. To visually display the effect of not tracking data we show the missing dates with dashed lines.

23.6 (Support Circle): Tim has not shared his data with any of his providers.

6.4.8 *Design Description Patient #8: Katy Mok*

Considering Katy's conditions, challenges, and needs (Table 24), we sketched a visualization representing her self-collected health data (Figure 24).

24.1 (Data Item): Katy tracks her food and water intake but does not feel comfortable sharing them with anyone even her healthcare providers. Thus, we only display the

Table 24: Design Descriptions for Patient #8

Number	Category	Requirement	Design Description
24.1	Data (Item)	Pain intensity, pain type, and pain location	We visualize pain intensity, type, and location in the design
24.2	Data (Focus)	Wants to understand the type and location of her pain	We show the data relevant to pain in the visualization
24.3	Data (Context)	Tracks any context she may find relevant to her pain	We added the ability to add notes to data points
24.4	Motivation	Wants to share her pain data with providers to help with diagnosis	We show an overview to the dates she experienced pain
24.5	Time Commitment	Tracks her pain data whenever she experience pain	We display as many times as pain occurs in a day
24.6	Support Circle	Shares her data with her providers	We show an overview to the dates she experienced pain

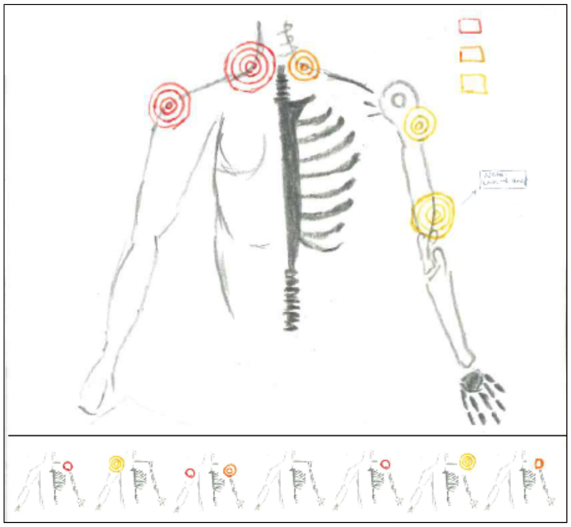

Figure 24: Preliminary visualization sketch for Patient #8.

relevant data items to Katy's pain including pain type, pain intensity, and pain body location.

24.2 (Data Focus): Katy currently uses a body drawing to mark the locations of her upper body pain. Thus, we also designed an upper body mock-up drawing visualization to help her track the type and location of her pain. In the visualization, the tensity of the pain is represented by the number of rings (1 to 10) and type of pain (stabbing, stinging, and shooting) is distinguished with different colours. We only have three types of pain that Katy told us she normally experiences. Pain is usually measured from 1 to 10 in medical assessments, thus we used the same scale in our design.

24.3 (Data Context): Katy writes side notes to her pain data to investigate if there is any relationship between the time of the day, her activities, and her pain level.

24.4, 24.6 (Motivation & Support Circle): Katy hopes to help her healthcare providers with diagnosing the causes of her pain by tracking her pain. We display an overview to her pain data by displaying a week of her pain data in form of small body mock-ups at the bottom of our design. This view will help providers to get an overview and to find possible patterns or trigger factors. There is a potential to expand this timeline to a month of data or even longer.

24.5 (Time Commitment): Every time Katy experiences pain, she records her pain data. Thus, we also allow for as many (pain) data entry as pain occur during a day in our visualization design.

6.5 DISCUSSION

From the results of our patient interviews, we have identified four main dimensions playing roles in shaping patient-generated data collections that we discuss in more details in this section: patient *data*, *motivation*, *time commitment*, and *support circle*. We acknowledge that these dimensions are a starting point towards characterizing patient-generated data processes, not a complete list. Here, we discuss the differences and the similarities between patients within these dimensions. We hope these characteristics help future designers and researcher to expand this design space by introducing more visualizations representing patient-generated data.

6.5.1 *Data*

Patients with different chronic conditions collect different *data items*. Patients collect a different number and type of data depending on the characteristics of their conditions, their treatment plan, or their prevention care. These factors are called *contextual factors* in the literature Ryan and Sawin (2009).

Although patients with similar conditions are usually asked to collect the same set of *data items*, depending on their conditions, their lifestyle, and their personal goals, they may *focus* on one data item over others.

Caring for chronic diseases is complex and having access to only raw collected data without the patient reflection on the data can be insufficient. Gathering the relevant side information (e.g., food, exercise, personal problems) about the data items can make a difference in diagnosing patient diseases, planning treatments for patients, or taking immediate actions by patients or their providers Storni (2011). Our results confirm the necessity of including complementary information while collecting health data. Some of the patients we interviewed were advised to track relevant *context* to the data they record, some patients were self-motivated to record side notes to their data, some patients were only tracking the relevant details in their mind, and some did not record any notes.

6.5.2 *Motivation*

The process of collecting patient-generated data can be either initiated by the patients themselves or by their healthcare providers' requests. The main reasons providers ask patients to track their data are to increase patient engagement in their care, assess patient problem, or discussing patient lifestyle changes and barriers for reaching their health goals Zhu et al. (2016). On the other hand, some patients are self-motivated to track their health data to gain more self-awareness about their conditions, better collaborate with their healthcare providers, or help change their treatment plan Zhu et al. (2016).

We also asked our patients about their motivation for tracking their health data and the results were mixed. Some patients (P01, P02) were tracking their data only because of their provider request and they did not show interests in engaging with their data.

The next group of patients (P04, P05, P06, P08) tracked data to fulfill both their own personal health goal and to share their data with healthcare providers. They showed interest in understanding and reflecting on their data (e.g., find trends and outliers, and ask questions). These patients were willing to get involved in their care to some extent such as setting personal goals. These goals can range from losing weight to control diabetes or control pain to attend a family event.

Our last group of patients (P03, P07) knew their conditions and numbers well and were collecting data to reach their personal goals. This group were not actively sharing their data with the providers. They showed interest in taking full control of their conditions and making everyday decisions by themselves based on their home monitored data.

6.5.3 *Time Commitment*

Previous literature investigated the benefits of self-management and found fewer hospital visits, better health status, smoother patient-provider communication Lorig et al. (1999, 2001). However, self-management can put extra pressure on the patient's shoulders and can be time-consuming Jerant et al. (2005). Patients invest time on tracking their health data depending on their conditions, their motivation, and their health goals. Patients in our study also spent different time and effort on tracking their health data.

Some patients (P03, P07) had their conditions under control and were only tracking data once or twice per week or every other week. These patients track their data to prevent any complications or in case they needed to share their data with healthcare providers for further diagnosis purposes. They collected only a few data items directly relevant to their conditions. So, these patients were spending a relatively short time on data tracking.

Some patients (P01, P02, P04, P08) had been only collecting their data for several months to stabilize their conditions. They were advised by their healthcare providers to track their data a few times a day, for instance after/before each meal, sleep, exercise, or when experiencing any discomfort (e.g., pain, mood swing). Since these patients were only diagnosed recently, they needed to spend more time on collecting data.

One patient (P05) was dealing with several chronic conditions and some undiagnosed conditions. He was advised by his healthcare providers to collect some data items but he decided to collect more data items since he thought they may have effects on his conditions or they may help his healthcare providers with diagnosis. This patients was tracking many data items; therefore, had to spend a lot of time during the day to measure and record his data.

Another patient (P06) wore an insulin pump measuring her glucose levels hourly or even a few times in an hour. This intensive data tracking is only possible with an automated measurement device, or manually for only a short time. This patient was diagnosed with her conditions a while ago, but was experiencing complications. To understand her conditions better, she was tracking a few data items directly relevant to her conditions requested by her providers and a few unrequested data items. Thus she was spending a lot of time on tracking her data and analyzing them.

6.5.4 *Support Circle*

Although patients are the expert in their own life Ballegaard et al. (2008), they lack medical judgment. Sharing and discussing patient-generated data collections is more successful if both patients and healthcare providers collaborate in this manner Chung et al. (2016). Data tracking for patient with chronic conditions is a multidimensional phenomena that can effect both patients and their families Ryan and Sawin (2009). Most patients receive help from their family with caring for their conditions. Although sometimes family barriers such as getting nagged at, getting criticized, or ignored can have negative effects on patient self-management Rosland et al. (2010). The results of our interviews also showed that not all the patients receive the support they need to manage their conditions and to track or analyze their health data.

Some patients (P03, P06) received help and support with tracking their data both from their caregivers at home and medical advice from their healthcare providers. These patients told us they spend time with their family member(s) discussing their eating plans or analyzing their self-tracked health data. Previous studies also reported on positive effects of family support such as eating healthy, encouraging exercise, or reminding of medications in patient self-management processes Rosland et al. (2010).

Some patients (P01, P02, P08) were advised by their healthcare providers to track their health data. Although they received some support from their healthcare providers in analyzing their data, they were not fully satisfied with the level of help they get during clinical visits. Previous work also mentioned the importance of setting expectations between patients and providers when discussing patient-generated data to reduce any tension during clinical visits Zhu et al. (2016).

In case of one patient (P04), he did not receive enough support from his healthcare providers and neither from his family. He was advised by his family to dismiss his medications that negatively impacted his care. The negative effects of family support in self-management care was also mentioned in the previous literature Rosland et al. (2010).

Finally, some patients (P05, P07) had no support and collected and analyzed their data all by themselves. They showed interest in sharing their data with others but felt alone in this process.

6.6 CONCLUSION

Patient-generated data collections are highly personal and complex. From the results of our design processes, we identified four dimensions characterizing patient-generated data collections and processes: patient's *data*, *motivation*, *time commitment*, and *support circles*. These dimensions highlight some of the ways that patients differ from each other. To gain a more holistic understanding of the difficulties working with patient-generated data, we need to first understand this space by studying more individual patients Card and Mackinlay (1997) with unique conditions and the ones with more common conditions and think about what is particular about each patient and their individualized needs. Our study is the first step towards characterizing patient-generated data collections. We encourage researchers and technology designers to start thinking of other dimensions shaping individualities and complexities in patient-generated data by studying more individuals. While one approach to technology design is to build based on generalizable patterns, we instead look to Card and Mackinlay (1997) who proposed starting from multiple individual solutions to build out a design space of possible technologies.

Part IV

PROVIDERS' REFLECTIONS ON VISUALIZATION DESIGNS AND TECHNOLOGY TRANSFER

Previously, we discussed patients' and providers' needs and challenges to make sense and to collaboratively discuss patient-generated data in the clinic (Chapter 5). We called this phase, *discovery*. Next, we designed visualizations representing patient-generated data, *design* (Chapter 6).

In this part, we address Objective 3: Seek healthcare providers' perspectives and goals when requesting and reviewing our proposed patient-generated data visualizations.

We discuss the next two stages of our design study, *reflect* and *implement*. We seek healthcare providers feedback on our visualization designs and how they envision to integrate these designs into their practices (Chapter 7). Drawing upon our discussions with healthcare providers, we chose a number of our visualizations for implementation (Chapter 8).

7

REVIEWING PATIENT-GENERATED DATA VISUALIZATIONS

7.1 INTRODUCTION

We investigate the challenges inherent to designing technology to best leverage patient-generated data. Our motivation comes from patients, particularly those with chronic conditions, who are increasingly willing to track their health data Ancker et al. (2015b) and have goals such as receiving more tailored medical advice Zhu et al. (2016), increasing engagement during clinical visits Huang et al. (2005); Swan (2009), and improving patient-provider communication Patel et al. (2012); Smith et al. (2007). Despite the shared interest for patient-generated data from both patients and healthcare providers, it remains challenging to use this data in an in-clinic visit to support medical discussions and decision making. This is due to providers receiving both requested and unrequested data. Limited time during a clinical visit to review patient-generated data which is often complex and individualized Rajabiyazdi et al. (2017a). Both patients with chronic conditions and their healthcare providers could benefit from using technology such as visualization to better leverage patient-generated data as a communication medium.

As discussed earlier (Chapter 5), a group of healthcare providers from a local hospital approached us about potential technological solutions to support them in reviewing patient-generated data. However, to design effective technology for providers' and patients' use, first it is necessary to gain an understanding of both patients' and providers' perspectives Rajabiyazdi et al. (2017b). We conducted an initial focus group with healthcare providers to learn about their needs and challenges. Then, to understand patients' perspectives, we interviewed eight chronically ill patients who were already collecting data. Based on patients' stories, their data collection samples, their medical conditions, and their patient-provider relationships, we designed a series of individually-tailored visualizations. Using these visualization designs as elicitation artifacts, we interviewed the healthcare providers who had initiated the request for this project, seeking their feedback on the designs, and asking how they could integrate these designs into their practice. In this chapter, we focus on findings from the healthcare provider interviews, which are grounded in and informed by our broader design and research process. Our results showed considerable differences between the role each provider expected patient-generated visualization to play in patient care. In addition to patients' and providers' preferences, we found that integrating the visualization designs into providers' practices, the state of clinical room environments, and the current technologies used in clinics are each important factors that need to be considered in the process of this design.

Through this exploratory design process, we hope to increase the general understanding of the multiple levels of challenges in leveraging patient-generated data effectively. These include:

- The extreme individual nature of this data, arising from what is recorded, and how it is collected and stored.
- The variations in healthcare providers' perspectives and intentions in reviewing patient-generated data.
- The considerable variation in healthcare providers' processes and as a result, the need for different types of technology.

The findings from our design process can provide future researchers with potential avenues for designing visualizations to support patients and providers in reviewing patient-generated data during clinical visits.

7.2 LEVERAGING PATIENT-GENERATED DATA FOR PATIENT-PROVIDER COMMUNICATION

Healthcare providers see value in patients collecting their health data and presenting them during clinical visits. Some providers think that by reviewing patient-generated data they will gain more insight into patient goals and will be able to provide a more tailored care to patients Huba and Zhang (2012). However, receiving a certain type and amount of data is an important factor for providers to be able to give useful suggestions. For instance, with diabetes patients, providers usually require more than just blood glucose monitoring, but also want to know about patient exercise, nutrition, cost barriers, behavioral issues, self-efficacy, and diabetes knowledge Nundy et al. (2014).

Providers also think patient-generated data can be useful in the clinics for setting appointment agendas, assessing self-care activities, identifying patient barriers, understanding patient perspectives, and increasing patient activation Nundy et al. (2014).

In addition, patient-generated data may contain less false positive data since patient data measured in the clinic may get affected by white coat effect and stress of clinical environment Verdecchia et al. (1995); Sands and Wald (2014). In some cases, patient-generated data might be more reliable than clinic measurements, because the data is collected at more frequent intervals and there is less recall bias Nundy et al. (2014); Huba and Zhang (2012). Providers mentioned that often a hospital's electronic medical record system will have misinformation or inaccuracies. In these situations, patient-generated data can be used to reconcile these inaccuracies Huba and Zhang (2012).

However, providers found patient-generated data complementary to clinical measurements and history taking, not a replacement Nundy et al. (2014) and they want patients to track their health data in a meaningful way that is easy to interpret. Providers sometimes expressed frustrations when patients did not track enough data, tracked excessive data, or tracked non-meaningful data Ancker et al. (2015b). For instance, patients may not be willing to record their data when they have abnormal readings due to fear of consequences Ancker et al. (2015b). Patients may be worried that their data will be part of their permanent clinical record Davidson et al. (2013). Providers think patients sometimes record and visualize their data in ways that are difficult to understand or even convey invalid correlations, especially if interpreted without any assistance from providers Choe et al. (2014, 2015).

Not all healthcare providers find patient-generated data useful due to healthcare system organizational and technical issues Zhu et al. (2016). Storing this data in a safe and secure manner can be challenging for providers and can add to their workload Tufano et al. (2008). In addition, most clinical visits are currently short, so finding the time to properly review large patient-generated data collections is difficult Deering et al. (2013).

There is still not a fully clear understanding of how, when, and what type of patient-generated data is most useful to share and discuss during clinical visits. In this project, we investigate how and if visualizing patient-generated data collections can be one answer to this problem.

7.3 METHODOLOGY

We were approached by a group of healthcare providers who were looking for potential technology or visualization solutions to support them in reviewing patient-generated data during clinical visits. These providers were particularly interested in reviewing patient-generated data from patients with chronic conditions who commonly track their personal health data. To design effective technological solutions, we first interviewed eight patients with chronic conditions who regularly collect their health data (Chapter 5), next we designed visualizations representing these patient-generated data collections (Chapter 6), and last we took our visualization designs back to three providers, who were among the group that initiated this project, seeking their feedback.

7.3.1 *Provider Interviews - Considering Patient-Generated Visualization Designs*

We interviewed one complex chronic specialist physician (C1), one internal medicine physician (C2), and one diabetes specialist physician (C3). Each session lasted between 40-60 minutes and was video recorded and transcribed. In the interview session, we first gave the providers a description of the patients' conditions, their personal stories, and their data collection processes. Then, we shared the visualization designs with the providers and observed their reactions walking through and talking out loud about the designs. As time allowed, and depending on the providers' expertise, we shared the visualization designs for the types of patients they usually visit. Both C1 and C2 are in direct interaction with patients with various chronic conditions, thus we shared all the designs with them (P1-P8) (Figure 15). For C3, we shared the designs of patients with diabetes (P2, P4, P6, P7) (Figure 15). Four researchers collaboratively analyzed these

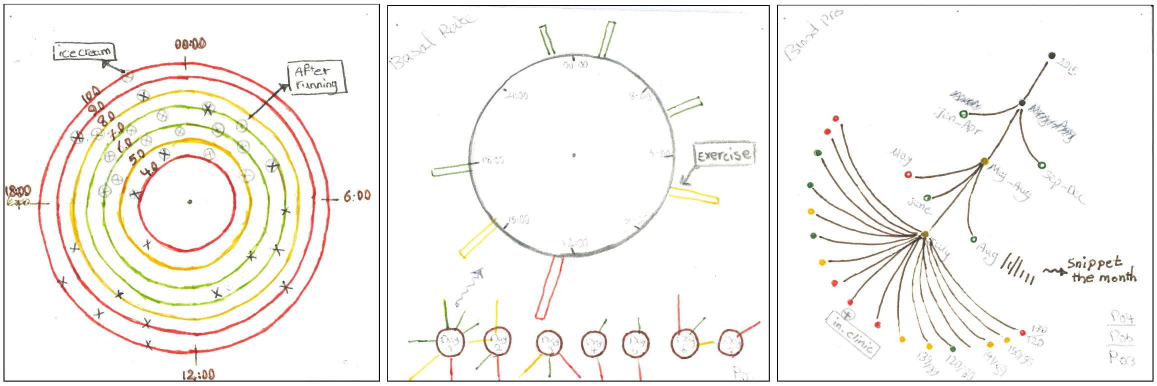

Figure 25: Glucose Clock (left), Glucose Spike (middle), Blood Pressure Tree (right)

sessions and used open coding methodology to identify prominent themes across the sessions Strauss and Corbin (1997). We present the results of our analysis in more detail in section 7.4. Before we go into explaining our results, we remind and name the three visualization designs that were focal points during the providers' interviews (Figure 25).

7.4 PROVIDERS' DESIGN INTERVIEW SESSIONS RESULTS

We presented the patient-generated data visualizations to three of the providers who initially requested visualizations and technological support for analyzing patient-generated data. We observed providers' reactions towards our visualization designs and asked for their feedback. The providers varied widely in why, when, and how to use patient-generated data visualizations in their practices. Here we discuss our results in detail.

7.4.1 *Providers' Perspectives on the Purpose of Patient-Generated Data Visualizations*

We observed that each provider had a unique interpretation of the role that visualizations of patient-generated data could have in patient care. One provider saw value in use of these visualizations by patients, one provider wanted to use them to collaboratively review data during clinical visits, and one thought of using them to support their medical judgment.

Encourage Patient Self-experimentation and Goal Setting: The complex chronic care specialist, C1, expected visualization views that would encourage patients to do more self-experiments. He thinks particularly for chronic symptom management where there is no complete treatment to resolve the symptoms but rather it is a matter of trying to track and manage them, experimenting to find trigger factors can be helpful for these patients: *"they may have somethings that they heard like, 'weather change will make headaches worse' or maybe they are dehydrated, they can do their own experiments. Like 'oh, it seems like on days where I don't drink enough water, I am more likely the next day to have a headache' "* (C1). The potential of self-experimenting with data can help patients find solutions to easily perform through their everyday life. In addition, C1 thinks visualization designs need to have the capacity to support patients in setting goals and tracking an intervention that patients may set in their mind to control their symptoms: *"so the ability to sort of visualize correlation between two symptoms and correlation between some type of intervention and symptoms [is useful]"* (C1). For example, taking three glasses of water per day may reduce headache. Although this provider was interested in encouraging patients to do self-experiments and set goals, he wanted patients to share the results of these data collections with him. In these circumstances the providers can help patients understand if there is a scientific correlation between variables and help patients understand the body mechanism that might explain this correlation.

Juxtapose Data for Collaborative Interpretation by both Patient and Provider: The internal medicine specialist, C2, was cautious about juxtaposing all the patient-generated data items in a single visualization view. He was concerned that juxtaposing patient data could imply a link that may not exist and falsely medicalize the relation between the health data: *" the minute you put them on a shared data exhibit, it is a correlation ... in science we present this kind of things this way, we are wanting to get a relationship maybe that required some thoughts to see whether or not that is necessary"* (C2). Although he was not enthusiastic about visualizing some data items such as blood pressure and glucose level in one view, he found coupling some data points useful. For instance, when seeing the Glucose Clock design he was keen to see patient food intake and their blood sugars displayed together to investigate their relationship.

Offer a Holistic Overview to the Provider: The diabetes specialist, C3, showed interest in a holistic visualization view of all the data items a patient collects. She found the visualization designs that represented all patient data items in one view very useful for planning complex chronic patient care. For example, for displaying blood pressure and glucose level in one view she said: *"you can see both changes in glucose and blood* *pressure it is one of those things that as a care provider, I can show that 'yeah, during these times these situations are really bad for you' "* (C3). She was also keen to see patient's physical activities such as steps taken per day presented in the same view to understand the effect of exercise on the patient's other health conditions. C3 was interested in having access to the patients' notes describing the context and the situation when this data was recorded. She told us that she encourages her patients to take notes of their emotional states, their meals, or any other relevant information when recording their health data. Knowing the context associated with the data, the provider has more information to decide on what strategies to employ to help protect the patient in special circumstances, such as experiencing unavoidable stress.

7.4.2 *Providers' Expectations of Patient-Generated Data Visualizations' Functionalities*

Despite our providers' different views of the role of patient-generated visualizations in patient care, there were *commonalities* among providers' expectations of a visualization's functionalities. The providers expected the visualizations to provide them with capabilities to select, summarize, view details, and overlap patient-generated data.

Select Relevant Data: The providers all complained about patients collecting and presenting unnecessary data without the providers' request: *"I suppose if somebody came with a whole bunch of BP readings written down and there had not been a discussion of a need to do it, sometimes it can be noise"* (C2). The providers thought that sometimes patients become obsessed with tracking their health data, which can interfere with their everyday life or even put them in danger. For example, a patient with hypertension could experience anxiety after monitoring his/her blood pressure, which could lead to a higher blood pressure reading, C2 said: *"In fact on the personal fact, my mum is charting her blood pressure* *and I asked her 'did you talk to your doctor about this? No, no, I am just doing it!' And actually the readings cause her a tremendous amount of anxiety, 'oh oh it is up to 148 over 90', and I say 'that is fine!' "*. The providers hoped that through visualization, they could select and focus on the part of patient-generated data that they find relevant and useful.

Summarize Data: Patients' data is often too large and complex to read at a glance: *"I always find with these data is that if there is too much detail, it become difficult to read, too"* (C3). Often the providers do not know how to act upon receiving the unrequested patient-generated data collections: *"you don't even know 'do I keep it?' and if I do, do I even put it in their chart or is it going to a garbage can? There is awkward moment because it is an explicit, non-negotiated thing that people have recorded"* (C2). The providers mentioned how they sometimes feel uncomfortable when dealing with unrequested data collections that cannot be dealt with during short clinical visits since they need more time to understand the patient data: *"your slow processing speed makes you feel uncomfortable in front of the patient. And the patient is frustrated because they put a lot of effort into it. So, it can be difficult"* (C3). Visualizing patient-generated data in a summarized way can help providers read them faster and easier. An overall view of patient-generated data can support providers in finding general patterns in patient health in a short time.

Provide Details on Demand: Although providers were interested in having access to all patient-generated data types in one overall view, they were cautious about having too many data points in one view. They were afraid it may look too busy and *"get dizzy"* if not well presented. They also wanted to be able to read the exact data numbers. One solution to this challenge is to provide a details-on-demand option, which can allow providers and patients to select parts of data for more detailed view. For instance, after reviewing the Glucose Spike design, C2 mentioned: *"I do like that, like this was a week and you could click on it and then it opens up a day"*.

Overlap Data: Another functionality that the providers found useful was the potential to overlay data collected across different situations or days. By overlapping patient data, providers may be able to find patterns in patients' data: *"they will put these overlays, so you can actually sort of see if from day to day if are we seeing a consistent pattern"* (C3). For instance, C1 was interested in overlapping patients' glucose data over a few days to find out the effect of biking for 30 minutes on patients' glucose level, *"because the nature of the adjustments is very rarely a single day"* (C1).

7.4.3 *Providers' Views on Benefits of Using New Patient-Generated Data Visualizations*

Providers usually acclimate to conventional patient data representations that are familiar from years of use in their practice. Thus, at first it was difficult for our provider participants to review patient-generated data through our different representations. However, after spending time during the evaluation sessions (only between 30-60 minutes), we could observe that they could see new insights in reviewing patient data represented in new non-conventional ways. Providers were able to quickly adapt to new visualization designs and warmed up to the idea of alternative views of data, promising for adoption in their practice. Here we talked about the reasons the providers found new visualizations more useful.

Easier to Read: When we shared the Glucose Clock design with C3, she was initially resistant towards using this new visualization: *"so, I have to admit, this display is not as intuitive to me. I like the idea of target, are you in target, out of target and the idea that being out of range is a problem [but it] takes me some time to figure out"* (C3). After exploring the visualization more carefully, she changed her mind and started to see value in presenting patient data differently. Particularly, she found the new visualization easier to read: *"now* *that I have articulated that, I kind of like this. I have to say, for the pump data, different companies always tabular the data. I always find it a bit tricky to read and it always takes a little bit of time to kind of orientate myself to it. I think actually this could be better"* (C3).

Provide Different Perspectives: Another provider, C1, said he appreciates the visualizations capability to display patient data differently. He said both patients and providers are used to seeing patient data in a standard tabular format. He thought showing patient data in different forms will give patients extra support in understanding their data and taking actions towards enhancing their health: *"so over the years I got used to this because before, that was all we had. We never had this kind of things [visualizations] and so, this is where the notion of 'same data, different lens' becomes useful, where the patient can look at their own data in different ways"* (C1).

Extendable to other Clinical Contexts: The providers in our study recognized that some of these visualization designs can be used to represent other measurements. One of the providers who was at first skeptical of using the Blood Pressure Tree design, after reviewing and discussing the design, suggested using this visualization for collectively displaying 24-hour blood pressure cuff machine data. Normally, providers order these machines to monitor the patient blood pressure for 24 hours, which can help with diagnosis: *"this is an attractive idea . . . maybe this kind of visualization can be used for a 24 hour report [for] every 10 minutes or so . . . you could potentially show this and have the color coding as well when reporting"* (C2).

7.4.4 *Providers' Preferences on Platforms for Implementing New Patient-Generated Data Visualizations*

The choice of visualization platform can make a difference in designing the right visualization to represent patient-generated data. The providers talked to us about their preferred patient-generated data platforms, and the rationales, benefits, and trade-offs of their choices. Different technology and platforms for implementing such visualizations include data booklets, websites, phone apps, and patient portals.

Data Booklets: Providers usually give patients tabular template booklets to record data. C1 mentioned that he preferred reading patient data in these booklets, since it is easier and faster for him to find trends: *"I find it easier to see trends when it is in a book format, spreadsheet kind of format because then what you can do is if you have say 4 times in a day and then this is lunch, supper, bed then what you can do is to see the trend for all lunch sugars to be all in one column"* (C1). To smoothly integrate visualizations into providers' practices, one challenge is to design the patient-generated data visualizations compatible and aligned with the current providers' practices. Booklets are familiar, easy to use, but do not support interactivity.

Websites: Some providers prefer to have patient data uploaded on designated websites. C3 thought that, if designed well, a website would be a good platform that could support both patients and providers to interact with patient-generated data and see the data in different ways. However, healthcare services usually have restrictive policies for use of websites in clinical settings: *"the number of web-based applications that we can upload on the computer is pretty limited"* (C3). Websites may require some data entry, but could potentially integrate patient-generated data into the patient's health records.

Phone Apps: Patients may not feel comfortable sharing all the data with one healthcare provider and may only be willing to share related data with a specific provider depending on their specialty. C3 thought that using a personal phone to record data could be a solution, since patients have full authority: *"I think right now, how it would functionally work is people would bring it on their phone, they review it, and that is okay. But there is a small display"* (C3). Small display real estate could cause limitations in designing visualizations that represent all patient-generated data collections at once. Also, sharing a small display between patients and providers during clinical visits can be difficult.

Patient Portals: Providers normally have a PC in their clinical rooms for taking specific notes about a patient's condition and recording them in a patient's healthcare portal. C2 was keen on the idea of asking patients to link their self-collected data into their healthcare portals ahead of time. He thought that having patient-generated data collections and visualizations available on the portal could not only save time, but could also be easily accessible for discussion: *"I said 'why don't you put some information into the portal and then my nurse or my clinic assistant is going to pull the things up'. When we come to the visit, we might have the dashboard information and these visualizations and we can look at them together at a glance in our visit. It is right there, that could be quite powerful"* (C2). However, implementing visualizations into these portals can be a long and difficult process, which also requires support from healthcare services.

7.5 DISCUSSION

While our providers may have different goals in mind when asking patients to collect and share their health data, these varying goals also share commonalities. Moreover the differing goals each suggest possible fruitful directions for technology design. Developing a variety of design options may be able to support differing provider styles. The four following overarching directions are possible ways forward to design patient-generated data technology/visualization.

Ensuring Data Validity: Some providers were concerned that patients could reach invalid medical conclusions if care was not taken with the data presentations. Some providers mentioned that viewing data without a conversation with a provider could lead to misinterpretations. For all types of goals, data validity arises as an important design consideration.

Supporting Patient Experimentation: Some providers were interested in helping patients self-managing their care or self-experiment with their data. Enabling technology that can help patients to find patterns, triggers, and trends in their data can be an alternate design goal.

Supporting Patient Engagement: Some providers asked patients to collect their data to help keep patients engaged in their care and in conversations during clinical visits. Previous studies also show that sharing health data during clinical visits can improve patient-provider collaboration Patel et al. (2012); Smith et al. (2007); Zhu et al. (2016). Our findings also confirm these results; sharing patient-generated data visualizations can give patients an opportunity to interact with data and contribute to discussions during clinical visits. Designing visualizations to support patient-provider collaborative exploration of patient-generated data may result in gaining rich insights. This could help keep patients involved in their care and help them make informed necessary decisions.

Considering Clinical Visit Dynamics: Naturally, the dynamics of clinical visits vary from provider to provider, as does the physical setup, and the currently available technology Chen et al. (2011). While this setup is not standardized, healthcare services may still have restrictive policies in regards to what types of hardware can be used, and in what manner patient portals can be linked to external apps or websites. Thus, in addition to providing the requested visualization functionalities (summarizing the data, querying the data, accessing data details, and overlapping data for comparisons), the constraints of the context must be considered. To maintain interactivity, some patients share their collected data via phones or tablets with their providers. Sometimes providers see value in incorporating patient-generated data into patient portals. One solution is for patients to record their data into predefined templates compatible with and linked to the healthcare services platforms. This will let providers bring up patient-generated data along with the patient portal during clinical visits. As discussed in our results section, using each technology platform (e.g., paper, phone, website, patient portal) to implement the patient-generated data visualizations has benefits and challenges that need to be considered in the design process. The listed technologies are just possible examples. It is likely that a good solution will need to involve one or more customized technologies.

Providers drastically differed in their principle goal of using patient-generated data. This has major implications on how we design for patients and providers, since we cannot assume that all providers have the same attitudes towards patient-generated data. This may affect the types of visualizations we consider for them and their patients. While equally valid, these attitudes can contradict each other, or be more or less prioritized. A solution that works for one provider may not work for another.

Although providers had different perspectives on the overall purpose of patient-generated data visualizations, they had commonalities in regards to necessary functionalities. All of our providers talked about how difficult it can be to cope with messy, inconsistent, and complicated data collections. This suggests that at-a-glance data comprehension is an important visualization design goal. While overarching intentions of the use of patient-generated data visualizations may differ, surprisingly, the providers quite consistently requested data interactions. This includes being able to get a summary of the data, to filter the data, to dig into data details, and to overlay different parts of the data for comparison.

With all providers, we could see an initial gravitation to the familiar but also a gradual increasing interest in the more unusual visualizations that were tailored to a given patient. As described in the foregoing section, a visualization could go from being discarded by providers, to being repeatedly reexamined, to finally being accepted with positivity. As a result of this shift in perspective, we should keep the visualization designs familiar, but still consider the potential advantages of tailoring a visualization to the specific patient and data.

In summary, both the providers and the patients we interviewed showed highly individualized perspectives on the gathering and use of patient-generated data. We suggest that respecting the different views of our providers reveals a rich potential of technology design options that can support different providers' styles.

7.6 CONCLUSION

There are many driving forces for designing effective patient-generated data visualizations. It is still unclear which direction works the best for both patients and providers. Therefore, the design of patient-generated visualizations needs to be developed based on both provider and patient preferences. The results of our provider focus group, patient interviews, and provider interview sessions revealed the importance and necessity of not only designing customizable individual patient-generated data visualizations for patients, but also considering the goals of the individual providers when using the visualizations. Therefore, as designers we first need to work towards designing and evaluating individual successful designs tailored to patient and provider preferences to gradually reach more general solutions for visualizing patient-generated data.

Healthcare systems have taken steps towards creating tailored personalized care plans for patients. The visualization literature also shows that personal visualizations can better inform behavior change and support self-reflection Huang et al. (2005). The evidence from the visualization literature, the medical literature, and the results of our interview study drove us to think about designing personalized visualization to represent patient-generated data instead of making one visualization design that fits all patients. We encourage future researchers and designers to contribute more patient stories to the research literature and to move towards thinking about designing more for individuals.

8

TECHNOLOGY TRANSFER - THE VISUALIZATION DESIGNS

During the course of my PhD, I established a close collaborations with the research groups at Ward of 21 st Century [1] in Foothills Hospital. Through this collaboration, I have been involved in the process of design and development of the first patient-centered care plan for patients to manage their care in the Province of Alberta. In this chapter, I will discuss our goal as a group for designing and developing the patient-centered care plan, my contributions to this project, and the future directions for further development of this web-based platform.

8.1 INTRODUCTION

The research literature is filled with evidence that involving patients in their care can have positive effects on their quality of life and treatment plans Doyle et al. (2013); Rathert et al. (2012). Healthcare providers are also starting to see value in involving patients in their care. However, the question of how and where to involve patients in their care still remains not fully answered.

Patient-centered care plans are a relatively new approach introduced for including patients in their care Luxford et al. (2011). Recently, there has been a movement towards strengthening patient-centered care plans within the Canadian healthcare systems The College of Family Physicians of Canada (2009); Health Government of Ontario Canada (2015). However, there is a lot of work that needs to be done towards better understanding the opportunities for involving patients in their own care in this space.

The university-based health research institute, Ward of 21 st Century (W21C) in part with Alberta Health Services (AHS) proposed to develop a patient-centered care plan

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[1] https://www.w21c.org/

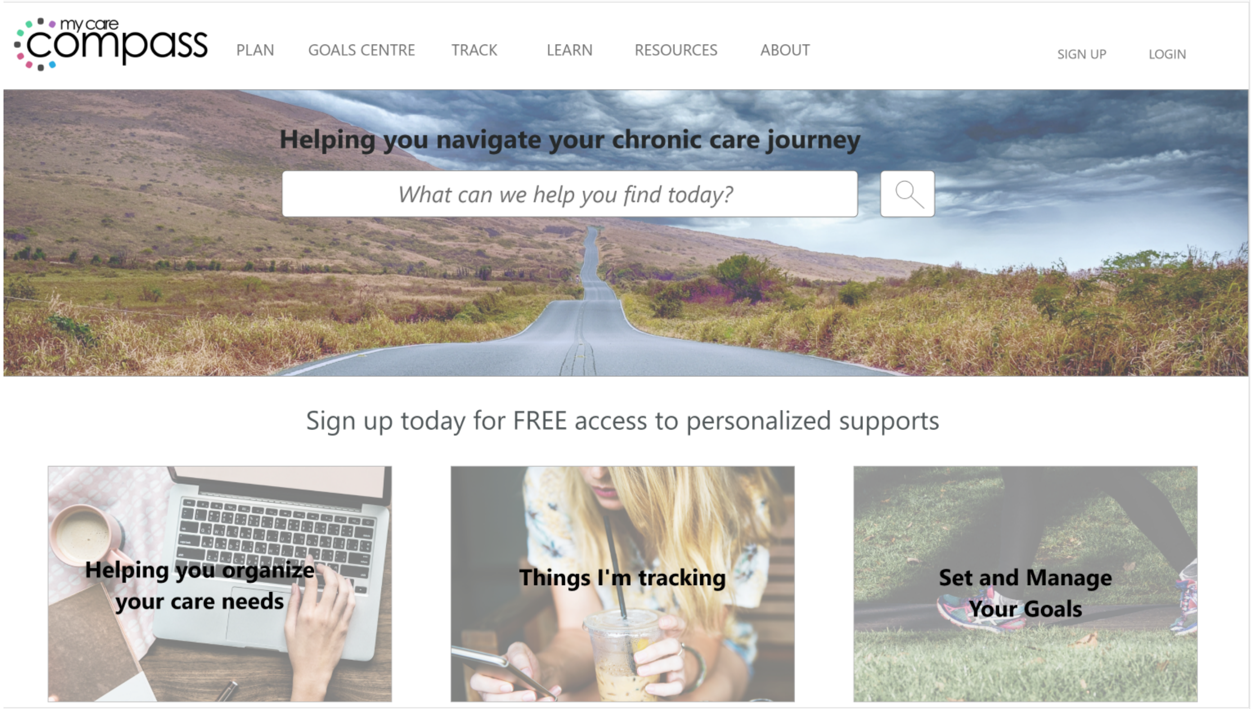
platform that will enhance the integration of best evidence, team-based clinical perspectives, and patient goals and preferences in the creation of their personal care plans.

There are many definitions of what a patient-centered care is Berwick (2009); therefore, we first developed our own definition based on the research we have conducted to contribute to the evolution of this concept. We define a patient-centered care plan as a living document (i.e., continually updated and refined) co-created by patients and their healthcare providers with considerations of patient goals and values with provider expertise and guidance to facilitate a holistic approach to care.

To develop a deep understanding of patient needs as well as thematic content for the patient-centered care plan platform, the w21C team conducted a series of focus groups and interviews with patients who have chronic conditions, and healthcare providers with differing expertise.

The results of these studies informed the creation of this innovative patient-centered care plan platform that addresses the needs of patients in creating and following their care plan. Ten patient supportive tools was identified for the development of this platform: Resource Finding Tool, Medication List Tool, Guided Learning Platform, Calendar Tool, Reminder Tool, Appointment Checklist Tool, Data Entry Tool, Tracking Insights Tool, and Report to Provider Tool.

This platform will be the first of its kind in Alberta, that empowers patients with chronic conditions to take control and manage different aspects of their conditions. MyCareCompass platform will be available by end of 2018 year for beta tests among a selected group of patients within the province of Alberta to plan their care and to discuss their issues via this platform with their healthcare providers (Figure 26).



Helping you navigate your chronic care journey

What can we help you find today?

Sign up today for FREE access to personalized supports

Helping you organize your care needs

Things I'm tracking

Set and Manage Your Goals

Figure 26: MyCareCompass Patient-Centered Care Plan Website Platform Home Page

8.2 MY CONTRIBUTIONS

The creation of the patient-centered care plan platform, MyCareCompass, involved a team of health researchers, physicians, designers, and technology developers. We discussed the potential use of our visualization designs with the healthcare provider team seeking their feedback on the design (Chapter 7). Next, in collaboration with the healthcare providers from W21C team who were involved in this project, we selected four of the visualization sketches (Figure 30, Figure 37, Figure 41, Figure 45) for implementation and integration into the MyCareCompass platform. We chose these visualizations based on the visualization potential for patients with chronic conditions to better understand their data, the visualization potential for healthcare providers to make more informed medical decisions, and the Alberta Health Services allocated budget for this project.

I contributed to the creation of three parts of this platform: 1) design of the data entry tracking tool interface, 2) design of the visualization representations to present patient self-tracked data, and 3) design of the patient-provider report presenting patient health status and patient progress over the past few months to physicians during clinical visits. In this section, I will discuss the details of the design of these tools.

8.2.1 *Data Entry Tool*

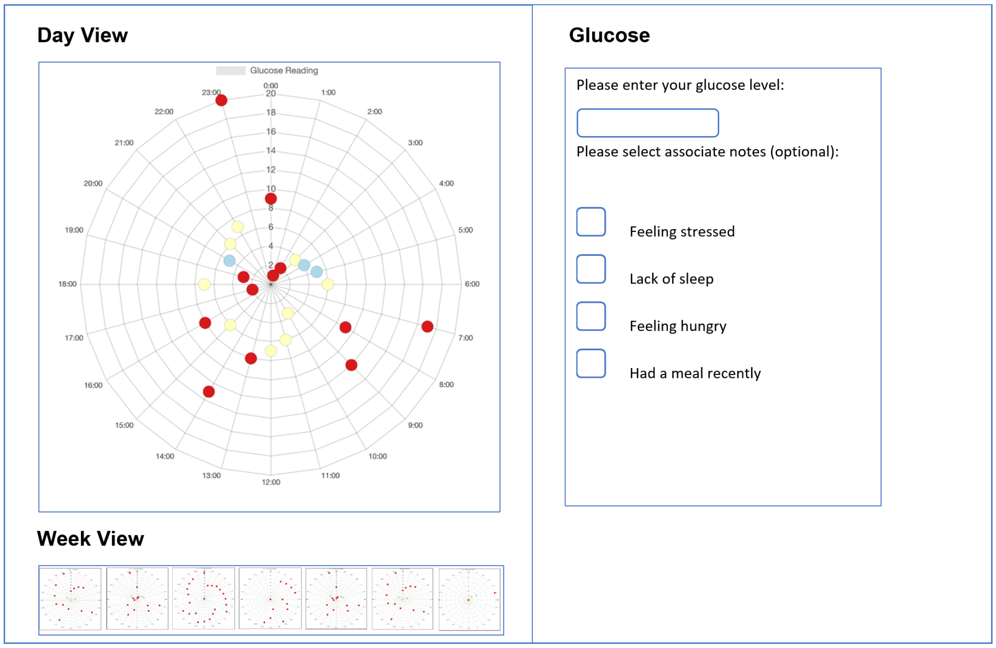
We designed a data entry tool that allows patients to record their self-generated health data. For the first version of this tool, we started by only including entry of three data items: blood glucose (Figure 27), blood pressure (Figure 29), and stress level (Figure 28). This tool will allow the patients to enter their health data for further insights, "*Tracking insights tool*".

8.2.2 *Tracking Insights Tool*

Although there are many self-tracking apps available, most of these tools did not consider both the patient and healthcare provider's perspective in its design. In our tool, we designed different visualizations that can provide context for healthcare providers and can encourage patients to better understand their data. Through this, patients may feel more in control of their care journey and empowered to live with their conditions.

Connected to the "*Data Entry Tool*" explained in the previous section, we get the patient data as input and visualize them. We designed various visualization representations that support patients in gaining insights and deeper understanding of their self-generated health data.

The process of choosing these visualizations took a few steps. First, we conducted interviews with our healthcare provider collaborators to get their feedback on their re-



Please enter your glucose level:

Please select associate notes (optional):

☐ Feeling stressed

☐ Lack of sleep

☐ Feeling hungry

☐ Had a meal recently

Figure 27: Sample Views of Data Entry Tool for Patients Entering Glucose Data

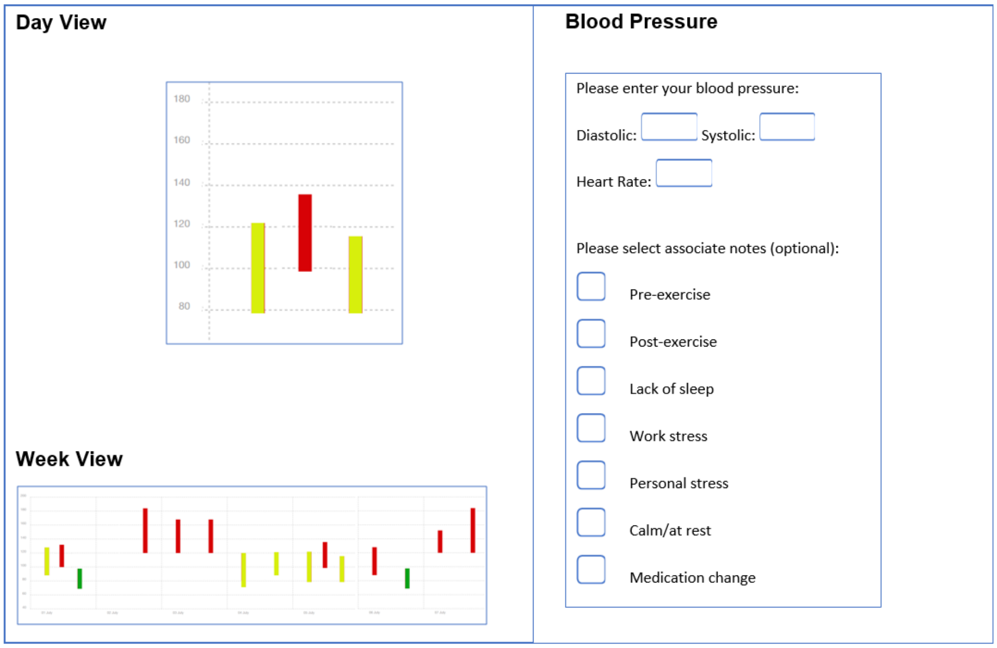
Please enter your stress level:

○ Feeling Very Calm and Relax
○ Feeling Calm
○ Feeling Moderately Calm
○ Feeling Irritated
○ Feeling Stressed
○ Feeling Extremely Stressed

Please select associate notes (optional):

☐ Lack of sleep
☐ Had an argument
☐ Had time for myself
☐ Work
☐ Relationship Problems

Figure 28: Sample Views of Data Entry Tool for Patients Entering Stress Level Data



Please enter your blood pressure:

Diastolic: ☐ Systolic: ☐

Heart Rate: ☐

Please select associate notes (optional):

☐ Pre-exercise
☐ Post-exercise
☐ Lack of sleep
☐ Work stress
☐ Personal stress
☐ Calm/at rest
☐ Medication change

Figure 29: Sample Views of Data Entry Tool for Patients Entering Blood Pressure Data

flection on our visualization designs (Chapter 7). Then, we had a series of discussions with the health researcher team from the W21C group along with the project development team to understand the scope of the project. We synthesized the results of the interviews and the discussions and carefully chose four of our visualization designs for implementation in this phase of the project.

8.2.2.1 *Glucose Clock - Radar Chart Daily View*

We received positive feedback from our interviews with the healthcare providers on the design of *Glucose Clock* sketch (Figure 30). This is an unconventional visualization representing patient blood glucose readings. Healthcare providers told us by looking at this visualization, they can find more insights and understand the patients' general wellbeing at a glance.

Following the development team criteria, we decided to implement the *Glucose Clock* sketch as a radar chart visualization. We had a few iterations before finalizing our design (Figure 31, Figure 32, Figure 33). Our final choice for implementation was selected after discussion with our healthcare provider collaborators (Figure 34). The blood glucose level is ranged from 0 to 20 in the chart shown on the vertical line in the center. We divided the chart into 24 points, each point representing one hour in the clock. Instead of colouring each ring in the original *Glucose Clock* sketch, we decided to colour code the data points placed in the visualization.

Patients with diabetes are more inclined to develop retina damage and colour blindness. Thus, we chose the colours of the data points using www.colorbrewer2.org website to make sure the colours are colorblind safe:

- Glucose reading below 3.0 is considered dangerous, so we colour them 'red' (#d7191c).

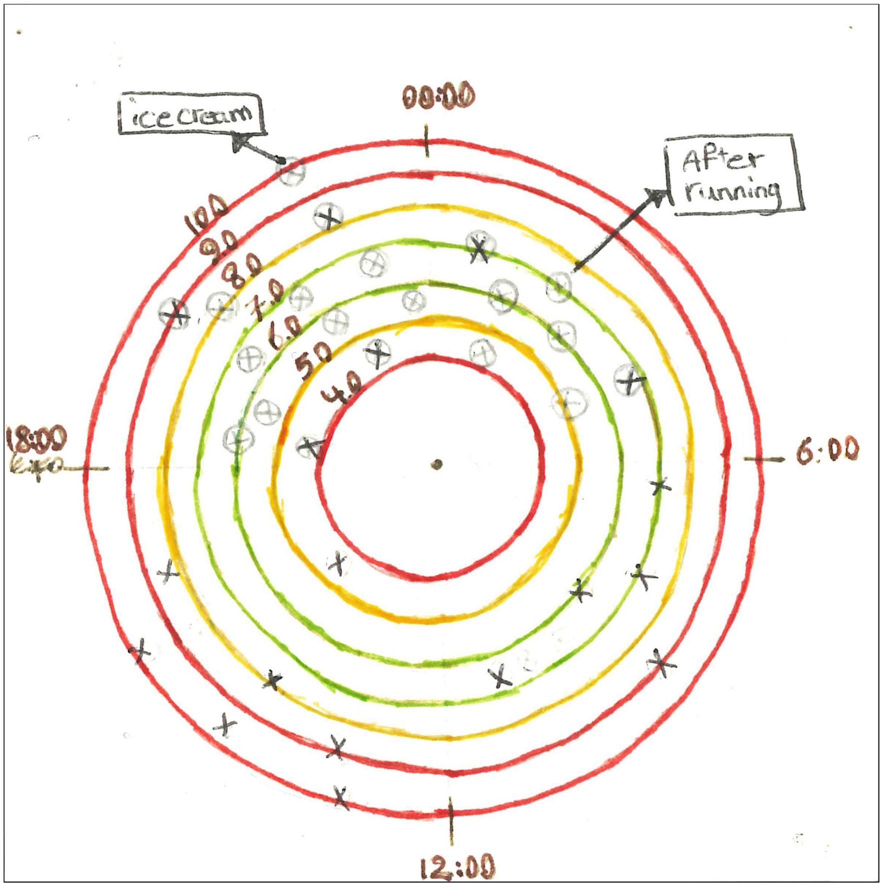


Figure 30: A Sample View of Patient-Generated Data Visualization - Original Sketch taken from Chapter 6

- Glucose reading between 3.0 and 3.8 is considered moderately dangerous, so we colour them 'yellow' (#ffffbf).
- Glucose reading between 3.8 and 5.4 is considered normal, so we colour them 'blue' (#abd9e9).
- Glucose reading between 5.4 and 7.8 is considered moderately dangerous, so we colour them 'yellow'.
- Glucose reading above 7.8 is considered dangerous, so we colour them 'red'.

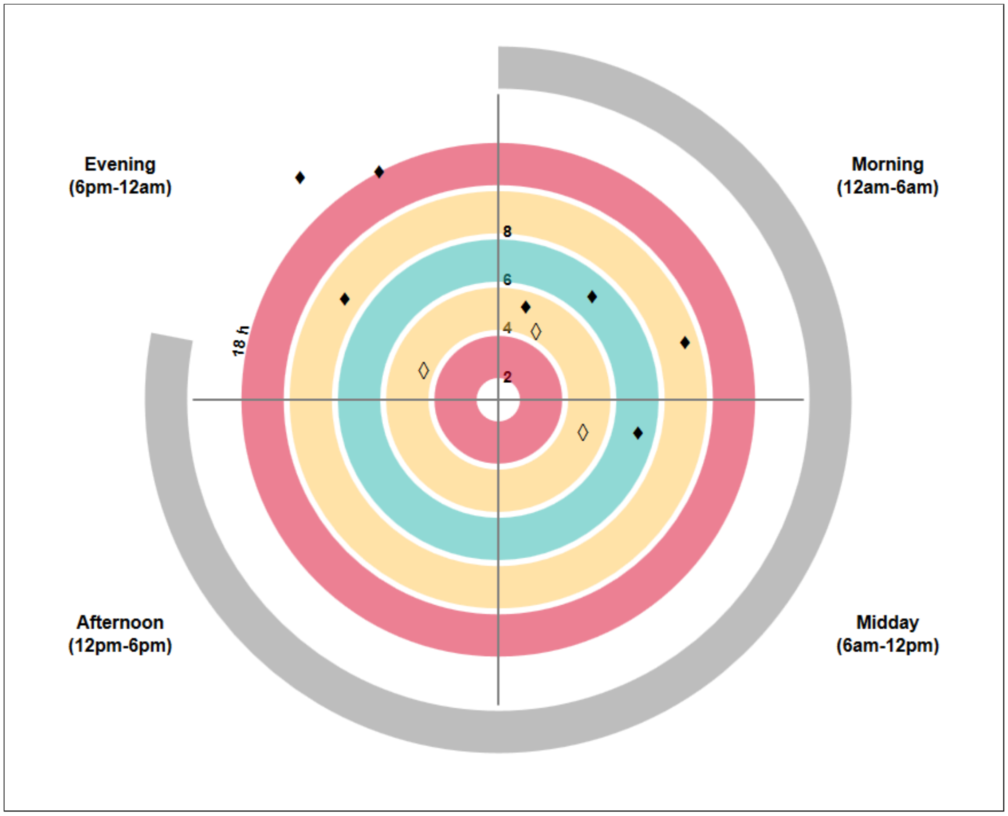


Figure 31: A Sample View of Patient-Generated Data Visualization - Daily Glucose Readings Version One

8.2.2.2 *Glucose Clock - Radar Chart Weekly View*

From the results of our interviews with patients and healthcare providers, we identified patients and their providers' need in looking at an overview of patients' wellbeing. The overview of patient-generated health data will lead patients and healthcare providers into making data driven decisions about patient care.

Thus, to fulfill this need, we included a weekly view of patients' glucose level (Figure 35). Each mini chart represents one day of patient glucose readings. We discussed two options of showing weekly glucose readings on a horizontal view or a circular view (Figure 22). Our healthcare provider collaborators showed more interests in reviewing

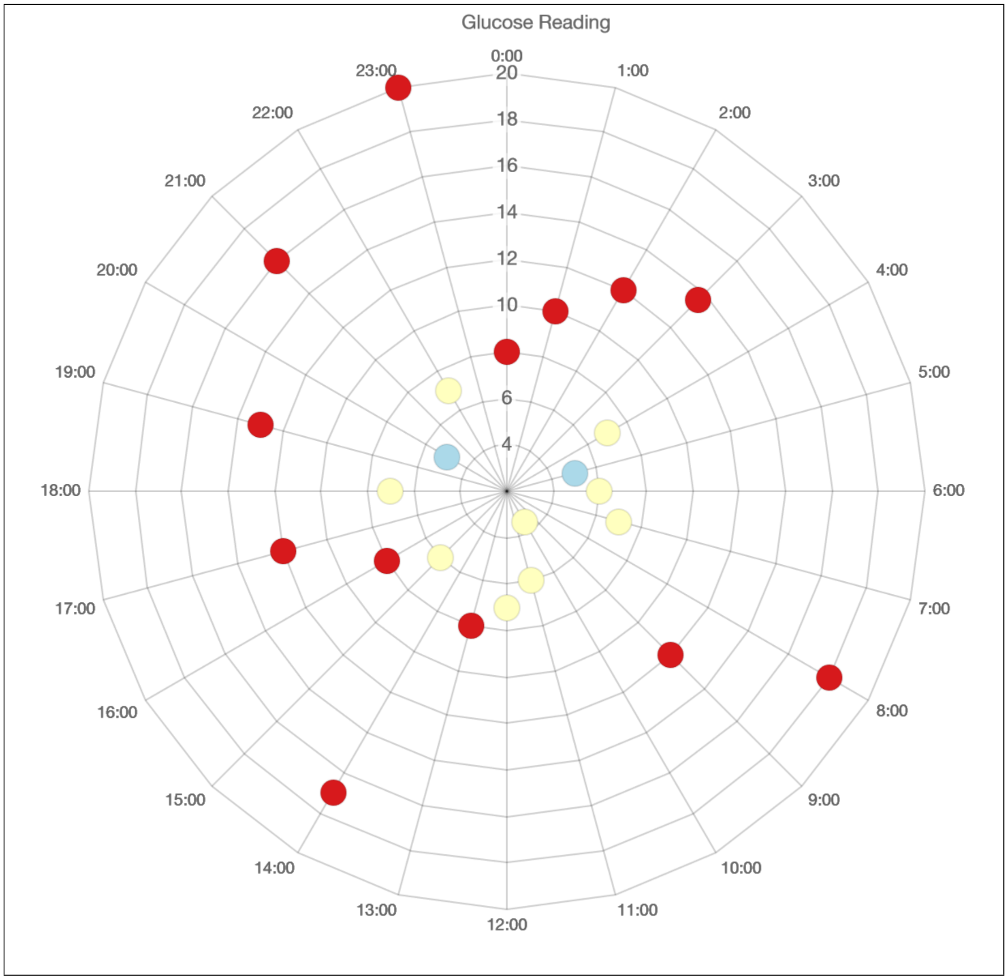


Figure 32: A Sample View of Patient-Generated Data Visualization - Daily Glucose Readings Version Two

the patient weekly data in the horizontal view (Figure 22 - right view). They were able to do an easier and faster comparison within the charts(days) if the charts are displayed horizontally. Thus, we decided to display the weekly view with a horizontal orientation.

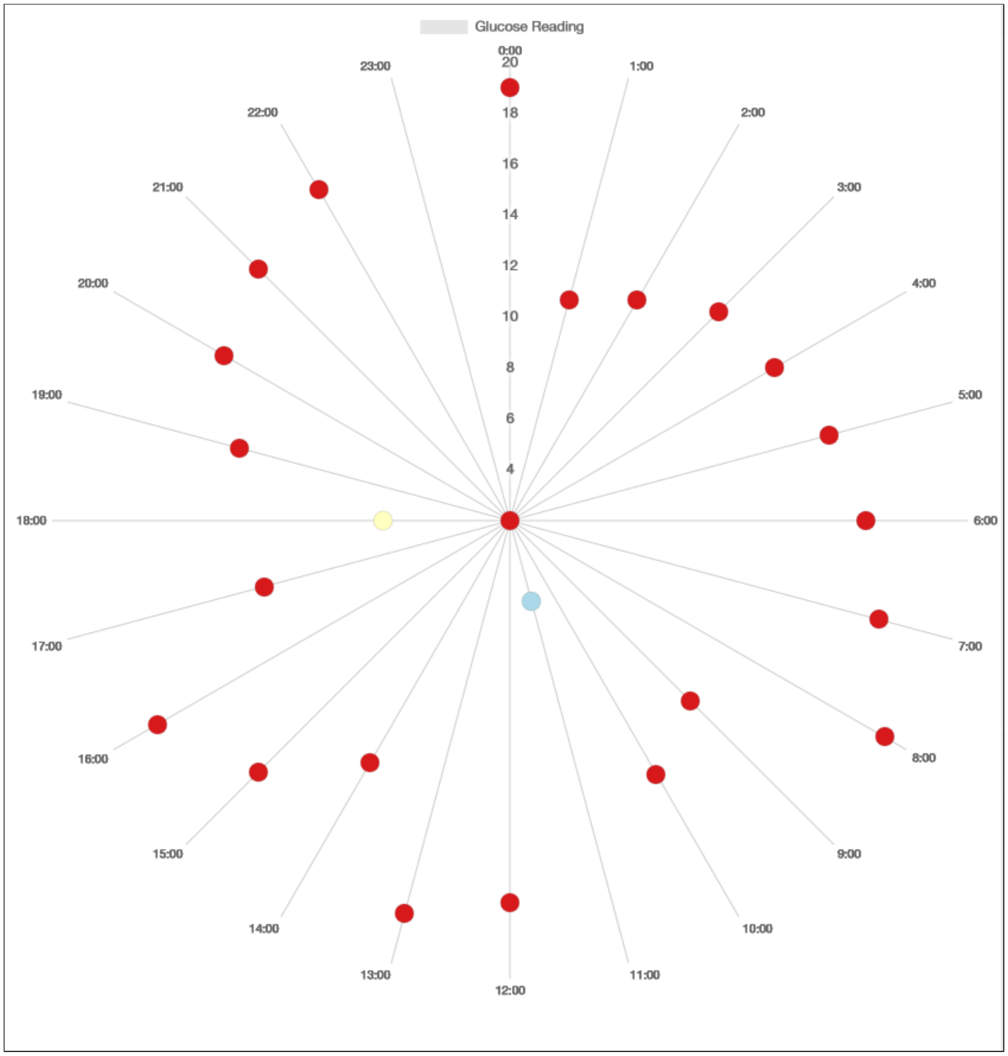


Figure 33: A Sample View of Patient-Generated Data Visualization - Daily Glucose Readings Version Three

8.2.2.3 *Glucose Clock - Radar Chart Interaction*

The results of our interviews with patients and healthcare providers revealed the importance of *data context* when recording and presenting patient-generated data. Thus, in the *Data Entry Tool* we added an option for patients to choose the most relevant context to their data point at the time. In the visualization, we display the context using interaction.

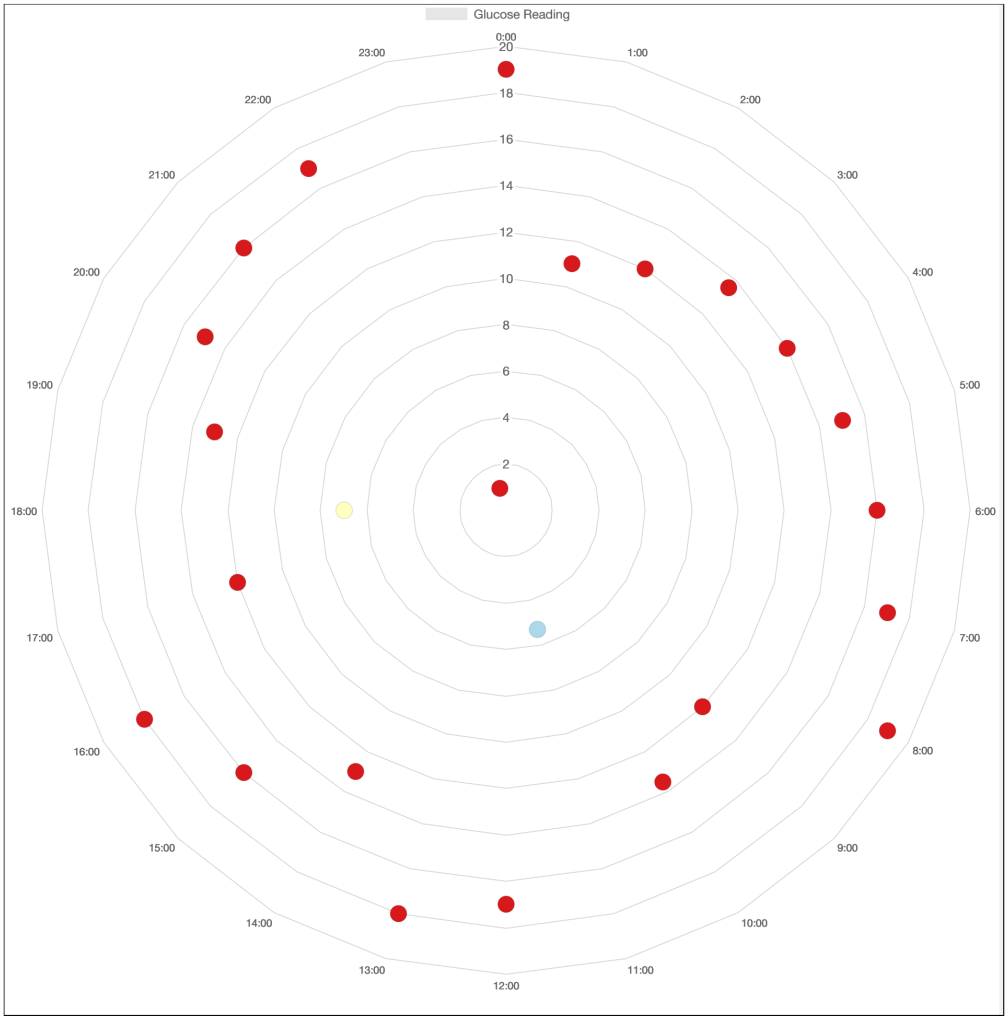


Figure 34: A Sample View of Patient-Generated Data Visualization - Daily Glucose Readings Version Four

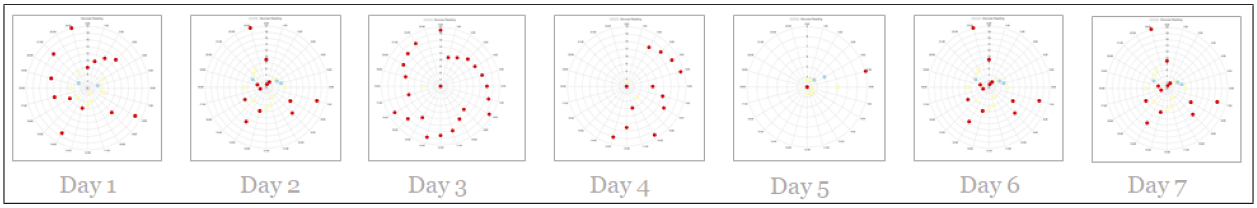


Figure 35: A Sample View of Patient-Generated Data Visualization - Weekly Glucose Readings

Each data point represents one data entry, a measured glucose data at a time of the day. Hovering over each point shows the time of the day that the glucose was measured, the glucose data, and the context (note) associated with the data (Figure 36).

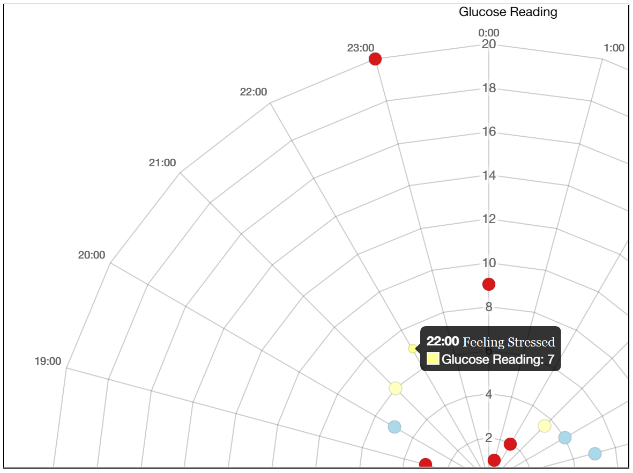


Figure 36: A Sample View of Patient-Generated Data Visualization - Glucose Readings Interaction

8.2.3 *Glucose Scatter Plot - Daily View*

We included one unconventional visualization design representing patient glucose readings. However, after discussions with the health researcher team at the W21C institute, we decided to also include one conventional visualization design to represent patient glucose readings. Patients can select their choice of visualization based on their own preference. Providing more than one visualization option can give patients a sense of freedom and a feeling of controlling their conditions. The results of our patient interviews also confirmed the importance of designing visualization for individuals rather than providing patients with a general solution (Chapter 5).

We selected (Figure 37) a visualization sketch, a scatter plot, a more common known chart type among the public. We implemented this sketch representing glucose data (Figure 38). To keep consistency between two glucose chart choices, we used the same choices of colours and glucose range as the Glucose Radar Chart visualization (Figure 32).

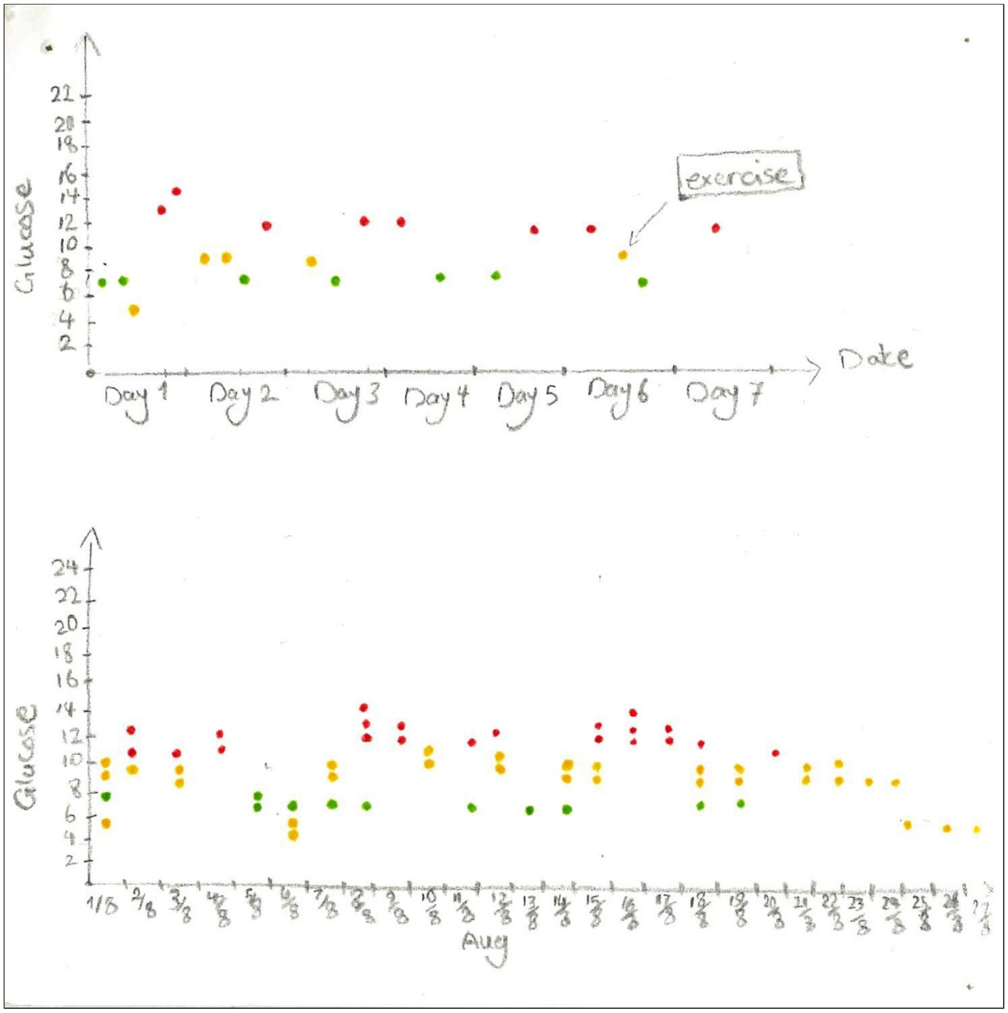


Figure 37: A Sample View of Patient-Generated Data Visualization - Original Sketch taken from Chapter 6

8.2.4 *Glucose Scatter Plot - Weekly View*

To provide an overview of patient glucose reading over a week, we designed a weekly view. This view can help patients and their healthcare providers to find potential patterns, trends, and anomalies in patient data. In our design, we included seven days of glucose measurements, each day divided by a vertical line (Figure 39). The colour ranges are defined with the same rules as the glucose scatter daily view.

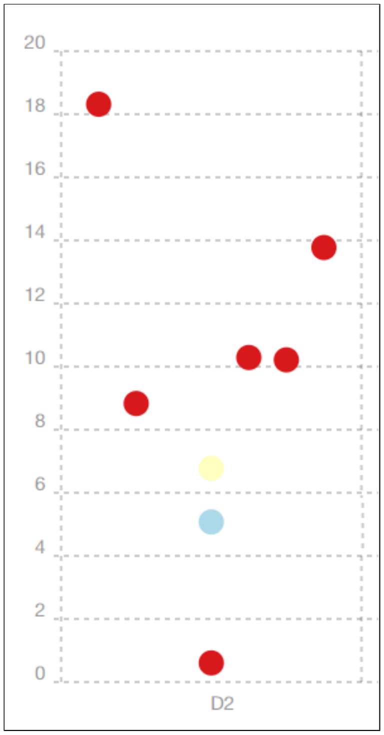


Figure 38: A Sample View of Patient-Generated Data Visualization - Daily Glucose Readings

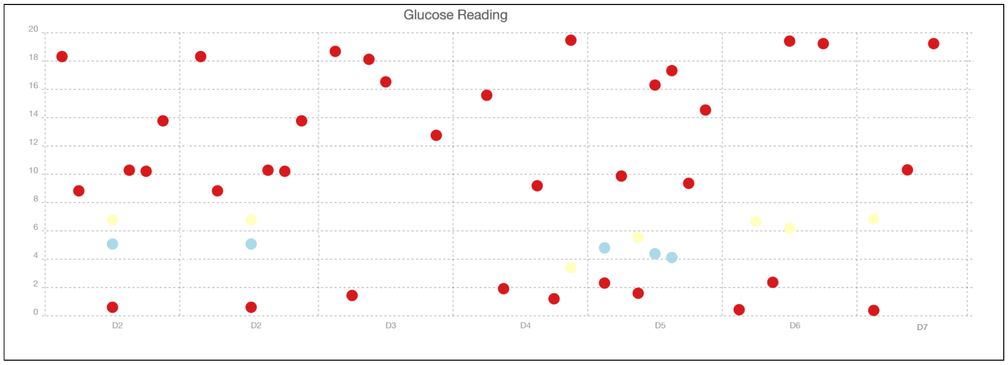


Figure 39: A Sample View of Patient-Generated Data Visualization - Weekly Glucose Readings

8.2.5 *Glucose Scatter Plot - Interaction*

In the *Data Entry Tool*, there is an option for patients to choose the most relevant context to their data point at the time of measurement. Thus, in the visualization, we added an optional hovering interaction for patients to view their data context. Hovering over each point shows the time of the day that the glucose reading was measured, the glucose reading, and the context of the data if selected in the data entry tool.

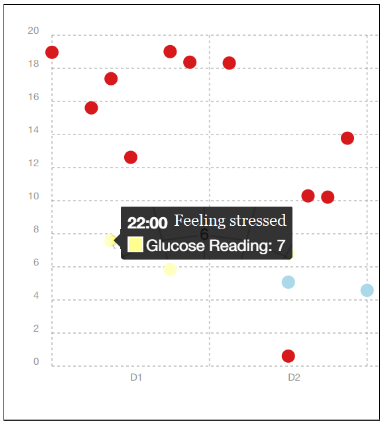


Figure 40: A Sample View of Patient-Generated Data Visualization - Glucose Reading Interaction

8.2.6 *Blood Pressure Bar Chart - Daily View*

The results of our interviews with patients showed that patients with hypertension are usually advised by their healthcare providers to regularly monitor their blood pressure. The healthcare providers will then have the opportunity to look into the patient's blood pressure readings for diagnosis, medication change, or treatment planning.

We showed three visualization designs representing patient blood pressure readings (Figure 16, Figure 18 - A and B) to our healthcare provider collaborators and asked for their feedback on the designs. Healthcare providers showed interests in the Blood Pressure Tree design sketch (Figure 18 - A) and they told us they could see this design get also used in other clinical contexts. However, after presenting this sketch for discussion

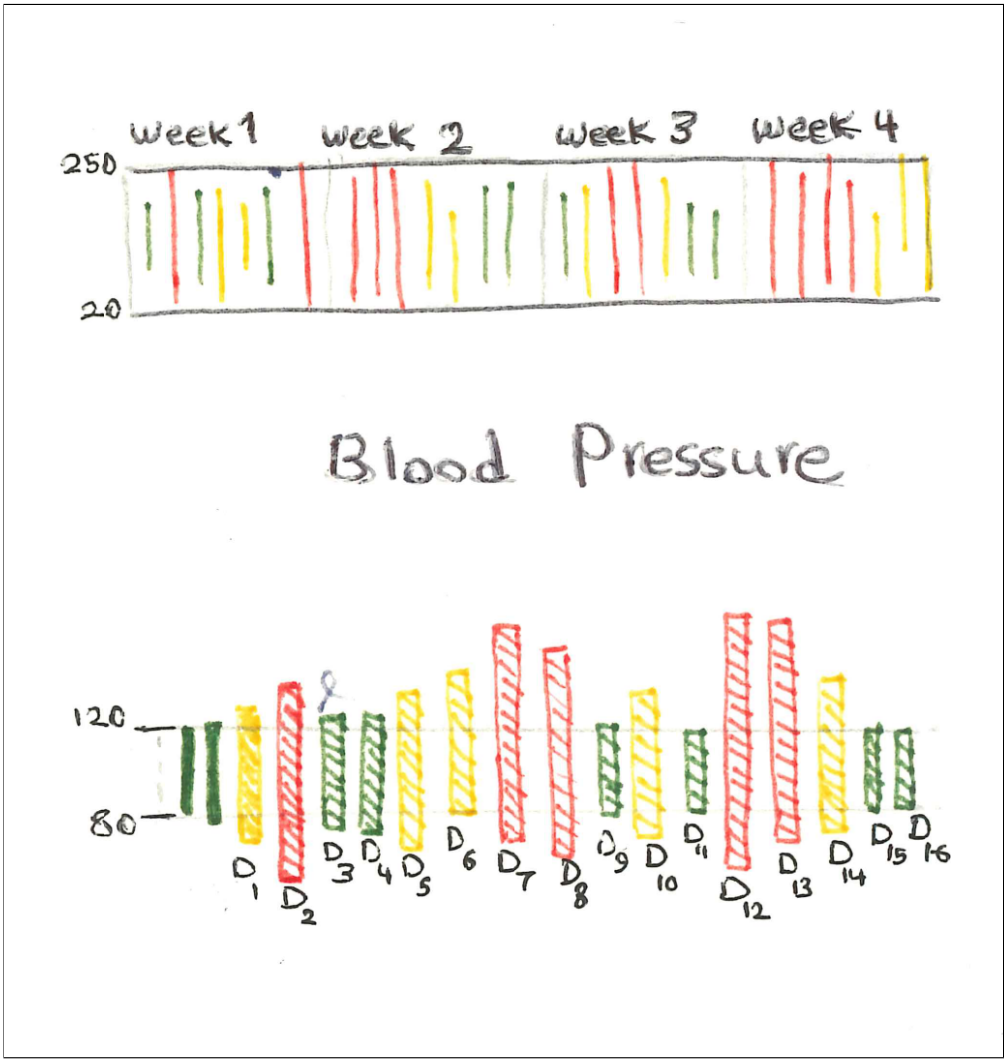


Figure 41: A Sample View of Patient-Generated Data Visualization - Original Sketch taken from Chapter 6

with the healthcare research and the project development team, they informed us that they cannot easily accommodate this design for this phase of the project.

Considering that the healthcare providers did not find (Figure 18 - B) easy to use and read, we decided to go with the blood pressure bar chart design (Figure 41). Healthcare providers found this design easily readable and scalable for viewing months of patient-generated blood pressure data.

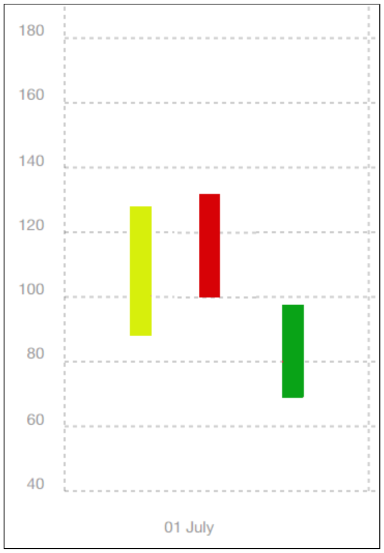


Figure 42: A Sample View of Patient-Generated Data Visualization - Blood Pressure Daily View

We designed a bar chart visualization where each bar represents one blood pressure reading (Figure 42). The bottom of the bar shows diastolic number and the upper part of the bar shows systolic number. To make it easy for patients to understand their number, we colour coded the blood pressure bars using the blood pressure chart for adults available from the UK Blood Pressure Association [2].

Later, we confirmed the credibility of this chart with one of our healthcare provider collaborators. To keep the blood pressure chart and our visualization consistent, we used the same colour scheme in our design. To show high blood pressure, we used 'red' (#D70206), to show pre-high blood pressure, we used 'yellow'(#D7EF0C), to show ideal blood pressure, we used 'green' (#09A317), and to show low blood pressure, we used 'blue' (#7659F5). From a visualization perspective, this use of colour categorizes continuous data we used it because it is in keeping with common medical practices.

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[2] http://www.bloodpressureuk.org/BloodPressureandyou/Thebasics/Bloodpressurechart

As shown in the blood pressure chart, the readings in the chart start from 40 to 190; thus, to be consistent with the medical literature [3], we also started the y-axis of our visualization from 40 and went up to 190 since it is unlikely for a patient to have a diastolic number lower than 40. While it is common visualization practice to consider that a non-zeroed y-axis can exaggerate data differences, as discussed above from medical literature, starting blood pressure number at 40 makes sense in this context.

The design choices for designing the visualizations were made by considering both visualization and medical literature O'brien et al. (2005); Leung et al. (2016). Thus, in some cases we made design choices to accommodate the medical experts' suggestions.

8.2.7 *Blood Pressure Bar Chart - Weekly View*

As mentioned earlier, both healthcare providers and patients see value in reviewing patient data over a period of time. Thus, we designed a weekly view of patient blood pressure readings (Figure 43). All the blood pressure readings per day are shown in one division in the order of the time collected. We do not display any information about the time the data was measured as our results showed this to be of less interest for both patients and providers. As shown in the design (Figure 43), a patient can have no blood pressure intake or have multiple readings per day.

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[3] http://www.bloodpressureuk.org/BloodPressureandyou/Thebasics/Bloodpressurechart

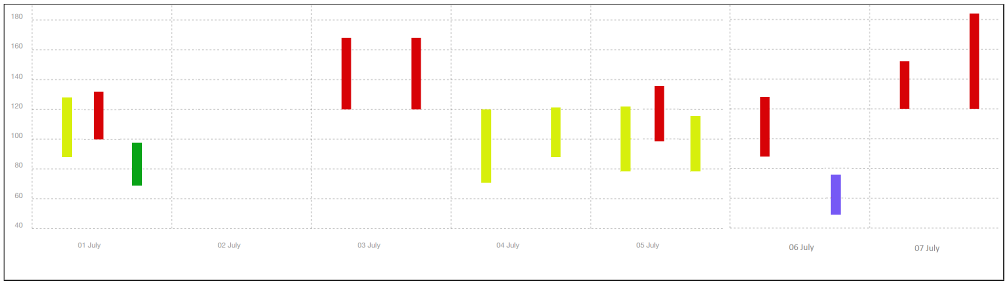


Figure 43: A Sample View of Patient-Generated Data Visualization - Blood Pressure Weekly View

8.2.8 *Blood Pressure Bar Chart - Interaction*

Our results show that patients are advised by healthcare providers to record relevant context with their data. Thus, to accommodate this need, we added an option for patients to keep track and view their notes. By hovering over each bar in the visualization, the blood pressure reading, pulse, and the associated note will appear on demand.

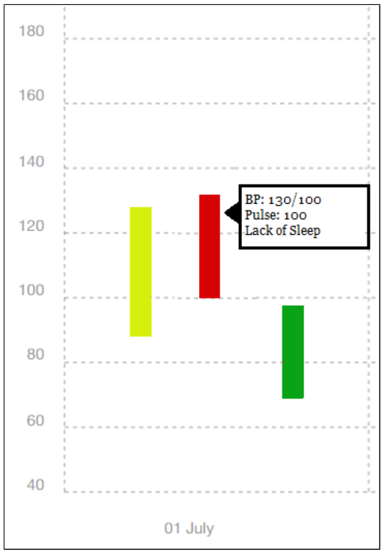


Figure 44: A Sample View of Patient-Generated Data Visualization - Blood Pressure Weekly View

8.2.9 *Stress Level Calendar - Daily View*

Patients with mental health problems or depression are either self-motivated or advised by their healthcare providers to monitor their stress level or mood to better understand their condition. We designed a calendar view visualization representing the patient stress/mood entry per day (Figure 45).

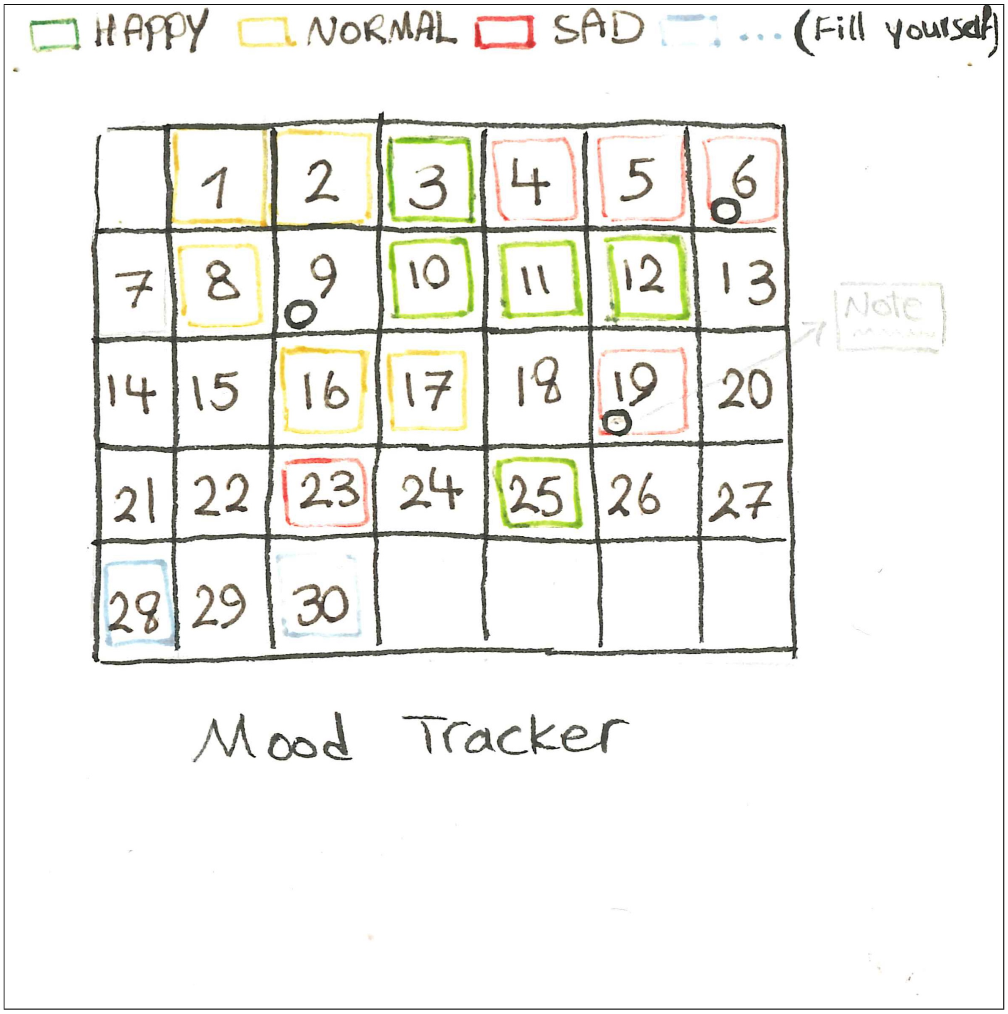


Figure 45: A Sample View of Patient-Generated Data Visualization - Original Sketch taken from Chapter 6

We chose six various colours representing a wide spectrum of moods. Three colours in blue hue showing calm days and three colours in the yellow hue to show stress days: 'Feeling Very Calm and Relax' is shown by (#33C0FC) colour, 'Feeling Calm' is shown by (#4AFFFE) colour, 'Feeling Moderately Calm' is shown by (#AFFFFF) colour, 'Feeling Irritated' is shown by (#FFFC63) colour, 'Feeling Stressed' is shown by (#FDBD2D) colour, and 'Feeling Extremely Stressed' is shown by (#FC8A25) colour.

Figure 46: A Sample View of Patient-Generated Data Visualization - Stress Calendar Daily View

8.2.10 *Stress Level Calendar - Monthly View*

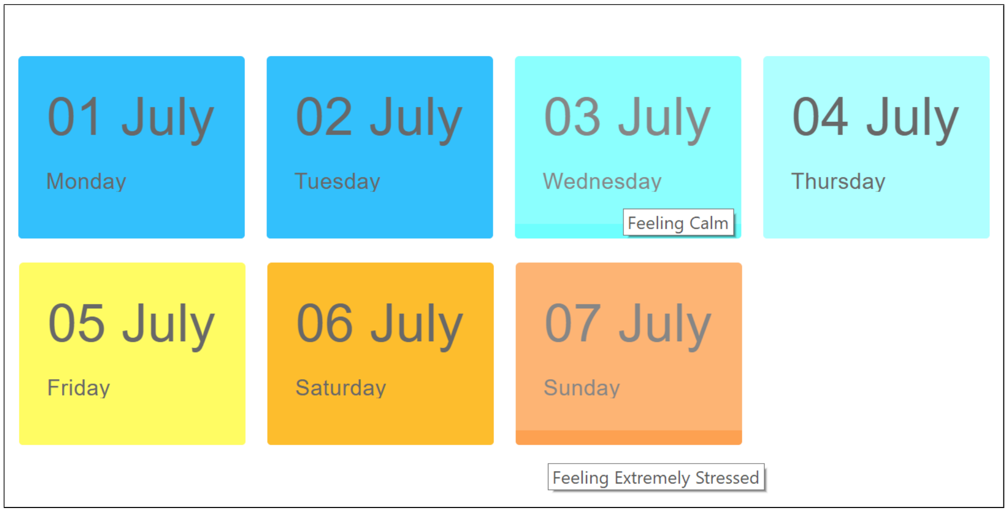
To display the patient's stress/mood over a month for an overview insight, we designed a monthly view visualization representing a patient's self-collected stress/mood for a month. This view can help patients and healthcare provides to find potential patterns in patient data for further investigation (Figure 47).

01 July Monday	02 July Tuesday	03 July Wednesday	04 July Thursday	05 July Friday	06 July Saturday	07 July Sunday
08 July Monday	09 July Tuesday	10 July Wednesday	11 July Thursday	12 July Friday	13 July Saturday	14 July Sunday
15 July Monday	16 July Tuesday	17 July Wednesday	18 July Thursday	19 July Friday	20 July Saturday	21 July Sunday
22 July Monday	23 July Tuesday	24 July Wednesday	25 July Thursday	26 July Friday	27 July Saturday	28 July Sunday

Figure 47: A Sample View of Patient-Generated Data Visualization - Stress Calendar Monthly View

8.2.11 *Stress Level Calendar - Interaction*

In addition to the colours associated with the stress level, we have explanatory notes with each colour. By hovering over each day in the calendar, the patient can see the note associated with their mood.

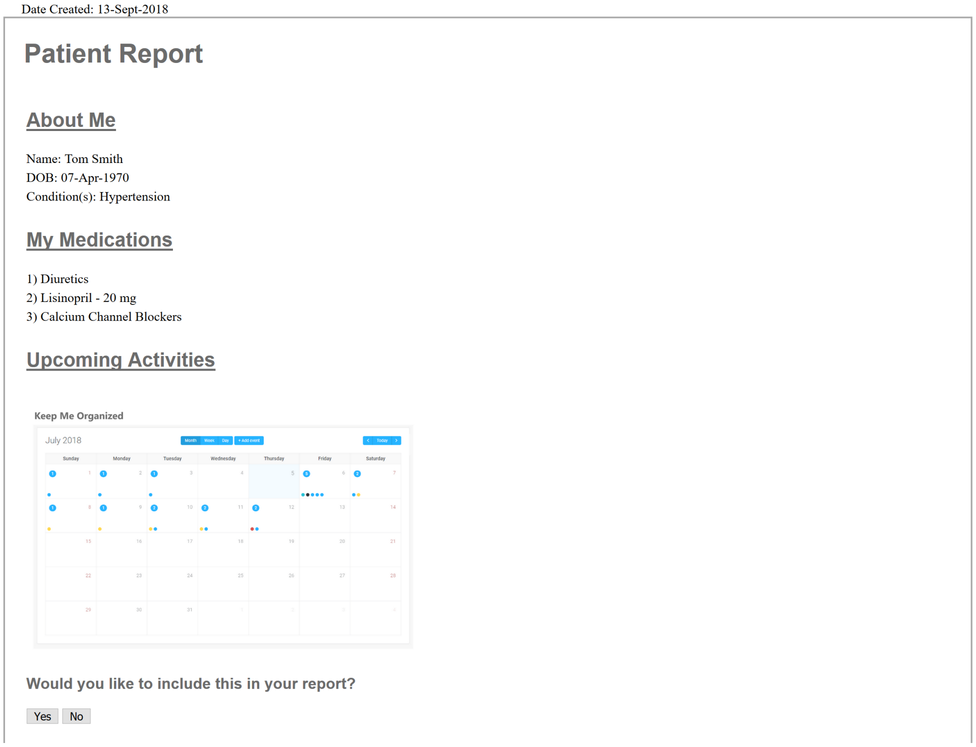


01 July Monday	02 July Tuesday	03 July Wednesday	04 July Thursday
05 July Friday	06 July Saturday	07 July Sunday	

Feeling Calm

Feeling Extremely Stressed

Figure 48: A Sample View of Patient-Generated Data Visualization - Stress Calendar Interaction



Date Created: 13-Sept-2018

Patient Report

About Me

Name: Tom Smith
DOB: 07-Apr-1970
Condition(s): Hypertension

My Medications

1) Diuretics
2) Lisinopril - 20 mg
3) Calcium Channel Blockers

Upcoming Activities

Keep Me Organized

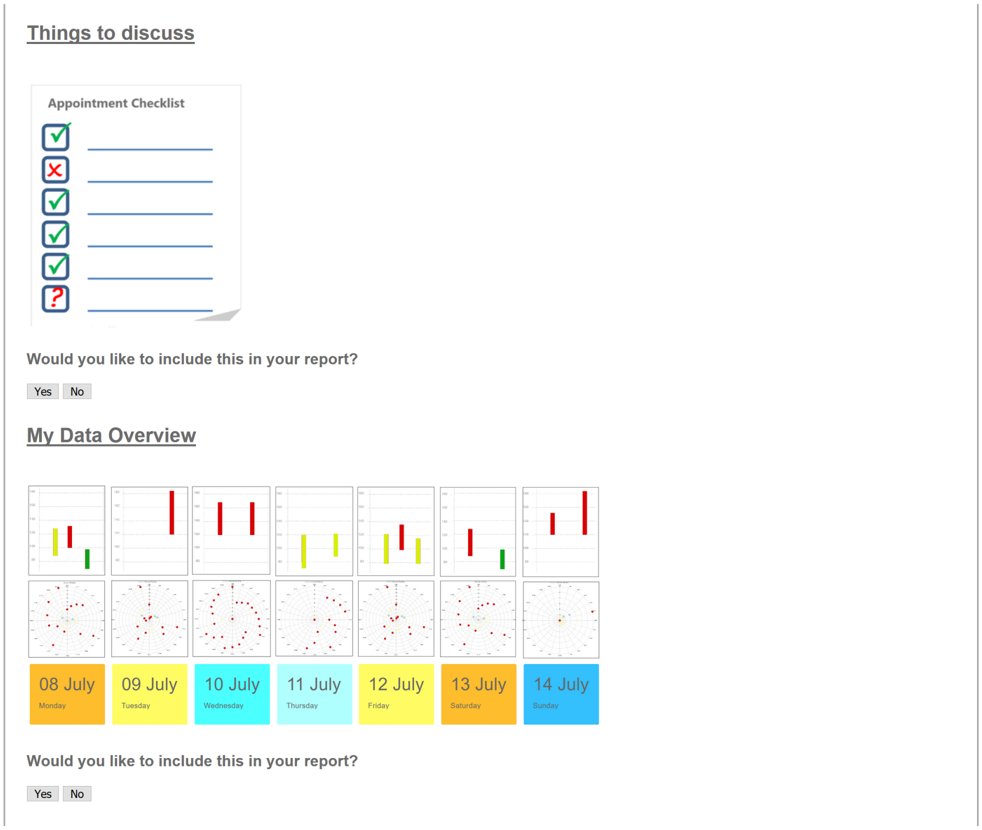
Would you like to include this in your report?

Figure 49: Patient-Provider Report Page Sample Design on the MyCareCompass Platform

8.2.12 *Report to Provider Tool*

This tool provides a report of a patient's health status including a summary of their profile, their medications, any upcoming activity including medical appointments, medical exams, a list of patient concerns and problems they would like to discuss with their healthcare providers, a at-a-glance view of their self-generated health data, and access to the patient raw tracked data.

The goal for this tool is to leverage a stronger communication between patients and healthcare providers and to support an efficient us of clinical visits. Patient will have the option to choose the part/tool of the platform to be included in this report and share a PDF report with their provider (Figure 49, Figure 50, Figure 51).



Things to discuss

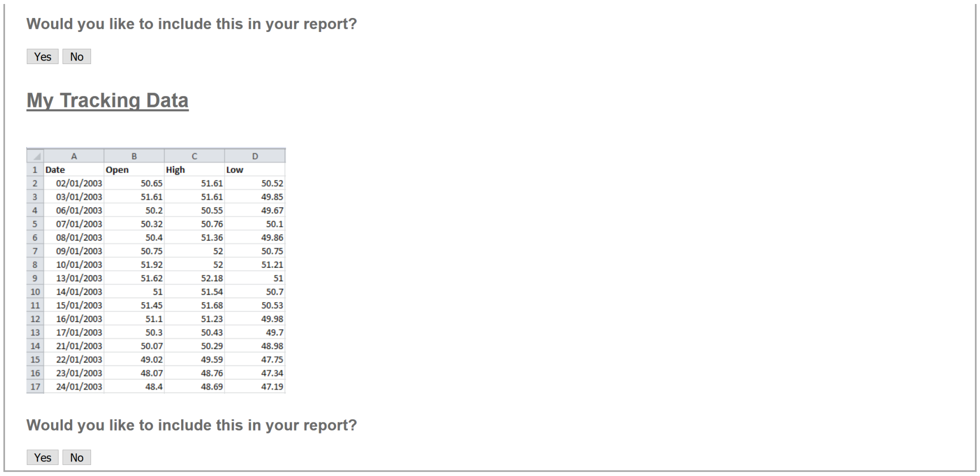
Appointment Checklist

Would you like to include this in your report?

My Data Overview

Would you like to include this in your report?

Figure 50: Patient-Provider Report Page Sample Design on the MyCareCompass Platform



Would you like to include this in your report?

My Tracking Data

	A	B	C	D
1	Date	Open	High	Low
2	02/01/2003	50.65	51.61	50.52
3	03/01/2003	51.61	51.61	49.85
4	06/01/2003	50.2	50.55	49.67
5	07/01/2003	50.32	50.76	50.1
6	08/01/2003	50.4	51.36	49.86
7	09/01/2003	50.75	52	50.75
8	10/01/2003	51.92	52	51.21
9	13/01/2003	51.62	52.18	51
10	14/01/2003	51	51.54	50.7
11	15/01/2003	51.45	51.68	50.53
12	16/01/2003	51.1	51.23	49.98
13	17/01/2003	50.3	50.43	49.7
14	21/01/2003	50.07	50.29	48.98
15	22/01/2003	49.02	49.59	47.75
16	23/01/2003	48.07	48.76	47.34
17	24/01/2003	48.4	48.69	47.19

Would you like to include this in your report?

Figure 51: Patient-Provider Report Page Sample Design on the MyCareCompass Platform

The patient-provider report has six parts: About Me, My Medications, Upcoming Activities, Things to Discuss, My Data Overview, and My Tracked Data. The information for each part is taken from the data stored from different tools in the MyCareCompass.

8.2.12.1 *Interactions*

The interactions were designed for patients to have the ability to include or exclude any information they wish to discuss and share with their providers. For each part of this report, we added an option "Would you like to include this in your report?". If a patient wants to share the information, they can choose "Yes" and the information will be loaded into the report. Otherwise, the patient can choose "No" and skip the information stored in that part. We also added an option "Edit" which only will appear after the patient clicked on "Yes" or "No" to include or exclude associated parts in the report.

8.3 DISCUSSION AND FUTURE DIRECTIONS

For the current state of implementation, this platform is designed on an online web based platform. This platform will be ready for beta tests among a selected group of patients with chronic conditions and their healthcare providers in the province of Alberta. We hope this platform will be a medium to support patients take more control over their conditions and to provide healthcare providers with access to more detailed information about patient wellbeing.

The patient and their healthcare provider usage will be recorded and analyzed using Google Analytics. Based on the results of this analysis, W21C will decide on the next phase of implementations for this platform.

In the current state, we only included a few visualization designs. However, upon receiving patient and healthcare provider feedback on these visualizations along with the Google Analytics results, we may decide to include more visualization design options.

Part V

CONCLUSIONS

9

FUTURE DIRECTIONS

The overarching approach taken in this thesis has been to inspire design of visualizations as mediums to facilitate a smooth patient-provider communication during clinical visits. The results of our studies, design processes, and technology transferring the visualization designs have opened up new directions for future research. Moreover, our methodology to answer this thesis research question can be applied to design other visualizations for patient-provider communication in the clinics. In this chapter, we summarize the future directions that can be taken based on the results of our research. At last, we discuss some of real world implications driven from this thesis and how they can be expanded in the future for use in the healthcare systems.

9.1 PATIENTS' AND PROVIDERS' PERSPECTIVES ON CLINICAL COMMUNICATION CHALLENGES

The results of our first study (Chapter 4) and the literature review (Chapter 2) revealed several patient-provider communication challenges during clinical visits. Our careful comparison and contrast of patient and provider perspectives on communication challenges during clinical visits led us to gain a better understandings of the differences of opinions between these two parties. While both patients and providers face similar communication challenges when discussing patient issues during clinical visits, their attitudes are different. Future work in this area might investigate:

- The role of the subtle differences between patients' and providers' perspectives in designing communication technologies and visualizations for clinical visits.
- How to design the right technologies and visualizations to address the patient-provider communication challenges we identified with considerations of the subtle differences between patients' and providers' perspectives.
- The reception of patients and providers when using communication technologies and visualizations designed with considerations of the subtle differences during clinical visits.
- The impacts of using communication technologies and visualizations designed with considerations of these subtle differences on patients' wellbeing and healthcare providers' practices.

Furthermore, based on the patients' and providers' current technology use and their suggestions for future technologies, we provided a series of technology design directions.

Taking these design directions that are heavily driven by patients' and providers' perspectives and designing possible technology solutions can be an immediate step from this study. It can be a good idea to first focus on the situations where providers and patients are starting to use communication technology support, since this use could indicate that they can be more ready to accept technology in these circumstances. If they are more willing to accept technologies in these areas, it is possible that further adoption would pose fewer disruptions.

9.2 PATIENTS' DIFFERENT APPROACHES TO TRACKING THEIR HEALTH DATA

As mentioned in the previous section, unveiling the differences between patients' and providers' perspectives during their in-clinic communication challenges opened up new opportunities for designing technologies and visualizations with potential to smoothly facilitate this communication. After discussing these communication challenges with our healthcare provider collaborators and based on our own review of the literature, we decided to focus on patient-generated data communication challenges due to the increase in use of these data in healthcare settings. Thus, we studied the details of eight patients' approaches to tracking and presenting their health data, their lifestyles, motivations, and hopes. Furthermore, we looked into a sample of our patient participants data collections to understand patients' methods of recording their data and their reasonings behind it. From the results of these studies, we shed lights on each of our eight patients' unique needs and challenges for tracking and communicating these data to their healthcare providers (Chapter 5). Future work in this area might study:

- More patients, their stories, lifestyles, hopes, fears, and motivations to unveil a wider range of patients' needs and challenges with tracking their health data.

- The positive and negative effects of discussing patient-generated data collections on patient-provider communication during clinical visits in an observational field study.

Although patients have commonalities, no two patients were the same. We discussed several characteristics and their variants articulating how patients differ from each other. However, this list is not exhaustive and there is room to explore other characteristics. The focus of our studies were on studying patients with chronic conditions and the providers who mainly visit chronic patients. One way to expand the current identified patient-generated data characteristics can be to explore a wider range of patient-generated data collections with different conditions (e.g., cancer, respiratory diseases, and nervous system diseases).

9.3 VISUALIZATION DESIGNS REPRESENTING PATIENT-GENERATED DATA

There is an increase rate of patients tracking their health data and presenting them to their healthcare providers during clinical visits. The results of our patient studies discussed in the forgoing section revealed the individualities of patient-generated data collections. Thus, the process of communicating and making sense of each patient's data collection can be a time-consuming and complicated task for healthcare providers. Perhaps one solution to smooth this communication can be visualizing patient-generated data. Thus, to represent patient-generated data collections and to accommodate each patient, we took steps towards designing *individualized* visualizations. Our visualization designs were drawn upon each patient's story, needs, and challenges. We designed multiple alternative visualizations for each patient. All of our visualizations together shaped a design space of variant patient-generated data representations (Chapter 6). Future work in this area can be studying:

- Patients' uses of the patient-generated data visualizations at home and during clinical visits in the presence of their healthcare providers.
- How to design customizable visualizations for patients to support their individualities but not putting extra effort on patients' shoulders.
- Design of other various alternative visualizations based on the patient profiles we listed.

We hope by contributing more visualization design alternatives and adding design elements that allow patients to customize their visualizations, eventually we can reach a better understanding of how to design visualizations that can be tailored to patients and providers for representing patient-generated data.

9.4 PROVIDERS' REFLECTIONS UPON PATIENT-GENERATED DATA VISUALIZATIONS

We took our visualization designs representing our patient participants' patient-generated data collections to several healthcare providers with expertise in chronic management care. From studying the healthcare providers' reflections upon our proposed patient-generated data visualizations, we learned that similarly to patients, providers also differ in their perspectives on the purpose and the use of patient-generated data collections and the visualization designs (Chapter 7). Thus, designing visualizations should not only be tailored to patients' situations, but also it needs to accommodate healthcare providers' perspectives and practices. Future research in this area can investigate:

- How to support healthcare providers' preferences when designing patient-generated data visualizations and how to design customizable visualization with consideration of healthcare providers' limited available time frame.
- Healthcare providers' responses while reviewing the patient-generated data visualizations during clinical visits in an observatory field study.
- How to incorporate patient-generated data visualizations in part of the healthcare services practices for medical decision making.

Some healthcare providers see value in incorporating patient-generated data into patient electronic medical health portal. However, designing the right visualization functionalities is highly dependent on the platform (e.g., desktop, tablet, large screen) and the environment (e.g., clinic private room, shared space between multiple providers and patients). In our study, we highlighted the trade-offs in employing different technology platforms to implement the patient-generated data visualizations. Thus, an important factor for future visualization designs is to carefully consider the dynamics of clinical visits: the clinic room environments and the current available technologies in the healthcare systems.

9.5 TECHNOLOGY TRANSFER OF PATIENT-GENERATED DATA VISUALIZATIONS

In addition to the future work listed above, there has been an immediate real world result from this thesis research. In collaboration with the W21C group at the Foothills Hospital, we took the first steps towards implementing a selected number of our visualization designs into the patient-care plan platform, MyCareCompass, as part of the Alberta Health Services. MyCareCompass is designed and developed by the W21C group to support patients with chronic conditions in managing different aspects of their conditions. One aspect of chronic patients care is to closely monitor their conditions by tracking their health data at home and presenting their data to healthcare providers for better planning their care.

Together with our healthcare provider collaborators, we selected four of the visualization designs resulted from this dissertation to support patients with tracking and presenting their data. We implemented and incorporated th selected visualization designs into MyCareCompass platform to be released for patient's use (Chapter 8). In the current version of this platform, we included a limited number of the visualization designs to scratch the surface and gain feedback from both patients and healthcare providers. Future work in this path can go towards:

- Observing patients and healthcare providers while using our visualization designs in MyCareCompass platform and analyzing the results of their usages.
- Including more visualization design alternatives based on responses gathered from patients and healthcare providers when using the current version of the platform.
- Initiating the process of formally including patient-generated data collections and visualizations in the healthcare electronic medical records.
- Encouraging healthcare services to take a more patient-centered approach in patient care planning and opening rooms for more active involvements of patients.
- Facilitating healthcare providers' use of the visualizations to better understand patient data and to better explain medical judgments, diagnoses, risks, and decisions to patients.

9.6 SUMMARY

The objective of this thesis has been to explore how to design visualizations to facilitate the patient-provider communication during clinical visits. The results of our studies revealed the importance of designing customizable visualizations to support one-to-one clinical communication between patients and healthcare providers.

Looking into medical literature and the approaches taken in healthcare services for patient care planning, we often see one-to-one interactions between a patient and their healthcare providers in clinical visits. These one-to-one interactions are tailored depending on individualities of each patient and their healthcare provider.

This one-to-one interaction model has been practiced for decades in medicine. For designing visualizations with the purpose of improving patient-provider communication, we, as visualization designers, should take directions from the medical literature and their practices. We should take steps towards designing more visualizations and more customization options based on both patient and provider preferences to be able to accommodate as many patient-provider communications as possible. However, patients are vulnerable population to possible physical or mental inabilities, limited time and energy, and in some cases low medical and technological literacy. On the other hand, healthcare providers have limited time and may visit many patients per day. Considering both patient and provider constraints, we need to design many visualizations to provide them with options. In addition, we need to design these visualizations with customization features that are easy to understand, fast to create, and feasible to modify.

10

CONCLUSION

We embarked on this research to determine how to design visualizations as a communication technological medium that can facilitate patient-provider communication during clinical visits. The studies we conducted to better understand patient-provider communication dynamics during clinical visits showed us their communication challenges and opportunities that may benefit when using visualizations as a communication medium. We discussed these opportunities with a team of healthcare providers and focused on exploring visualization design options for representing patient-generated data during clinical visits. Through an iterative design approach with close involvements of both patient and healthcare provider, we designed various alternative visualization designs. Furthermore, we implemented a selected number of our designed visualizations in the Alberta Healthcare Services patient-centered care platform.

Our first objective was to *expand our current understanding of patient-provider communication challenges during in-clinic visits from both patients' and providers' perspectives*. We did this by conducting a literature review (Chapter 2), in which we studied patients' and healthcare providers' communication challenges during clinical visits discussed in the literature and by conducting interviews (Chapter 4), in which we studied healthcare providers' communication challenges during clinical visits. We then compared and contrasted the results of these two studies to unveil the differences between patients and healthcare providers' perspectives (See Figure 52). In both these cases, our analysis was done with a technology design lens. Our major contributions towards expanding our understanding of communication challenges were:

Figure 52: Affinity Analysis of Patients' and Providers' interviews - from Chapter 4.

- A list of main communication challenges between patients and providers during clinical visits from reviewing medical science and computer science literature. The challenges were patients' anxiety, emotions, different expectations, challenges of engagement, incomplete information, information sources, and the use of medical terminology. (Chapter 2).
- The differences between patients' and healthcare providers' perspectives on communication challenges and how these differences can play a role in design considerations (Chapter 4).

10.2 PATIENTS TRACKING AND PRESENTING THEIR PATIENT-GENERATED DATA

Our second objective was to *explore the reality of patients monitoring and recording their health data, understand their challenges, and design potential visualizations representing their data*. To do this, we collected samples of patient-generated data collections from patients and studied how these patients monitor, record, and present their data to the healthcare providers during clinical visits. The patients' studies illuminated the importance of designing visualizations with close attention to patients' individualities, with customizable features to accommodate patients' individualities. Based on this understanding, we designed various alternative visualizations for each patient. These designs shaped a design space of visualization representations of the patients' patient-generated data collections (See Figure 53). Overall, we contributed:

- Eight patient stories with detailed information on the patients' conditions, how their conditions affected their everyday lifestyle, their goals and fears, the support

Figure 53: Design Board: Visualization designs for patient-generated data - from Chapter 6.

they receive from their caregiver team, and their expectations from the healthcare provider team (Chapter 5).

- A design space of various alternative visualizations that represent patient-generated data collections. (Chapter 6)

10.3 HEALTHCARE PROVIDERS REVIEWING PATIENT-GENERATED DATA

Our last objective was to *investigate healthcare providers' perspectives and goals when requesting and reviewing our proposed patient-generated data visualizations*. We did this by studying healthcare providers' perspectives when requesting and reviewing patient-generated data collections. We also asked these healthcare providers' to reflect on our patient-generated data visualization design space. Based on these studies, we contributed:

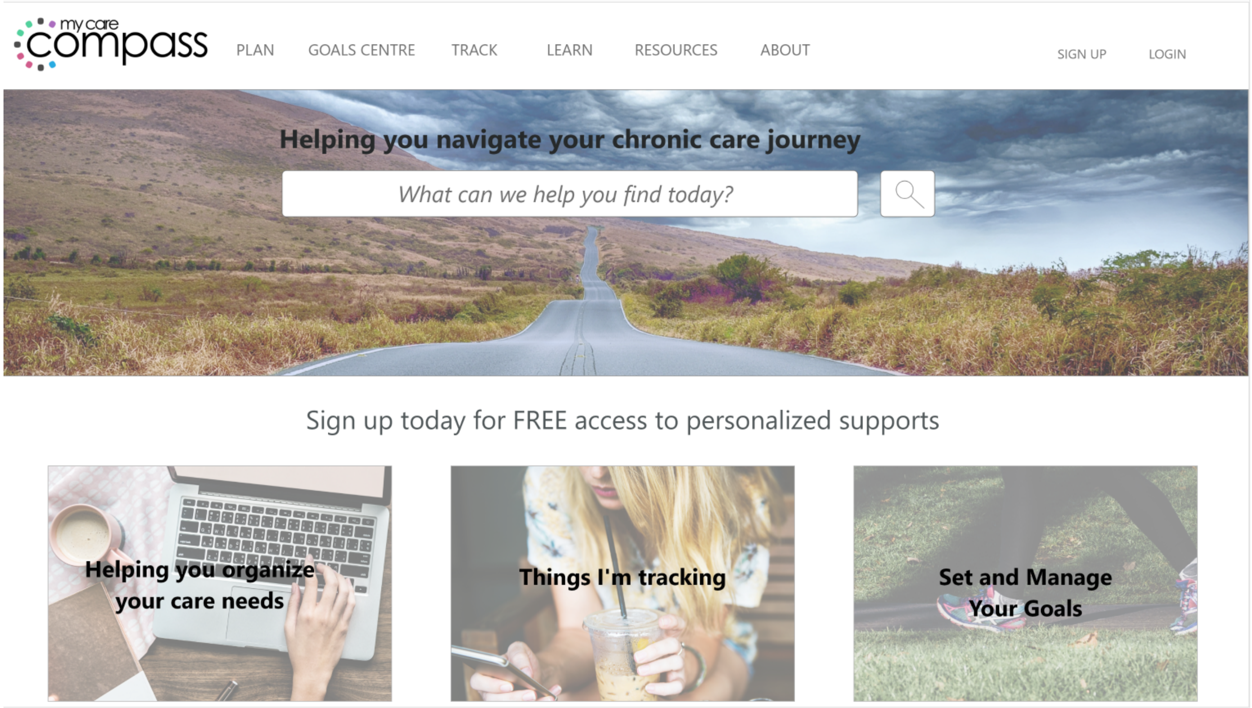


Figure 54: MyCareCompass Patient-Centered Care Plan Website Platform Home Page - from Chapter 8.

- The realization of healthcare providers' differences in their goal for requesting data from their patients and their approaches in reviewing the patient-generated data collections (Chapter 7).
- The healthcare providers' differences in the platform of preferences (desktop based, mobile and tablet based, printouts) for reviewing patient-generated data and how this choice of platform can potentially affect the decisions of visualization designs (Chapter 8).

Based on the healthcare providers' reflection of the visualization design space, we selected several visualizations for implementation purposes. These designs were implemented into the first patient-centered care plan platform, MyCareCompass, designed and developed with the Alberta Healthcare Services collaboration (See Figure 54).

10.4 SUMMARY

Establishing a smooth patient-provider communication can help patients feel understood and help healthcare providers get all the necessary information they need to make proper medical decisions. Previous work looked into improving patient-provider communication using different ways to address this problem such as training healthcare providers to strength their communication skills, educating patients to prime their expectations from the healthcare providers, designing communication technologies as mediums to help healthcare providers teach patients about their conditions, and developing tools for patients to track their data at home.

By exploring the possibilities of using visualizations representing patient-generated data to facilitate patient-provider communication, we have added another way that can support patients and healthcare providers when communicating during clinical visits. We hope our proposed visualizations provide patients and healthcare providers better opportunities to communicate, review, and gain insights on patient-generated data. Further, we took the initial steps of incorporating these visualizations designed with considerations of patients' and healthcare providers' individualities into the patient-centered care plan platform as part of Alberta Health Services.

As a whole, the results of all our studies led us to one message: the importance of designing visualizations by considering each patient and provider individually rather than designing for generalization. However, it may seem impossible to either design a unique set of visualizations for each patient or expect patients to design their own visualizations. We, as healthcare technology designers, need to provide patients and providers with a set of visualization designs as starting points. This approach would be to let each patient and provider choose the visualization designs that works the best for them based on their lifestyle, conditions, data, their relationships. We hope that in the long term, the results of this exploration contributes to support patients' and healthcare providers' individualities using visualizations for establishing smooth clinical communications.

Part VI

APPENDIX

A

ADDITIONAL MATERIAL FOR UNDERSTANDING PROVIDERS' PERCEPTIVE ON COMMUNICATION CHALLENGES

We provided supplementary material for the healthcare providers' interview in Chapter 4.

A.1 INTRODUCTORY INTERVIEW SCRIPT

We used this script to introduce the study to the healthcare providers.

You will be asked to provide some contact and demographic information. You will then be asked to take part in a semi-structured interview where you will be asked a series of questions related to your visit experience. The objective of the research is to better understand how patients communicate with healthcare professionals. The research will focus on how patients communicate with healthcare professionals. Your participation is entirely voluntary. You may refuse to participate altogether, or may withdraw from the study at any time without penalty by stating your wish to withdraw to the researchers.

A.2 INTERVIEW QUESTIONS

This was a semi-structured interview. Questions similar to those below were asked to participants by members of the research team.

- How would you communicate with patients that come to you for the first time?
- Are there ways that patients describe their problem clear enough? How does this make problem if any?
- What ways have patients described their situations and been difficult for you to understand? What would you do when this happens? Why it is useful?
- Are there any method you find helpful in clarifying patient comments?
- Is there any case that patients don't understand you? What do you suggest as a solution?

- Assuming remembering a patient and their problems is part of the communication, how important do you see that in provider-patient communication? Why?

B

ADDITIONAL MATERIAL FOR UNDERSTANDING PATIENTS' PERCEPTIVE ON THEIR HEALTH DATA COLLECTION

We provided supplementary material for the patients' interviews in Chapter 5.

B.1 INTRODUCTORY PATIENT INTERVIEW SCRIPT

We used this script to introduce the study to the patients.

You have been invited here today because you may be a potential end user of the patient-centered care planning solution. Today we would like you to draw on your experiences around your care management experience, what information you think is useful and relevant to managing your care. Thank you again for your participation. There are no right or wrong answers. We are interested in all comments, both positive and negative, so with your permission, we are taking detailed notes and also audio and video recording today's discussion, because we don't want to miss any of your comments and feedback. We will only be recording your voice and the table area. The recording will only be used to help us determine how to improve care management experience, and will only be reviewed by the people working on this project.

Please be assured that any information we record will remain confidential and any information you provide will be kept in a locked cabinet or stored in a password protected folder on a secure server, accessible only by members of the research team. We would also like to remind you that you are not obligated to share anything that you are not comfortable sharing.

We are going to start with an overview of the topic. Patient-centered care is defined as the provision of safe, high quality care based on active engagement of patients developing their own goals of care. For patients with multiple chronic conditions or complex situations, this includes access to and influence over their own care plan at home and in the community where they are making and carrying out most of their health related decisions. Care across multiple clinics is a chance for patients to be involved in their own care while still including the pieces that care providers see as important. By working together, providers and their patients can create a care plan together that may improve continuity of care and lead to better patient results. We want to look at what a truly patient-centered care looks like so we can create technology solutions to support care planning, based in part on our discussions here today. The solutions we create may empower patients like you to participate in their care planning and help providers deliver patient-centered care while improving the continuity of care.

B.2 PATIENT INTERVIEW QUESTIONS

- Background
  - Could you please tell me about your condition (Tell me your story)?
- Data Collection
  - Why do you collect data? How did you get the idea of collecting data? Were you advised by your provider to collect data?
  - How long you have been collecting data?
  - What type of data do you collect?
  - How do you collect your data? Do you use any tool?
  - Do you use any tool to visualize your data?
  - Ask them about some parts of their data in more details (Depending on the context)
  - What are your hopes to learn from these data?
- Communicating data with healthcare providers
  - Have you ever shown your data to your health providers?
    - If yes?
      1. Have you done any preparation on your data before your clinical visit? Why do you think that was necessary?
      2. How was your experience sharing the data with providers?
      3. What did you hope to gain from sharing your data with providers?

   4. Have you reached your goals? If not, why? If yes, how was that experience?

- If no?
   1. Why not?
   2. Could you explain the barriers that stopped you from sharing your data?
   3. Have you shared your data with anyone else? Including your family members, your care takers, or in any social group that you are involved?

C

ADDITIONAL MATERIAL FOR UNDERSTANDING PROVIDERS' PERCEPTIVE ON PATIENT-GENERATED DATA VISUALIZATION

We provided supplementary material for the healthcare providers' focus group and interviews in Chapter 7.

C.1 HEALTHCARE PROVIDERS FOCUS GROUP QUESTIONS

In this focus group, first we would like to get an understanding of activities related to patients and data they collect. We're looking to learn about who decides what to collect and what for, and then how the data is collected.

- We would first like to start with a round table of introductions. If each of you could please tell us your specialties and the chronic conditions that you most commonly see patient-collected data for?
- Tell us a little bit about the data your patients collect?
- Who decides to collect the data? patient-initiated, provider asked, joint decision
- If you ask your patients to collect data, how does what they bring you match up with what was agreed upon to collect?
- How do your patients bring in the data? paper, apps, spreadsheets, notebooks
- How frequently is the data collected? long-term, short-term, episodic context?

Next, we would like to learn about how you interpret the data patients provide. In this section, we would like to discuss the time you spend evaluating patient collected data and what information you are looking for to assist in your assessment of the patient.

- How much time do you spend reviewing the data?
  - Are you able to review information before the appointment? If so, how long do you spend on it?
  - How do you receive the data before the appointment? What is your preferred method to receive the data?

  - Do you only review information during the appointment? If so, for how long?

- When reviewing patient data, how do you interpret or make sense of the data?
  - Looking for trends (e.g., time of day)
  - Specific condition related variables (e.g., blood glucose levels, activity levels)
- When patients bring in data, how do you evaluate the data?
  - On your own before/after the patient appointment?
  - Together?
- What barriers might prevent you from making better use of the data your patients collect? Time, format of data, legibility, completeness, reliability, sharing from patient device

In this section, we would like to discuss how you communicate with your patients about the data that is collected.

- How do you talk to them about what they've brought? Relevance? Importance?
- What do you do when patients bring in data in addition to what you've asked for? Ignore? Discuss with the patient to get an understanding of why they collected it? Let the patient explain why and leave it at that?
- What do you do to reconcile different perspectives of what data is important to a patient's ongoing care? With a specific lens to highlight how it is relevant to their disease/condition?

Lastly, we would like to talk about the role that patient collected data can have in the patient's ongoing care. As an aside, when we refer to ongoing care we are referring to all aspects of the patient's health, which is not limited to but could include things such as improvements in disease management (for example, a reduction in medications), increased activity, or improved mental health.

- What role does this data have in a patient's ongoing management of their chronic conditions, in your practice?
- How effective do you think patient-collected data is in supporting a patient's ongoing care?
  - Mental health by feeling in control/taking action.
  - Patients being an active member of their healthcare.

C.2 INTRODUCTORY INTERVIEW SCRIPT WITH HEALTHCARE PROVIDERS

We used this script to introduce the study to the healthcare providers.

Thank you for taking the time to join our discussion. First, I am going to give a short summary of our path and progress. Then, we are going to show you our potential designs and hopefully get your feedback on them.

We interviewed with eight patients who are dealing with chronic conditions. We collected their self-generated data and asked them about how they collect, analyze, and share this data. We understand that the complex and heavily personal nature of this data make it challenging for both patients and healthcare providers to understand and analyze patient self-generated data. However, we think visualization has the potential to summarize data and to clarify presentation which could be a possible solution to this challenge.

To address this challenge, based on the data we collected from eight patients we interviewed and the series of discussion we had as a group, we started to design several visualizations to represent the individualized patient's data based on their unique condition. We designed several solution point visualizations for each patient. We are going to show you the patient profile along with the preliminary sketches representing the patient data. We would like to get your feedback on the designs.

C.3 A SAMPLE OF PATIENT PROFILE AND PATIENT DATA VISUALIZATION

A sample of patient profile including detailed information about the patient and his/her conditions, diagnosis, healthcare provider care team, motivation for data collections, data collected, lifestyle, hopes, and fear.

Patient Profile:

- Andrew Gellar, 52 years old, Male
- Teacher – has a regular schedule

Diagnosis:

- Type 1 diabetes - diagnosed over 16 years ago
- At first, he was mistakenly diagnosed with type 2 diabetes because of his age
- His age puts him in a unique position since there is less support available for adults with type 1 diabetes

Healthcare Provider Care Team:

- A nurse educator - he found his nurse educator very helpful supporting him in reading, analyzing his data, and giving him advice based on his numbers
- A foot care clinic
- An endocrinologist in a diabetic neuropathology clinic

Motivation for Data Collection:

- He was advised by his endocrinologist and nurse educator to track his numbers (glucose, basal rate) for 5 days – not necessary in a row - to find patterns

Data Collected:

- Tracks his basal rate and glucose for a 5-day cycle.
- Before each meal, he measures his blood sugar using the glucose meter and put the number into his insulin pump. The insulin pump calculates the amount of insulin the pumps needs to give him.
- The pump is connected to the diabetic nurse and it automatically sends Andrew's insulin intake to her.
- Andrew also keeps track of his basal rates that he measures using the glucose meter, recording his numbers on a notebook to share with his nurse educator later in his visit.
- He does A1C test every 3 months.

Lifestyle:

- Another factor impacting Andrew's insulin intake and glucose level is his daily activity level. Sometimes when he rides his bike for 15 minutes to school, he experiences two days of low glucose level that he needs to manage to get back to a normal range.
- He thinks routine exercise helps him have a more balanced reaction to the amount of insulin he takes.

Hopes and Fears:

- He has a hard time analyzing and finding trends in his data to be able to adjust his life style based on those patterns.
- He hopes to understand the factors impacting his glucose level. Specially, he is interested in finding out about the impact of exercise on his glucose level.
- Andrew does not have access to an exercise specialist and he thinks his nurse educator is not knowledgeable enough about the effect of exercise on a diabetes patient's numbers.

"Data management is very complex for diabetics. There's so many factors that come to play with your blood sugars and trying to get everything in the right spot". (TOM)

- What is your general view on this sketch? Do you like to see more or less details?
- Do you think this is easy to read and understandable at a glance? Do the colors make sense to you?
- Can you see the information you like to know about the patient in this design? Patterns, anomalies, missing data, . . . ?
- How do you see this visualization be used?
    1. During your discussion with the patient?
    2. Or would you prefer to see this visualization before the patient arrives?
    3. Or do you prefer the patient to bring in the visualization with herself/himself and talk over it?
- What type of technology would you see useful for presenting this visualization?
    1. Wall sized display?
    2. On your computer along with their EMR document?
    3. On the tablet – sharable screen with the patient?
- How often would you like to see this visualization? Do you like to have live access to it?

D

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Type of material: Short Paper

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Dr. Diane Gromala, **PhD** [redacted]

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Wed 11/28/2018 9:37 AM

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Fri 11/23/2018 3:56 PM

To:Fatemeh Rajabiyazdi [redacted]

Cc:hemacleo@indiana.edu [redacted]

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REFERENCES

Aarhus, R. and Ballegaard, S. A. (2010). Negotiating boundaries: Managing disease at home. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '10, pages 1223–1232, New York, NY, USA. ACM. (Cited on pages 20, 21, and 61.)

Abyholm, A. and Hjortdahl, P. (1999). Being believed is what counts. a qualitative study of experiences with the health service among patients with chronic back pain. *Journal of the Norwegian Medical Association*, 119(11):1630–1632. (Cited on page 56.)

Aggarwal, D., Ploderer, B., Vetere, F., Bradford, M., and Hoang, T. (2016). Doctor, can you see my squats?: Understanding bodily communication in video consultations for physiotherapy. In *DIS '16*, pages 1197–1208. ACM. (Cited on page 60.)

Almalki, M., Gray, K., and Sanchez, F. M. (2015). The use of self-quantification systems for personal health information: big data management activities and prospects. *Health Information Science and Systems*, 3(1):S1. (Cited on page 23.)

Ananthanarayan, S., Sheh, M., Chien, A., Profita, H., and Siek, K. (2013). Pt viz: Towards a wearable device for visualizing knee rehabilitation exercises. In *CHI '13*, pages 1247–1250. ACM. (Cited on pages 27, 28, and 44.)

Ancker, J. S., Witteman, H. O., Hafeez, B., Provencher, T., Van de Graaf, M., and Wei., E. (2015a). The invisible work of personal health information management among people with multiple chronic conditions: qualitative interview study among patients and providers. *Journal of medical Internet research*, 17(6). (Cited on pages 23, 79, and 111.)

Ancker, J. S., Witteman, H. O., Hafeez, B., Provencher, T., Van de Graaf, M., and Wei, E. (2015b). "you get reminded you're a sick person": Personal data tracking and patients with multiple chronic conditions. *Journal of medical Internet research*, 17(8). (Cited on pages 23, 110, 111, 147, and 150.)

Andersen, T., Bansler, J., Kensing, F., Moll, J., and Nielsen, K. D. (2014). Alignment of concerns: A design rationale for patient participation in ehealth. In *HICSS'14*, pages 2587–2596. IEEE. (Cited on page 69.)

Arai, Y. and Farrow, S. (1995). Access, expectations and communication: Japanese mothers' interaction with gps in a pilot study in north/london. *Public Health*, 109(5):353–361. (Cited on page 57.)

Asan, O., Young, H., Chewning, B., and Montague, E. (2015). How physician electronic health record screen sharing affects patient and doctor non-verbal communication in primary care. *Patient education and counseling*, 98(3):310–316. (Cited on pages 44 and 53.)

Attfield, S. J., Adams, A., and Blandford, A. (2006). Patient information needs: pre- and post-consultation. *Health Informatics Journal*, 12(2):165–177. (Cited on page 63.)

Ballegaard, S. A., Hansen, T. R., and Kyng, M. (2008). Healthcare in everyday life: Designing healthcare services for daily life. In *CHI '08*, pages 1807–1816. ACM. (Cited on page 141.)

Barry, M. J. and Edgman-Levitan, S. (2012). Shared decision making — the pinnacle of patient-centered care. *New England Journal of Medicine*, 366(9):780–781. PMID: 22375967. (Cited on page 24.)

Bartram, L. (2015). Design challenges and opportunities for eco-feedback in the home. *IEEE Computer Graphics and Applications*, 35(4):52–62. (Cited on page 112.)

Bass, M. J., Buck, C., Turner, L., Dickie, G., Pratt, G., and Robinson, H. C. (1986). The physician's actions and the outcome of illness in family practice. *The Journal of family practice*, 23(1):43–47. (Cited on page 3.)

Bertakis, K. D., Roter, D., and Putnam, S. M. (1991). The relationship of physician medical interview style to patient satisfaction. *Journal of Family Practice*, 32(2):175–182. (Cited on page 56.)

Bertelsen, O., Bödker, S., Eriksson, E., Hoggan, E., and Vermeulen, J. (2018). Beyond generalization: Research for the very particular. *interactions*. (Cited on page 11.)

Berwick, D. M. (2009). What 'patient-centered' should mean: confessions of an extremist. *Health Affairs*, 28(4):555–565. (Cited on page 167.)

Bessière, K., Pressman, S., Kiesler, S., and Kraut, R. (2010). Effects of internet use on health and depression: a longitudinal study. *Journal of Medical Internet Research*, 12(1):e6. (Cited on page 64.)

Beyer, H. and Holtzblatt, K. (1998). Contextual design: Defining customer-centered design. (Cited on page 49.)

Bodenheimer, T., Lorig, K., Holman, H., and Grumbach, K. (2002). Patient self-management of chronic disease in primary care. *JAMA*, 288(19):2469–2475. (Cited on pages 19, 24, and 69.)

Bowes, P., Stevenson, F., Ahluwalia, S., and Murray, E. (2012). 'i need her to be a doctor': patients' experiences of presenting health information from the internet in GP consultations. *British Journal of General Practice*, 62(604):732–738. (Cited on page 63.)

Boyle, C. M. (1970). Difference between patients' and doctors' interpretation of some common medical terms. *British Medical Journal*, 2(5704):286–289. (Cited on page 66.)

Bradley, A., MacArthur, C., Hancock, M., and Carpendale, S. (2015). Gendered or neutral?: Considering the language of hci. In *Proceedings of the 41st Graphics Interface Conference*, GI '15, pages 163–170, Toronto, Ont., Canada, Canada. Canadian Information Processing Society. (Cited on page 35.)

Broom, A. (2005). Virtually he@lthy: the impact of internet use on disease experience and the doctor-patient relationship. *Qualitative health research*, 15(3):325–345. (Cited on pages 20 and 63.)

Brown, C. E., Roberts, N. J., and Partridge, M. R. (2007). Does the use of a glossary aid patient understanding of the letters sent to their general practitioner? *Clinical Medicine*, 7(5):457–460. (Cited on page 57.)

Buller, M. K. and Buller, D. B. (1987). Physicians' communication style and patient satisfaction. *Journal of Health and Social Behavior*, 28(4):pp. 375–388. (Cited on page 3.)

Card, S. K. and Mackinlay, J. (1997). The structure of the information visualization design space. In *Proc. of InfoVis' 97*, pages 92–99. IEEE. (Cited on page 143.)

Care, P.-C. (2010). Patient-centered care. *OntariO Medical review*, page 34. (Cited on page 36.)

Casarett, D., Pickard, A., Fishman, J. M., Alexander, S. C., Arnold, R. M., Pollak, K. I., and Tulsky, J. A. (2010). Can metaphors and analogies improve communication with seriously ill patients? *Journal of palliative medicine*, 13(3):255–260. (Cited on page 65.)

Castro, C. M., Wilson, C., Wang, F., and Schillinger, D. (2007). Babel babble: Physicians' use of unclarified medical jargon with patients. *American Journal of Health Behavior*, 31(1):85–95. (Cited on pages 21 and 66.)

Cegala, D. J. and Post, D. M. (2009). The impact of patients' participation on physicians' patient-centered communication. *Patient Education and Counseling*, 77(2):202 – 208. (Cited on pages 1, 3, and 44.)

Chen, Y., Ngo, V., Harrison, S., and Duong, V. (2011). Unpacking exam-room computing: Negotiating computer-use in patient-physician interactions. In *CHI '11*, pages 3343–3352. ACM. (Cited on pages 18, 28, 29, 53, 54, and 162.)

Chiauzzi, E., Rodarte, C., and DasMahapatra, P. (2015). Patient-centered activity monitoring in the self-management of chronic health conditions. *BMC medicine*, 13(1):77. (Cited on pages 78 and 79.)

Choe, E. K., Lee, B., and m. c. schraefel (2015). Characterizing visualization insights from quantified selfers' personal data presentations. *IEEE Computer Graphics and Applications*, 35(4):28–37. (Cited on page 150.)

Choe, E. K., Lee, N. B., Lee, B., Pratt, W., and Kientz, J. A. (2014). Understanding quantified-selfers' practices in collecting and exploring personal data. In *Proceedings* *of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '14, pages 1143–1152. ACM. (Cited on pages 24, 61, 106, 108, 113, and 150.)

Chung, C., Cook, J., Bales, E., Zia, J., and Munson, S. A. (2015). More than telemonitoring: Health provider use and nonuse of life-log data in irritable bowel syndrome and weight management. *Journal of medical Internet research*, 17(8). (Cited on pages 78 and 79.)

Chung, C.-F., Dew, K., Cole, A., Zia, J., Fogarty, J., Kientz, J. A., and Munson, S. A. (2016). Boundary negotiating artifacts in personal informatics: Patient-provider collaboration with patient-generated data. In *CSCW '16*, pages 770–786. ACM. (Cited on pages 18, 55, 56, 57, 63, 68, 108, and 141.)

Clayton, M. F. and Dudley, W. N. (2009). Patient-centered communication during oncology follow-up visits for breast cancer survivors: content and temporal structure. *Oncol Nurs Forum*, 36(2):68–79. (Cited on page 57.)

Consolvo, S., McDonald, D. W., Toscos, T., Chen, M. Y., Froehlich, J., Harrison, B., Klasnja, P., LaMarca, A., LeGrand, L., Libby, R., Smith, I., and Landay, J. A. (2008). Activity sensing in the wild: A field trial of ubifit garden. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '08, pages 1797–1806, New York, NY, USA. ACM. (Cited on page 113.)

Constantino, M., Hoskins, P., Fowler, P., Pech, C., McFarlane, R., Flack, J., Forrest, J., Yue, D., and Turtle, J. (1991). Interaction between diabetic patients, their general practitioners and a hospital diabetic clinic. *The Medical journal of Australia*, 155(8):515–518. (Cited on page 57.)

Cook, J. and Hirsch, T. (2014). Monologger: visualizing engagement in doctor-patient conversation. In *Proceedings of the 2014 companion publication on Designing interactive systems*, pages 37–40. ACM. (Cited on page 27.)

Coulter, A. (1997). Partnerships with patients: The pros and cons of shared clinical decision-making. *Journal of Health Services Research*, 2(2):112–121. (Cited on page 44.)

Crampton, N. H., Reis, S., and Shachak, A. (2016). Computers in the clinical encounter: a scoping review and thematic analysis. *JAMIA*, 23(3):654. (Cited on page 67.)

Davidson, E., Simpson, C. R., Demiris, G., Sheikh, A., and McKinstry, B. (2013). Integrating telehealth care-generated data with the family practice electronic medical record: qualitative exploration of the views of primary care staff. *Interactive journal of medical research*, 2(2). (Cited on page 150.)

Dedding, C., van Doorn, R., Winkler, L., and Reis, R. (2011). How will e-health affect patient participation in the clinic? a review of e-health studies and the current evidence for changes in the relationship between medical professionals and patients. *Social Science & Medicine*, 72(1):49 – 53. (Cited on page 64.)

Deering, M. J., Siminerio, E., and Weinstein, S. (2013). Issue brief: patient-generated health data and health it. *Office of the National Coordinator for Health Information Technology*, pages 1–11. (Cited on page 150.)

Denzin, N. K. and Lincoln, Y. S. (2011). *The SAGE handbook of qualitative research*. Sage, 4 edition. (Cited on pages 37 and 38.)

Detmar, S., Aaronson, N., Wever, L. V., Muller, M., and Schornagel, J. (2000). How are you feeling? who wants to know? patients' and oncologists' preferences for discussing health-related quality-of-life issues. *Journal of Clinical Oncology*, 18(18):3295–3301. (Cited on page 18.)

Detmar, S. B., Muller, M. J., Schornagel, J. H., Wever, L. D. V., and Aaronson, N. K. (2002). Health-related quality-of-life assessments and patient-physician communication: A randomized controlled trial. *JAMA*, 288(23):3027–3034. (Cited on pages 3, 18, and 20.)

Donetto, S., Tsianakas, V., and Robert, G. (2014). Using experience-based co-design (ebcd) to improve the quality of healthcare: mapping where we are now and establishing future directions. *London: King's College London*. (Cited on page 36.)

Doyle, C., Lennox, L., and Bell, D. (2013). A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open*, 3(1). (Cited on page 166.)

Eddy, D. M. (1990a). The challenge. *JAMA*, 263(2):287–290. (Cited on page 5.)

Eddy, D. M. (1990b). Practice policies: Where do they come from? *JAMA*, 263(9):1265–1275. (Cited on page 5.)

Egbert, L. D., Battit, G. E., Welch, C. E., and Bartlett, M. K. (1964). Reduction of postoperative pain by encouragement and instruction of patients: a study of doctor-patient rapport. *New England Journal of Medicine*, 270(16):825–827. (Cited on page 3.)

Engel, G. L. (1981). The clinical application of the biopsychosocial model. *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine*, 6(2):101–124. (Cited on page 11.)

Evans, B. J., Kiellerup, F. D., Stanley, R. O., Burrows, G. D., and Sweet, B. (1987). A communication skills programme for increasing patients' satisfaction with general practice consultations. *British Journal of Medical Psychology*, 60(4):373–378. (Cited on page 3.)

Factor, M., Gelernter, D., Kolb, C., Miller, P., and Sittig, D. (1991). Real-time data fusion in the intensive care unit. *Computer*, 24(11):45–54. (Cited on page 112.)

Fallowfield, L. J., Hall, A., Maguire, G. P., and Baum, M. (1990). Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. *Bmj*, 301(6752):575–580. (Cited on pages 3 and 24.)

Falvo, D. R. and Smith, J. K. (1983). Assessing residents' behavioral science skills: Patients' views of physician–patient interaction. *The Journal of family practice*, 17(3):479–483. (Cited on page 58.)

Ferguson, T., Rowlands, A. V., Olds, T., and Maher, C. (2015). The validity of consumer-level, activity monitors in healthy adults worn in free-living conditions: a cross-sectional study. *International Journal of Behavioral Nutrition and Physical Activity*, 12(1):42. (Cited on page 78.)

Fitzpatrick, G. and Ellingsen, G. (2013). A review of 25 years of cscw research in healthcare: Contributions, challenges and future agendas. *Computer Supported Cooperative Work (CSCW)*, 22(4-6):609–665. (Cited on page 25.)

Fonville, A., Choe, E. K., Oldham, S., and Kientz, J. A. (2010). Exploring the use of technology in healthcare spaces and its impact on empathic communication. In *IHI '10*, pages 497–501. ACM. (Cited on pages 17, 28, and 29.)

Fox, S. and Duggan, M. (2013). *Tracking for health*. Pew Research Center's Internet & American Life Project. (Cited on pages 4, 23, 78, and 110.)

Giroldi, E., Veldhuijzen, W., de Leve, T., van der Weijden, T., Bueving, H., and van der Vleuten, C. (2015). 'i still have no idea why this patient was here': An exploration of the difficulties GP trainees experience when gathering information. *Patient Education and Counseling*, 98(7):837–842. (Cited on pages 47 and 57.)

Given, L. M. (2008). *The Sage encyclopedia of qualitative research methods*. Sage Publications. (Cited on page 36.)

Gonzales, M. J. and Riek, L. D. (2013a). Co-designing patient-centered health communication tools for cancer care. In *Pervasive Computing Technologies for Healthcare (PervasiveHealth), 2013 7th International Conference on*, pages 208–215. IEEE. (Cited on page 24.)

Gonzales, M. J. and Riek, L. D. (2013b). Co-designing patient-centered health communication tools for cancer care. In *PervasiveHealth '13*, pages 208–215. IEEE. (Cited on pages 63 and 65.)

Gorter, S., Scherpbier, A., Brauer, J., Rethans, J.-J., van der Heijde, D., Houben, H., van der Vleuten, C., and van der Linden, S. (2002). Doctor-patient interaction: standardized patients' reflections from inside the rheumatological office. *The Journal of rheumatology*, 29(7):1496–1500. (Cited on page 57.)

Greatbatch, D., Heath, C., Campion, P., and Luff, P. (1995). How do desk-top computers affect the doctor-patient interaction. *Family Practice*, 12(1):32–36. (Cited on pages 54 and 67.)

Greatbatch, D., Luff, P., Heath, C., and Campion, P. (1993). Interpersonal communication and human-computer interaction: an examination of the use of computers in medical consultations. *Interacting with Computers*, 5(2):193–216. (Cited on pages 54 and 67.)

Greenfield, S., Kaplan, S., and Ware, Jr., J. E. (1985). Expanding patient involvement in careeffects on patient outcomes. *Annals of Internal Medicine*, 102(4):520–528. (Cited on page 3.)

Hahn, S. R. (2001). Physical symptoms and physician-experienced difficulty in the physician-patient relationship. *Annals of Internal Medicine*, 134:897–904. (Cited on pages 55 and 57.)

Hall, J. and Roter, D. (1995). Patient gender and communication with physicians: results of a community-based study. *Women's health (Hillsdale, N.J.)*, 1(1):77–95. (Cited on page 19.)

Hancock, M., ten Cate, T., Carpendale, S., and Isenberg, T. (2010). Supporting sandtray therapy on an interactive tabletop. In *CHI '10*, pages 2133–2142. ACM. (Cited on pages 26, 27, and 44.)

Health Government of Ontario Canada (2015). Patients first: A proposal to strengthen patient-centred health care in ontario. (Cited on page 166.)

Heitkemper, M. M., Jarrett, M. E., Levy, R. L., Cain, K. C., B., R. L., Feld, A., Barney, P., and Weisman, P. (2004). Self-management for women with irritable bowel syndrome. *Clinical Gastroenterology and Hepatology*, 2(7):585–596. (Cited on pages 4 and 78.)

Helft, P. R., Eckles, R. E., Johnson-Calley, C. S., and Daugherty, C. K. (2005). Use of the internet to obtain cancer information among cancer patients at an urban county hospital. *Journal of Clinical Oncology*, 23(22):4954–4962. (Cited on page 64.)

Heszen-Klemens, I. and Lapińska, E. (1984). Doctor-patient interaction, patients' health behavior and effects of treatment. *Social Science & Medicine*, 19(1):9–18. (Cited on page 3.)

Holtzblatt, K., Wendell, J. B., and Wood, S. (2004). *Rapid contextual design: a how-to guide to key techniques for user-centered design*. Elsevier. (Cited on page 49.)

Howie, J., Porter, A., Heaney, D., and Hopton, J. (1991). Long to short consultation ratio: a proxy measure of quality of care for general practice. *British Journal of General Practice*, 41(343):48–54. (Cited on page 17.)

Huang, E. S., Gorawara-Bhat, R., and Chin, M. H. (2005). Self-reported goals of older patients with type 2 diabetes mellitus. *Journal of the American Geriatrics Society*, 53(2):306–311. (Cited on pages 147 and 164.)

Huba, N. and Zhang, Y. (2012). Designing patient-centered personal health records (phrs): Health care professionals' perspective on patient-generated data. *Journal of Medical Systems*, 36(6):3893–3905. (Cited on pages 22, 23, and 149.)

Hudelson, P., Dao, M. D., Perron, N. J., and Bischoff, A. (2013). Interpreter-mediated diabetes consultations: a qualitative analysis of physician communication practices. *BMC family practice*, 14(1):163. (Cited on page 19.)

Huh, J., McDonald, D. W., Hartzler, A., and Pratt, W. (2013). Patient moderator interaction in online health communities. *AMIA'13*, 2013:627–636. (Cited on page 64.)

Huh, J., Patel, R., and Pratt, W. (2012a). Tackling dilemmas in supporting 'the whole person' in online patient communities. In *Proceedings of the 30TH Annual ACM Conference on Human Factors in Computing Systems*, CHI '12, pages 923–926. ACM. (Cited on page 64.)

Huh, J. and Pratt, W. (2014). Weaving clinical expertise in online health communities. In *Proceedings of the 32Nd Annual ACM Conference on Human Factors in Computing Systems*, CHI '14, pages 1355–1364. ACM. (Cited on page 64.)

Huh, J., Yetisgen-Yildiz, M., Hartzler, A., McDonald, D., Park, A., and Pratt, W. (2012b). Text classification to weave medical advice with patient experiences. *AMIA'12*. (Cited on page 64.)

Hulka, B., Kupper, L., Cassel, J., and Mayo, F. (1975). Doctor-patient communication and outcomes among diabetic patients. *Journal of Community Health*, 1(1):15–27. (Cited on page 3.)

Jackson, J. L. (2005). Communication about symptoms in primary care: impact on patient outcomes. *Journal of Alternative & Complementary Medicine*, 11(supplement 1):51–56. (Cited on page 57.)

Jackson, J. L. and Kroenke, K. (2001). The effect of unmet expectations among adults presenting with physical symptoms. *Annals of Internal Medicine*, 134:889–897. (Cited on page 58.)

Jang, A., MacLean, D. L., and Heer, J. (2014). Bodydiagrams: Improving communication of pain symptoms through drawing. In *Proceedings of the 32Nd Annual ACM Conference on Human Factors in Computing Systems*, CHI '14, pages 1153–1162, New York, NY, USA. ACM. (Cited on page 26.)

Jerant, A. F., von Friederichs-Fitzwater, M. M., and Moore, M. (2005). Patients' perceived barriers to active self-management of chronic conditions. *Patient education and counseling*, 57(3):300–307. (Cited on page 140.)

Johnson, J. E., Nail, L. M., Lauver, D., King, K. B., and Keys, H. (1988). Reducing the negative impact of radiation therapy on functional status. *Cancer*, 61(1):46–51. (Cited on page 3.)

Julliard, K., Vivar, J., Delgado, C., Cruz, E., Kabak, J., and Sabers, H. (2008). What latina patients don't tell their doctors: a qualitative study. *The Annals of Family Medicine*, 6(6):543–549. (Cited on pages 19, 52, 57, and 60.)

Kaplan, S. H., Greenfield, S., and Ware Jr, J. E. (1989). Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Medical care*, 27(3):S110–S127. (Cited on page 3.)

Kaziunas, E., Ackerman, M. S., and Veinot, T. C. (2013). Localizing chronic disease management: Information work and health translations. *Proceedings of the American Society for Information Science and Technology*, 50(1):1–10. (Cited on page 25.)

Kelley, J. M., Kraft-Todd, G., Schapira, L., Kossowsky, J., and Riess, H. (2014). The influence of the patient-clinician relationship on healthcare outcomes: a systematic review and meta-analysis of randomized controlled trials. *PloS one*, 9(4):e94207. (Cited on page 15.)

Kerr, J. (2003). Doctor-patient communication. *Diseases of the Colon & Rectum*, 46(8):1038–1046. (Cited on page 3.)

Klitzman, R. (2007). "patient-time" "doctor-time", and "institution-time": Perceptions and definitions of time among doctors who become patients. *Patient education and counseling*, 66(2):147–155. (Cited on page 52.)

Kravitz, R. L., Callahan, E. J., Paterniti, D., Antonius, D., Dunham, M., and Lewis, C. E. (1996). Prevalence and sources of patients' unmet expectations for care. *Annals of internal medicine*, 125(9):730–737. (Cited on page 18.)

Lee, S., Tang, C., Park, S. Y., and Chen, Y. (2012). Loosely formed patient care teams: Communication challenges and technology design. In *CSCW '12*, pages 867–876. ACM. (Cited on page 25.)

Leong, S. L., Gingrich, D., Lewis, P. R., Mauger, D. T., and George, J. H. (2005). Enhancing doctor-patient communication using email: a pilot study. *The Journal of the American Board of Family Practice*, 18(3):180–188. (Cited on page 25.)

Leung, A. A., Nerenberg, K., Daskalopoulou, S. S., McBrien, K., Zarnke, K. B., Dasgupta, K., Cloutier, L., Gelfer, M., Lamarre-Cliche, M., Milot, A., Bolli, P., Tremblay, G., McLean, D., Tobe, S. W., Ruzicka, M., Burns, K. D., Vallée, M., Prasad, G. R., Lebel, M., Feldman, R. D., Selby, P., Pipe, A., Schiffrin, E. L., McFarlane, P. A., Oh, P., Hegele, R. A., Khara, M., Wilson, T. W., Penner, S. B., Burgess, E., Herman, R. J., Bacon, S. L., Rabkin, S. W., Gilbert, R. E., Campbell, T. S., Grover, S., Honos, G., Lindsay, P., Hill, M. D., Coutts, S. B., Gubitz, G., Campbell, N. R., Moe, G. W., Howlett, J. G., Boulanger, J.-M., Prebtani, A., Larochelle, P., Leiter, L. A., Jones, C., Ogilvie, R. I., Woo, V., Kaczorowski, J., Trudeau, L., Petrella, R. J., Hiremath, S., Drouin, D., Lavoie, K. L., Hamet, P., Fodor, G., Grégoire, J. C., Lewanczuk, R., Dresser, G. K., Sharma, M., Reid, D., Lear, S. A., Moullec, G., Gupta, M., Magee, L. A., Logan, A. G., Harris, K. C., Dionne, J., Fournier, A., Benoit, G., Feber, J., Poirier, L., Padwal, R. S., and Rabi, D. M. (2016). Hypertension canada's 2016 canadian hypertension education program guidelines for blood pressure measurement, diagnosis, assessment of risk, prevention, and treatment of hypertension. *Canadian Journal of Cardiology*, 32(5):569 – 588. (Cited on page 184.)

Li, I., Dey, A. K., and Forlizzi, J. (2011). Understanding my data, myself: Supporting self-reflection with ubicomp technologies. In *UbiComp '11*, pages 405–414. ACM. (Cited on page 25.)

Lim, C., Berry, A. B., Hirsch, T., Hartzler, A. L., Wagner, E. H., Ludman, E., and Ralston, J. D. (2016). "it just seems outside my health": How patients with chronic conditions perceive communication boundaries with providers. In *DIS '16*, pages 1172–1184. ACM. (Cited on pages 61 and 62.)

Liu, L. S., Hirano, S. H., Tentori, M., Cheng, K. G., George, S., Park, S. Y., and Hayes, G. R. (2011). Improving communication and social support for caregivers of high-risk infants through mobile technologies. In *CSCW '11*, pages 475–484. ACM. (Cited on page 19.)

Liu, L. S., Inkpen, K. M., and Pratt, W. (2015). "i'm not like my friends": Understanding how children with a chronic illness use technology to maintain normalcy. In *CSCW '15*, pages 1527–1539. ACM. (Cited on page 25.)

Loorak, M. H., Perin, C., Kamal, N., Hill, M., and Carpendale, S. (2016). Timespan: Using visualization to explore temporal multi-dimensional data of stroke patients. *IEEE Transactions on Visualization and Computer Graphics*, 22(1):409–418. (Cited on page 112.)

Loos, J. R. and Davidson, E. J. (2016). Wearable health monitors and physician-patient communication: The physician's perspective. In *HICSS'16*, pages 3389–3399. IEEE. (Cited on page 62.)

Lorig, K., Sobel, D., Ritter, P., Laurent, D., and Hobbs, M. (2001). Effect of a self-management program on patients with chronic disease. *Effective clinical practice : ECP*, 4(6):256—262. (Cited on page 140.)

Lorig, K. R., Sobel, D. S., Stewart, A. L., Brown, B. W., Bandura, A., Ritter, P., Gonzalez, V. M., Laurent, D. D., and Holman, H. R. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: A randomized trial. *Medical Care*, 37(1):5–14. (Cited on page 140.)

Luff, P., Heath, C., and Greatbatch, D. (1992). Tasks-in-interaction: Paper and screen based documentation in collaborative activity. In *CSCW '92*, pages 163–170. ACM. (Cited on page 67.)

Luxford, K., Safran, D. G., and Delbanco, T. (2011). Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. *International Journal for Quality in Health Care*, 23(5):510–515. (Cited on page 166.)

MacLeod, H., Oakes, K., Geisler, D., Connelly, K., and Siek, K. (2015). Rare world: Towards technology for rare diseases. In *CHI '15*, pages 1145–1154. ACM. (Cited on pages 1, 20, 21, 22, 24, 59, 61, 65, and 66.)

Makonin, S., Kashani, M. H., and Bartram, L. (2014). The affect of lifestyle factors on eco-visualization design. *CoRR*, abs/1405.5263. (Cited on page 113.)

Mancuso, C. A., Rincon, M., Robbins, L., and Charlson, M. E. (2003). Patients' expectations of asthma treatment. *Journal of Asthma*, 40(8):873–881. (Cited on page 18.)

Mancuso, C. A., Salvati, E. A., Johanson, N. A., Peterson, M. G., and Charlson, M. E. (1997). Patients' expectations and satisfaction with total hip arthroplasty. *The Journal of Arthroplasty*, 12(4):387 – 396. (Cited on page 18.)

Matthias, M. S., Parpart, A. L., Nyland, K. A., Huffman, M. A., Stubbs, D. L., Sargent, C., and Bair, M. J. (2010). The patient–provider relationship in chronic pain care: Providers' perspectives. *Pain Medicine*, 11(11):1688–1697. (Cited on pages 24 and 55.)

McDuff, D., Karlson, A., Kapoor, A., Roseway, A., and Czerwinski, M. (2012). Affectaura: An intelligent system for emotional memory. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '12, pages 849–858, New York, NY, USA. ACM. (Cited on pages 112 and 113.)

McGrath, J. E. (1995). Methodology matters: Doing research in the behavioral and social sciences. In BAECKER, R. M., GRUDIN, J., BUXTON, W. A., and GREENBERG, S., editors, *Readings in Human–Computer Interaction (Second Edition)*, Interactive Technologies, pages 152 – 169. Morgan Kaufmann, second edition edition. (Cited on page 37.)

Mentis, H. M., Reddy, M., and Rosson, M. B. (2010). Invisible emotion: Information and interaction in an emergency room. In *CSCW '10*, pages 311–320. ACM. (Cited on page 44.)

Milewski, J. and Parra, H. (2011). Gathering requirements for a personal health management system. In *CHI EA '11*, pages 2377–2382. ACM. (Cited on pages 24 and 61.)

Moen, A. and Brennan, P. F. (2005). Health@home: The work of health information management in the household (himh): Implications for consumer health informatics (chi) innovations. *Journal of the American Medical Informatics Association*, 12(6):648 – 656. (Cited on page 23.)

Moffat, M., Cleland, J., van der Molen, T., and Price, D. (2006). Sub-optimal patient and physician communication in primary care consultations: its relation to severe and difficult asthma. *Primary Care Respiratory Journal*, 15(3):159–165. (Cited on page 61.)

Monroe, M., Lan, R., Lee, H., Plaisant, C., and Shneiderman, B. (2013). Temporal event sequence simplification. *IEEE Transactions on Visualization and Computer Graphics*, 19(12):2227–2236. (Cited on page 112.)

Nettleton, S., Watt, I., O'Malley, L., and Duffey, P. (2005). Understanding the narratives of people who live with medically unexplained illness. *Patient education and counseling*, 56(2):205–210. (Cited on page 52.)

Ni, T., Karlson, A. K., and Wigdor, D. (2011). AnatOnMe: Facilitating Doctor-patient Communication Using a Projection-based Handheld Device. In *CHI '11*, pages 3333–3342. ACM. (Cited on pages 26, 27, 44, and 64.)

Nundy, S., Lu, C.-Y. E., Hogan, P., Mishra, A., and Peek, M. E. (2014). Using patient-generated health data from mobile technologies for diabetes self-management support: Provider perspectives from an academic medical center. *Journal of Diabetes Science and Technology*, 8(1):74–82. PMID: 24876541. (Cited on page 149.)

Nunes, F., Verdezoto, N., Fitzpatrick, G., Kyng, M., Grönvall, E., and Storni, C. (2015). Self-care technologies in hci: Trends, tensions, and opportunities. *ACM Trans. Comput.-Hum. Interact.*, 22(6):33:1–33:45. (Cited on page 69.)

O'brien, E., Asmar, R., Beilin, L., Imai, Y., Mancia, G., Mengden, T., Myers, M., Padfield, P., Palatini, P., Parati, G., et al. (2005). Practice guidelines of the european society of hypertension for clinic, ambulatory and self blood pressure measurement. *Journal of hypertension*, 23(4):697–701. (Cited on page 184.)

Ong, L., de Haes, J., Hoos, A., and Lammes, F. (1995). Doctor-patient communication: A review of the literature. *Social Science & Medicine*, 40(7):903 – 918. (Cited on pages 1, 22, 44, and 78.)

Ong, L., Visser, M., Lammes, F., and de Haes, J. (2000). Doctor-patient communication and cancer patients' quality of life and satisfaction. *Patient Education and Counseling*, 41(2):145 – 156. (Cited on page 3.)

Organization, W. H. (2008). The world health report 2008 - primary health care (now more than ever). (Cited on page 36.)

Orth, J. E., Stiles, W. B., Scherwitz, L., Hennrikus, D., and Vallbona, C. (1987). Patient exposition and provider explanation in routine interviews and hypertensive patients' blood pressure control. *Health Psychology*, 6(1):29. (Cited on page 3.)

Page, A., editor (2004). *Keeping patients safe: Transforming the work environment of nurses*. National Academies Press. (Cited on page 29.)

Patel, R. A., Hartzler, A., Pratt, W., Back, A., Czerwinski, M., and Roseway, A. (2013). Visual feedback on nonverbal communication: A design exploration with healthcare professionals. In *Proceedings of the 7th EAI International Conference on Pervasive Computing Technologies for Healthcare*, pages 105–112. ACM. (Cited on pages 110 and 111.)

Patel, R. A., Klasnja, P., Hartzler, A., Unruh, K. T., and Pratt, W. (2012). Probing the benefits of real-time tracking during cancer care. In *AMIA Annual Symposium Proceedings*. American Medical Informatics Association. (Cited on pages 76, 78, 147, and 161.)

Pea, R. D. (1987). User Centered System Design: New Perspectives on Human-Computer Interaction. *Journal educational computing research*, 3(1):129–134. (Cited on page 35.)

Peel, E., Douglas, M., and Lawton, J. (2007). Self monitoring of blood glucose in type 2 diabetes: longitudinal qualitative study of patients' perspectives. *BMJ*, 335(7618):493. (Cited on pages 110 and 111.)

Perin, C., Dragicevic, P., and Fekete, J.-D. (2014). Revisiting bertin matrices: New interactions for crafting tabular visualizations. *Visualization and Computer Graphics, IEEE Transactions on*, 20(12):2082–2091. (Cited on page 49.)

Piper, A. M. and Hollan, J. D. (2008). Supporting medical conversations between deaf and hearing individuals with tabletop displays. In *CSCW '08*, pages 147–156. ACM. (Cited on pages 27 and 44.)

Plaisant, C., Milash, B., Rose, A., Widoff, S., and Shneiderman, B. (1996). Lifelines: Visualizing personal histories. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '96, pages 221–227, New York, NY, USA. ACM. (Cited on pages 25 and 112.)

Powsner, S. M. and Tufte, E. R. (1994). Graphical summary of patient status. *Lancet*, 344(8919):386–389. (Cited on page 111.)

Quinn, P. M. (2005). *Qualitative Research*. American Cancer Society. (Cited on page 37.)

Rainey, L. C. (1985). Effects of preparatory patient education for radiation oncology patients. *Cancer*, 56(5):1056–1061. (Cited on page 3.)

Rajabiyazdi, F. (2016). Designing and developing technologies to facilitate clinician-patient communication. In *Proceedings of the 2016 ACM Companion on Interactive Surfaces and Spaces*, ISS Companion '16, pages 19–24, New York, NY, USA. ACM. (Cited on page 73.)

Rajabiyazdi, F., Perin, C., Oehlberg, L., and Carpendale, S. (2017a). The challenges of individuality to technology approaches to personally collected health data. In *Proceedings of the 11th EAI International Conference on Pervasive Computing Technologies for Healthcare*, PervasiveHealth '17, pages 448–451, New York, NY, USA. ACM. (Cited on pages 74, 76, 79, 113, 114, and 147.)

Rajabiyazdi, F., Perin, C., Oehlberg, L., and Carpendale, S. (2018). Personal Patient-Generated Data Visualizations for Diabetes Patients. In *IEEE VIS 2018 Electronic Conference Proceedings*, Berlin, Germany. (Cited on page 74.)

Rajabiyazdi, F., Perin, C., Vermeulen, J., MacLeod, H., Gromala, D., and Carpendale, S. (2017b). Differences that matter: In-clinic communication challenges. In *Proceedings of the 11th EAI International Conference on Pervasive Computing Technologies for Healthcare*, pages 251–260. ACM. (Cited on pages 22, 24, 42, 76, 114, and 147.)

Rathert, C., Wyrwich, M. D., and Boren, S. A. (2012). Patient-centered care and outcomes: A systematic review of the literature. *Medical Care Research and Review*. (Cited on page 166.)

Rind, A., Aigner, W., Miksch, S., Wiltner, S., Pohl, M., Turic, T., and Drexler, F. (2011). Visual exploration of time-oriented patient data for chronic diseases: Design study and evaluation. In Holzinger, A. and Simonic, K.-M., editors, *Information Quality in e-Health*, pages 301–320, Berlin, Heidelberg. Springer Berlin Heidelberg. (Cited on page 112.)

Rittel, H. W. J. and Webber, M. M. (1973). Dilemmas in a general theory of planning. *Policy Sciences*, 4(2):155–169. (Cited on pages 7, 31, 32, 33, and 34.)

Roberts, N. (2000). Wicked problems and network approaches to resolution. *International public management review*, 1(1):1–19. (Cited on page 31.)

Root, M. J. (1987). Communication barriers between older women and physicians. *Public Health Reports*, 102(supplement 4):152–155. (Cited on page 57.)

Rosland, A.-M., Heisler, M., Choi, H.-J., Silveira, M. J., and Piette, J. D. (2010). Family influences on self-management among functionally independent adults with diabetes or heart failure: do family members hinder as much as they help? *Chronic Illness*, 6(1):22–33. PMID: 20308348. (Cited on pages 141 and 142.)

Ryan, P. and Sawin, K. J. (2009). The individual and family self-management theory: Background and perspectives on context, process, and outcomes. *Nursing Outlook*, 57(4):217 – 225.e6. (Cited on pages 138 and 141.)

Sada, Y., Street Jr, R. L., Singh, H., Shada, R., and Naik, A. D. (2011). Primary care and communication in shared cancer care: a qualitative study. *The American journal of managed care*, 17(4):259. (Cited on page 54.)

Sands, D. and Wald, J. (2014). Transforming health care delivery through consumer engagement, health data transparency, and patient-generated health information. *Yearbook of medical informatics*, 9(1):170. (Cited on pages 23 and 149.)

Schillinger, D., Bindman, A., Wang, F., Stewart, A., and Piette, J. (2004). Functional health literacy and the quality of physician-patient communication among diabetes patients. *Patient Education and Counseling*, 52(3):315 – 323. Special Section: Chronic Obstructive Pulmonary Disease. (Cited on page 19.)

Schouten, B. C. and Meeuwesen, L. (2006). Cultural differences in medical communication: A review of the literature. *Patient Education and Counseling*, 64(1–3):21 – 34. (Cited on page 19.)

Schroeder, J., Hoffswell, J., Chung, C., Fogarty, J., Munson, S., and Zia, J. (2017). Supporting patient-provider collaboration to identify individual triggers using food and symptom journals. In *roceedings of the Conference on Computer-Supported Cooperative Work*, pages 1726–1739. NIH Public Access. (Cited on page 78.)

Seçkin, G. (2010). Cyber patients surfing the medical web: Computer-mediated medical knowledge and perceived benefits. *Computers in Human Behavior*, 26(6):1694 – 1700. Online Interactivity: Role of Technology in Behavior Change. (Cited on page 63.)

Shachak, A. and Reis, S. (2009). The impact of electronic medical records on patient–doctor communication during consultation: a narrative literature review. *Journal of Evaluation in Clinical Practice*, 15(4):641–649. (Cited on page 28.)

Shields, C. G., Coker, C. J., Poulsen, S. S., Doyle, J. M., Fiscella, K., Epstein, R. M., and Griggs, J. J. (2009). Patient-centered communication and prognosis discussions with cancer patients. *Patient Education and Counseling*, 77(3):437 – 442. (Cited on page 56.)

Siek, K. A., Connelly, K. H., and Rogers, Y. (2006). Pride and prejudice: Learning how chronically ill people think about food. In *CHI '06*, pages 947–950. ACM. (Cited on pages 65 and 66.)

Siu, J. Y. (2015). Communicating under medical patriarchy: gendered doctor-patient communication between female patients with overactive bladder and male urologists in hong kong. *BMC women's health*, 15(1):1. (Cited on page 57.)

Smith, B. K., Frost, J., Albayrak, M., and Sudhakar, R. (2007). Integrating glucometers and digital photography as experience capture tools to enhance patient understanding and communication of diabetes self-management practices. *Personal and Ubiquitous Computing*, 11(4):273–286. (Cited on pages 76, 78, 147, and 161.)

Smith, P. C., Araya-Guerra, R., Bublitz, C., Parnes, B., Dickinson, L. M., Van Vorst, R., Westfall, J. M., and Pace, W. D. (2005). Missing clinical information during primary care visits. *JAMA*, 293(5):565–571. (Cited on page 23.)

Spruill, T. M., Pickering, T. G., Schwartz, J. E., Mostofsky, E., Ogedegbe, G., Clemow, L., and Gerin, W. (2007). The impact of perceived hypertension status on anxiety and the white coat effect. *Annals of Behavioral Medicine*, 34(1):1–9. (Cited on page 54.)

Stacey, D., Bennett, C. L., Barry, M. J., Col, N. F., Eden, K. B., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A., Légaré, F., and Thomson, R. (2011). Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*, 10(10). (Cited on page 25.)

Starcevic, V. and Berle, D. (2013). Cyberchondria: towards a better understanding of excessive health-related internet use. *Expert Review of Neurotherapeutics*, 13(2):205–213. (Cited on page 63.)

Step, M. M., Siminoff, L. A., and Rose, J. H. (2009). Differences in oncologist communication across age groups and contributions to adjuvant decision outcomes. *Journal of the American Geriatrics Society*, 57(s2):279–282. (Cited on page 57.)

Stewart, M. A. (1995). Effective physician-patient communication and health outcomes: a review. *CMAJ: Canadian Medical Association Journal*, 152(9):1423. (Cited on page 3.)

Storni, C. (2011). Complexity in an uncertain and cosmopolitan world. rethinking personal health technology in diabetes with the tag-it-yourself. *PsychNology Journal*, 9(2). (Cited on page 138.)

Strauss, A. and Corbin, J. M. (1997). *Grounded theory in practice*. Sage. (Cited on pages 17, 48, 81, 83, 115, and 152.)

Sullivan, F. and Wyatt, J. C. (2005). How computers can help to share understanding with patients. *BMJ*, 331(7521):892–894. (Cited on pages 25 and 114.)

Sun, S., Zhou, X., Denny, J. C., Rosenbloom, T. S., and Xu, H. (2013). Messaging to your doctors: Understanding patient-provider communications via a portal system. In *CHI '13*, pages 1739–1748. ACM. (Cited on pages 18, 55, and 56.)

Swan, M. (2009). Emerging patient-driven health care models: An examination of health social networks, consumer personalized medicine and quantified self-tracking. *International Journal of Environmental Research and Public Health*, 6(2):492–525. (Cited on page 147.)

The College of Family Physicians of Canada (2009). Patient-centred primary care in canada: Bring it on home. (Cited on page 166.)

Thomasma, D. C. (1983). Beyond medical paternalism and patient autonomy: A model of physician conscience for the physician-patient relationship. *Annals of Internal Medicine*, 98(2):243–248. (Cited on pages 19, 24, and 69.)

Thompson, S. C., Nanni, C., and Schwankovsky, L. (1990). Patient-oriented interventions to improve communication in a medical office visit. *Health Psychology*, 9(4):390. (Cited on page 3.)

Thorne, S., Armstrong, E.-A., Harris, S. R., Hislop, T. G., Kim-Sing, C., Oglov, V., Oliffe, J. L., and Stajduhar, K. I. (2009). Patient real-time and 12-month retrospective perceptions of difficult communications in the cancer diagnostic period. *Qualitative Health Research*, 19(10):1383–1394. (Cited on page 54.)

Thorne, S., Hislop, T. G., Kuo, M., and Armstrong, E.-A. (2006). Hope and probability: Patient perspectives of the meaning of numerical information in cancer communication. *Qualitative Health Research*, 16(3):318–336. (Cited on page 57.)

Thudt, A., Lee, B., Choe, E. K., and Carpendale, S. (2017). Expanding research methods for a realistic understanding of personal visualization. *IEEE Computer Graphics and Applications*, 37(2):12–18. (Cited on pages 113 and 114.)

Topol, E. (2011). *The Creative Destruction of Medicine: How the Digital Revolution Will Create Better Health Care*. (Cited on page 11.)

Torbjørnsen, A., Jenum, A. K., Småstuen, M. C., Årsand, E., Holmen, H., Wahl, A. K., and Ribu, L. (2014). A low-intensity mobile health intervention with and without health counseling for persons with type 2 diabetes, part 1: baseline and short-term results from a randomized controlled trial in the norwegian part of renewing health. *JMIR mHealth and uHealth*, 2(4). (Cited on page 24.)

Tory, M. and Carpendale, S. (2015). Personal visualization and personal visual analytics [guest editors' introduction]. *IEEE Computer Graphics and Applications*, 35(4):26–27. (Cited on pages 112 and 114.)

Tufano, J. T., Ralston, J. D., and Martin, D. P. (2008). Providers' experience with an organizational redesign initiative to promote patient-centered access: A qualitative study. *Journal of General Internal Medicine*, 23(11):1778–1783. (Cited on page 150.)

Unruh, K. T., Skeels, M., Civan-Hartzler, A., and Pratt, W. (2010). Transforming clinic environments into information workspaces for patients. In *CHI '10*, pages 183–192. ACM. (Cited on pages 19, 60, and 63.)

van der Weegen, S., Verwey, R., Spreeuwenberg, M., Tange, H., van der Weijden, T., and de Witte, L. (2013). The development of a mobile monitoring and feedback tool to stimulate physical activity of people with a chronic disease in primary care: a user-centered design. *JMIR mHealth and uHealth*, 1(2). (Cited on pages 22 and 111.)

Van Wieringen, J. C., Harmsen, J. A., and Bruijnzeels, M. A. (2002). Intercultural communication in general practice. *The European journal of public health*, 12(1):63–68. (Cited on pages 61 and 62.)

Vegni, E., Leone, D., Biasoli, C., and Moja, E. A. (2014). Difficult encounters with a hemophilic patient: The inner perspective of physicians. *Journal of health psychology*, 19(12):1499–1507. (Cited on page 57.)

Verdecchia, P., Schillaci, G., Borgioni, C., Ciucci, A., Zampi, I., Gattobigio, R., Sacchi, N., and Porcellati, C. (1995). White coat hypertension and white coat effect similarities and differences. *American Journal of Hypertension*, 8(8):790 – 798. (Cited on page 149.)

Weibel, N., Emmenegger, C., Lyons, J., Dixit, R., Hill, L. L., and Hollan, J. D. (2013). Interpreter-mediated physician-patient communication: Opportunities for multimodal healthcare interfaces. In *PervasiveHealth' 13*, pages 113–120. IEEE. (Cited on pages 19 and 60.)

White, R. W. and Horvitz, E. (2009). Cyberchondria: Studies of the escalation of medical concerns in web search. *ACM Trans. Inf. Syst.*, 27(4):23:1–23:37. (Cited on pages 20 and 63.)

Wilcox, L., Feiner, S., Elhadad, N., Vawdrey, D., and Tran, T. (2013). Remedy: Supporting consumer-centered medication information search. In *PervasiveHealth' 13*, pages 317–318. IEEE. (Cited on page 63.)

Wilcox, L., Feiner, S., Elhadad, N., Vawdrey, D., and Tran, T. H. (2014). Patient-centered tools for medication information search. In *PervasiveHealth '14*, pages 49–56. IEEE. (Cited on page 63.)

Wolfe, A. (2001). Institute of medicine report: Crossing the quality chasm: A new health care system for the 21st century. *Policy, Politics, & Nursing Practice*, 2(3):233–235. (Cited on pages 35 and 36.)

Wongsuphasawat, K., Guerra Gómez, J. A., Plaisant, C., Wang, T. D., Taieb-Maimon, M., and Shneiderman, B. (2011). Lifeflow: Visualizing an overview of event sequences. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '11, pages 1747–1756, New York, NY, USA. ACM. (Cited on pages 25 and 112.)

Wood, J. (2015). Visualizing personal progress in participatory sports cycling events. *IEEE Computer Graphics and Applications*, 35(4):73–81. (Cited on pages 112 and 113.)

Wright, E. B., Holcombe, C., and Salmon, P. (2004). Doctors' communication of trust, care, and respect in breast cancer: qualitative study. *BMJ*, 328(7444):864. (Cited on page 3.)

Zan, S., Agboola, S., Moore, S. A., Parks, K. A., Kvedar, J. C., and Jethwani, K. (2015). Patient engagement with a mobile web-based telemonitoring system for heart failure self-management: a pilot study. *JMIR mHealth and uHealth*, 3(2). (Cited on page 24.)

Zhou, X., Zheng, K., Ackerman, M., and Hanauer, D. (2012). Cooperative documentation: The patient problem list as a nexus in electronic health records. In *CSCW '12*, pages 911–920. ACM. (Cited on page 25.)

Zhu, H., Colgan, J., Reddy, M., and Choe, E. K. (2016). Sharing patient-generated data in clinical practices: An interview study. In *AMIA Annual Symposium Proceedings*, volume 2016, pages 1303–1312. American Medical Informatics Association. (Cited on pages 23, 78, 112, 114, 139, 142, 147, 150, and 161.)