Designing Technologies to Support Patient Engagement in the Hospital

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Abstract

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Patient engagement in the hospital affects health outcomes and satisfaction with care. Furthermore, granting patients access to information about their care and encouraging them to voice their concerns has the potential to help patients prevent medical errors. Yet hospitalized patients often face enormous difficulties in engaging with their care. Moreover, much of the work examining the nature of and support for patient engagement has focused on the outpatient and home contexts, outside of the hospital.

In this dissertation, I examine the nature of patient engagement in the hospital. I demonstrate that patients, as well as their caregivers (family and friends who help the patient in the hospital), often seek to actively engage with their care in a variety of ways, including by monitoring the patient's condition, jointly making decisions about care with clinicians, and even acting as a nexus point for members of the clinical team to connect with each other. I illustrate individual variation in the degree to which patients and caregivers desire or feel able to engage with their care. I discuss factors which affect patients' and caregivers' willingness to engage in their care, both in terms of general engagement and specifically in terms of their safety behaviors. For the latter, I explore specifically how the patient-clinician relationship encourages or discourages patients and caregivers from performing behaviors that could increase their safety in the hospital. In addition, I explore how technologies should be designed to support patient engagement. First, I discuss the design of technologies to support self-tracking of health and care in the hospital—an important part of engagement that helps patients and caregivers monitor the patient's health and make decisions about care. Second, I discuss how technologies should be designed to encourage patients and caregivers to speak up about issues in their care. The contributions of this work illustrate how we can design technologies to improve the safety and quality of hospital care nationwide.

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Chapter 1. INTRODUCTION

Most Americans will, at some point or other in their lives, be hospitalized. We are born in hospitals;[1] we die in hospitals;[2] and we spend much of our time in between trying our best to stay out of hospitals. But every year, millions of Americans[3] are consigned to spend some amount of time in an unfamiliar bed in a white-walled room, wearing a flimsy gown that does not close in the back, listening to the alarming beeps of mysterious equipment and surrendering their care to an army of clinicians they may never have encountered before.

Adding to the inherent vulnerability of hospitalization, hospitalized patients (inpatients) face many challenges in taking ownership of their care. For instance, inpatients frequently struggle to get access to information about their care, including important logistical information such as the care schedule for the day (Kendall, Mishra, Pollack, Aaronson, & Pratt, 2015) and information about who is coming to their room and when (Miller, Pollack, & Pratt, 2016). Their physical environment can also make it difficult for them to effectively use electronic or paper-based systems to access care information, even when it is available (Kendall et al., 2015). Additionally, inpatients with a poor clinician-patient relationship may be less willing to proactively participate in their care (Doherty & Stavropoulou, 2012).

As researchers and designers of healthcare systems, it is our responsibility to create systems that empower hospitalized patients to overcome these challenges and engage with their care—

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[1] 98.64% of Americans were born in a hospital in 2012 (MacDorman, Mathews, & Declercq, 2014)

[2] 30%-60% of American deaths occur in hospitals, based on different estimates (M. J. Hall, Levant, & Defrances, 2000; Weitzen, Teno, Fennell, & Mor, 2003)

[3] According to the CDC, 7.6% of Americans were hospitalized overnight in 2017 (Centers for Disease Control and Prevention, 2017); according to the US Census Bureau, US Population on Dec 31 2017 was 326,213,213 (United States Census Bureau, 2019), meaning more than 24 million Americans were hospitalized in 2017.

meaning, to understand their care, monitor care administration, and actively participate in care activities. Supporting patient engagement is an ethical imperative from two moral frameworks: deontology and consequentialism. From a deontological perspective, enabling patient engagement serves the Kantian precept of respect for persons (Danis & Solomon, 2013). Creating health systems that recognize patients as independent actors who can and should make their own choices, rather than passive recipients of care administered by clinicians, is the only path consonant with Kant's imperative to treat each individual, "whether in thine own person or in that of any other, in every case as an end withal, never as a means only" (Kant, 1879)—in other words, to treat respect for, and support for the autonomy of, each individual as a worthy and necessary end in and of itself.

From a consequentialist perspective, enabling patient engagement has the potential to yield better outcomes for patients. Higher patient engagement has been linked with better experiences of care (Jessica Greene, Hibbard, Sacks, & Overton, 2013), better performance on multiple clinical indicators (J. Greene, Hibbard, Sacks, Overton, & Parrotta, 2015), and higher self-management ability (Mosen et al., 2007). It has also been associated with lower long-term costs (J. Greene et al., 2015), and a study of one health care organization found that patient-centered care was associated with shorter inpatient stays (Charmel & Frampton, 2008).

Supporting patient engagement also means empowering patients to detect and prevent medical errors. The number of medical errors that occur each year in the United States—and the resultant harm—is disputed, with estimates ranging from 25,000 (Hogan et al., 2015; Shojania & Dixon-Woods, 2017) to 400,000 (James, 2013) deaths each year as a result of preventable harm to hospitalized patients. Estimates vary because of the difficulty of determining whether any individual death was actually preventable, and because researchers contest the validity of the methods used to generate these estimates (Bates & Singh, 2018). Whatever the rates of medical errors, however, it is incontrovertible that medical errors happen; and since the Institute of Medicine recognized medical errors as an urgent priority for improving patient safety in the United States (Institute of Medicine, 1999), healthcare organizations and researchers have invested heavily in investigating how to prevent medical errors by improvements to clinical structures and workflows.

But clinicians are not the only actors with the potential to prevent errors. As early as 400 BCE, Hippocrates recognized the impossibility of clinician omniscience[4]; more recently, researchers have highlighted the potential for patients to prevent errors (David L.B. Schwappach, 2010; Unruh & Pratt, 2007). Patients and their caregivers (family and friends who help the patient manage their life and care in the hospital) have to the potential to prevent medical errors. They can be the first to spot breakdowns in care or intervene to resolve issues (Gallagher & Mazor, 2015). Empirically, patients have been found to be both willing and able (David L.B. Schwappach, 2010; Unruh & Pratt, 2007) to prevent medical errors—patient involvement in their safety is associated with fewer adverse events (Weingart et al., 2011), and fewer medication errors (Longtin et al., 2010). In addition, patients are able to identify a range of error types (Harrison et al., 2015; Prey et al., 2018; Unruh & Pratt, 2007; Wilcox et al., 2016), including problems with hospital care that may not be in the medical record (Weissman et al., 2013).

Given the potential for higher patient engagement to improve outcomes for patients and help them prevent medical errors, it is imperative for us, as HCI researchers, to use our skills to

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[4] From Hippocrates's *Aphorisms*. Best known in Latin as *Ars longa, vita brevis, occasio praeceps, experimentum periculosum, iudicium difficile,* in Greek *Ὁ βίος βραχύς, ἡ δὲ τέχνη μακρή, ὁ δὲ καιρὸς ὀξύς, ἡ δὲ πεῖρα σφαλερή, ἡ δὲ κρίσις χαλεπή*, in English *Life is short, the art long, opportunity fleeting, experiment treacherous, judgment difficult*. (Hippocrates of Cos, 1931) In other words, it is impossible for clinicians to learn everything about their craft.

devise technologies that can help patients engage with their care and speak up to clinicians when they suspect an error. In this dissertation, I investigate patients' and caregivers' needs for technologies to help them engage with their care, and the kinds of technologies that could help them feel more motivated and empowered to speak up if they suspect a medical error or detect another quality issue in their care. I give an overview of this dissertation below.

1.1 DISSERTATION OVERVIEW

In this dissertation, I explore the following research questions:

RQ1: What does engagement in the hospital look like from patients' and caregivers' perspectives? As will be described in more detail in Chapters 2, existing models of patient engagement have generally not been devised for the hospital context, where the burden of care is split differently between patients and clinicians than in the outpatient context. In this dissertation, I will explore how patients and caregivers wish to participate in their care in the hospital, and what factors impact their ability to engage as they desire.

RQ2: How does the clinician-patient relationship impact patients' and caregivers' willingness to engage in safety behaviors in the hospital? In the hospital environment, patients and caregivers are dependent on clinicians to a much greater extent than in the outpatient context, and interact with them much more frequently. My second research question explores how different aspects of the relationship patients and caregivers have with clinicians impact people's willingness to engage with their care, in particular as regards to safety-related behaviors like seeking out information about care and speaking up about problems.

RQ3: How we can design technologies to help patients and caregivers in the hospital engage with their care and safety? I explore patients' and caregivers' needs for the design of technologies to support them in engaging with their care in two different ways. In the first, I investigate patients' and caregivers' perspectives on how they can engage with their care by *collaborating* with clinicians to monitor the patient's condition and keep track of care-related activities. In the second, I uncover patients' and caregivers' perspective on what kinds of technologies would help them feel more comfortable engaging with their care by *confronting* clinicians about issues and errors that arise in their care—in other words, by speaking up about their needs and concerns. Both kinds of engagement are vital for achieving better outcomes and preventing medical errors.

1.2 DISSERTATION STRUCTURE

This dissertation will contain 6 chapters. In this thesis, there is no dedicated related work section. Instead, related work is presented in each chapter as it pertains to the study described therein. Each chapter presents the methods and findings of a study or studies designed to explore one of the research questions listed above. All studies took place with hospitalized patients and their caregivers at two hospital sites: Seattle Children's Hospital, which treats primarily pediatric patients, and Virginia Mason Hospital, which treats only adult patients. Because all participants discussed in this thesis were hospitalized patients, I frequently use the word 'patients' rather than 'inpatients' or 'hospitalized patients', for simplicity. I summarize the contents of each chapter below.

Chapter 1 is the introduction you are reading now.

In Chapter 2, I describe work relating to RQ1. I summarize related work pertaining to models of patient engagement, and describe the methods and findings of a semi-structured interview study aimed at understanding patient and caregiver perspectives on their engagement with their care. I illustrate how patients and caregivers envision themselves working together with the care team by assuming a number of different roles in their care, and how individual patients and caregivers engage with each of those roles to varying degrees. I cover what factors impact patients' and caregivers' willingness and ability to engage with their care, and discuss the resulting implications for the design of patient-facing technologies to promote engagement with care.

In Chapter 3, I describe work relating to RQ2. I summarize existing literature about patient safety behaviors and the influence of the clinician-patient relationship on those behaviors, and describe the methods and findings of two studies aimed at understanding how different aspects of that relationship impact patients' and caregivers' willingness to engage in safety behaviors. I describe how different aspects of the clinician-patient relationship encourage or discourage patients and caregivers to engage in safety behaviors, and the resulting implications for the design of patient-facing technologies.

In Chapter 4, I describe work relating to RQ3. I summarize existing literature on patient-facing informational interventions, as well as on clinician-patient collaboration over patient-generated data. I present the findings of a low-fidelity prototype study done to understand patient and caregiver perspectives on how tools can support patient-clinician collaboration within the hospital through all stages of the personal informatics model, from decided what data should be tracked to collecting data and deciding on a course of action based on that data. I discuss the implications of these findings both for the design of patient-facing technologies in the hospital and for the stage-based model of personal informatics.

In Chapters 5 and 6, I describe additional work relating to RQ3. In these chapter, instead of exploring how technologies can support patient-clinician collaboration, I explore how patient-facing technologies can support confrontation. After describing related work about health behavior models, I examine what kinds of motivational factors influence patients' and caregivers' willingness to speak up to clinicians about issues in their care, and how patient-facing technologies can be designed to motivate patients to speak up about their concerns. Chapter 5 focuses on methodological considerations that arose in conducting the study. Chapter 6 presents findings based on interviews with patients and caregivers, and design recommendations for interventions to encourage patients to speak up in the hospital.

In Chapter 7, I summarize the key findings and contributions of Chapters 2-6. I summarize limitations on my work and discuss ideas for future directions.

Chapter 2. UNDERSTANDING PATIENT AND CAREGIVER ENGAGEMENT IN THE HOSPITAL

My first research question (**RQ1**) is: **What does patient engagement in the hospital look like from patients' and caregivers' perspectives?** How do patients and caregivers envision themselves participating in their care in this clinical environment, where clinicians have traditionally held sway? To answer this question, I used semi-structured interviews to holistically examine how patients and caregivers envisioned their *role* in their care. I found that patients and caregivers saw themselves as important members of the care team, playing not one but several different roles. In addition, I found that individual patients and caregivers varied in the extent to which they were willing to engage with each of these roles, and I uncovered several factors internal and external factors that affect people's willingness to take on these roles in their care—both internal factors like attitudes, and external factors like barriers to information access.

In this chapter, I first describe what related work tells us about patient and caregiver engagement in the hospital. I then describe the semi-structured interview study I performed, and the resulting findings about 1) the kinds of roles patients and caregivers see themselves taking on in the hospital, and 2) the factors that affect people's willingness to enact those roles in the hospital.

2.1 RELATED WORK

In this section, I present related work from health informatics and medical informatics about existing patient engagement frameworks, and explain why more work is needed to understand engagement in the hospital context. I describe work on interventions to support patient engagement, and explain why they are insufficient to fully support patient engagement. Finally, I present related work on the role of caregivers in health management and explain why caregivers should be studied alongside patients in the hospital.

2.1.1 Patient Engagement Frameworks

Much of the work analyzing the role patients play in their care has fallen under the umbrella of *patient engagement*. Patient engagement has been conceptualized in a variety of ways across disciplines (Aujoulat, D'Hoore, & Deccache, 2007; Barello, Graffigna, Vegni, & Bosio, 2014); confusingly, the phrase "patient engagement" has been applied both to organizational practices by health care organizations to seek patient input in their care, and to patient behaviors that patients themselves perform to involve themselves in their care. Indeed, in an environmental scan for the Agency for Healthcare Research and Quality, Maurer et al. (Maurer, Dardess, Carman, Frazier, & Smeeding, 2012) included both aspects in the definition of "patient engagement," calling it "a set of behaviors by patients, family members, and health professionals and a set of organizational policies and procedures that foster both the inclusion of patients and family members as active members of the health care team and collaborative partnerships with providers and provider organizations." Because my concern in this thesis is supporting patient needs and encouraging particular patient health behaviors, in this literature review I will focus on patient engagement work that deals with patient health behaviors and actions rather than with organizational policies and procedures.

Much of the patient engagement literature thus far has been situated in the context of chronic care or other conditions outside the hospital. Corbin and Strauss's description of illness work was situated in the context of people managing chronic disease at home (Corbin & Strauss, 1985). Similarly, Aujoulat et al. (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008) and Graffigna et al. (Graffigna & Barello, 2015) conceptualize patient engagement as the psychological journey patients go through in chronic illness. Patient engagement frameworks that spotlight the actions performed by patients over the course of disease management, like Gruman et al.'s Engagement Behavior Framework (Gruman et al., 2010) and Valdez's patient work framework (Valdez, Holden, Novak, & Veinot, 2015), were also created to describe patient engagement in the outpatient and home contexts and include behaviors specific to those contexts such as comparing insurance coverage options, making appointments, and self-managing health at home. Although these two frameworks include some in-clinic behaviors, such as asking providers about evidence for the efficacy of different treatment options (Gruman et al., 2010), their primary concern is the outpatient and home contexts, where patients are largely away from clinicians and able to live their lives and manage their care independently.

In contrast to the home or outpatient context, patients in the hospital are removed from their home environments, meaning they are likely to face the difficulties attendant upon "unanchored" information work (as described in (Klasnja, Hartzler, Unruh, & Pratt, 2010)). They are frequently suffering from a serious condition, and often confined to their rooms or their bed. They encounter difficulty in getting basic information about their care, such as what the schedule for the day is, when they can expect to see the doctor next (Kendall et al., 2015), and what medications they are being given (Cumbler, Wald, & Kutner, 2010). And they are expected to be "completely passive recipients" of care until discharge (Bickmore, Pfeifer, & Jack, 2009), and in at least some hospitals must cede their own responsibility for their care completely over to the hospital, even if it is something they self-manage at home (for example, Seattle Children's Hospital advises parents to promote their child's safety by not giving their child any medicine they have brought from home (Seattle Children's Hospital, 2014)). Because the hospital environment imposes such unique constraints on patients, work focusing on the outpatient environment cannot be directly extended without further examination of patient needs and behaviors in this inpatient context.

In the hospital, no generally accepted set of behaviors constitute patient engagement or participation (Weingart et al., 2011), and very little work examining what hospitalized patients themselves believe constitutes engagement. The closest existing literature is Weingart et al.'s 2011 survey of patient participation in hospital care, which characterized participation as a combination of knowledge about care, ability to find and to communicate with clinicians and informal caregivers, ability to participate in shared decision-making, and experience checking that they were getting the right medications (Weingart et al., 2011). This characterization was based off existing literature (Unruh & Pratt, 2007) and focus groups, and targeted at behaviors directly related to patient safety (Weingart et al., 2011). Carman et al.'s patient engagement framework, developed for the hospital context, describes a few specific engagement behaviors performed by patients such as communicating with clinicians, participating in decision making, and contributing to the medical record (Carman et al., 2013). However, Carman et al.'s intention was not to describe the patient view of engagement. Instead, Carman et al. took a view of engagement from an organizational perspective, focusing on how hospitals can reach out to involve patients and caregivers rather than elucidating what patients and caregivers themselves seek to own in their care. In Carman et al.'s framework, engagement is a continuum where organizations can involve patients at the levels of direct care, organizational design and governance, and policy making. Organizations can involve patients to a greater or lesser degree at each level. For instance, at the direct care level, organizations can provide information to patients about care (low engagement) or practice shared decision-making, encouraging patients to be involved in their own care (high engagement). This focus on organizational initiatives means that this patient engagement framework too fails to illuminate how patients themselves wish to engage in their care in the hospital. More work is needed to understand, from the patient perspective, what patient health behavior in the hospital environment consists of and what role patients seek to play in their care.

2.1.2 Patient Engagement Interventions in the Hospital

In recent years, researchers have begun to develop a variety of interventions to improve patient engagement in the hospital. A systematic review by Prey et al. (Prey et al., 2014) classified technological patient engagement interventions into five categories: entertainment, enhanced communication, personalized decision-support, and generic and patient-specific health information. Entertainment interventions can distract patients from pain (Baños et al., 2013; Das, Grimmer, Sparnon, McRae, & Thomas, 2005). Enhanced communication interventions include remote care tracking systems (Safran, 2003) and video conferencing support for patients and clinicians (Anthony et al., 2005).

Personalized decision support applications include tools to help patients make decisions about their care, such as a tool to help parents make decisions about their children in the NICU (Prey et al., 2014; Weyand, Frize, Bariciak, & Dunn, 2011). This type of personalized decision support tool aligns with research into shared-decision making. Shared decision-making occurs when patients collaborate with clinicians to make decisions about their care, sharing information about their preferences and values with clinicians and gaining from clinicians information about their care options to guide their decisions (Coulter & Collins, 2011), and it is one of the primary ways in which patient autonomy and independence has been traditionally been considered (Vikki A. Entwistle, Carter, Cribb, & McCaffery, 2010). Research on supporting shared decision-making has included both the development and evaluation of patient decision aids, like that described earlier, and exploration into the degree to which patients want to share power over decisions in their care with clinicians (Degner, Sloan, & Venkatesh, 1997; Redley et al., 2018).

Lastly, Prey et al. identify interventions that offer generic or patient-specific health information as two separate categories of interventions (Prey et al., 2014). Generic health information delivery interventions include videos that patients are expected to watch prior to, during, or after hospitalization (Mahler & Kulik, 1998) and more inventive interventions like an interactive novel (Yin, Ring, & Bickmore, 2012). Much of the work to support patient engagement in the hospital has fallen into the category of delivery of patient-specific information. In addition to mobile phone apps, large in-room displays, and virtual agents (Bickmore et al., 2009; Prey et al., 2014; Vardoulakis et al., 2012; Wilcox, Morris, Tan, & Gatewood, 2010), researchers have explored interactive medication tracking tools (Wilcox et al., 2012, 2016), inpatient portals and health records (Kelly, Hoonakker, & Dean, 2016; K. J. O'Leary et al., 2016; Schnock et al., 2019; Vawdrey et al., 2011; Woollen et al., 2016), and interfaces to share doctors' notes with patients (Bell et al., 2017; Klein et al., 2016) and improve the intelligibility of those notes (Hong et al., 2017).

As will be discussed in more detail in succeeding chapters, researchers have also explored interventions to engage patients with their safety. Some of these interventions have been informational, for instance by informing patients of their fall risks and safety plans (Duckworth et al., 2017). Others have encouraged patients to take certain actions, for instance to report errors (S Collins et al., 2016; Couture et al., 2015), encourage patients to ask clinicians about hand hygiene (R. Davis, Parand, Pinto, & Buetow, 2015), or engage in activities related to medication adherence and infection control (Coulter & Ellins, 2007).

This body of work represents extremely valuable progress in understanding how best to support patient needs in the hospital setting. However, these interventions have generally been targeted at meeting specific information needs or promoting specific behaviors. What is still missing from the literature is a holistic understanding of how patients themselves desire to engage in their care in the hospital, and how current technologies and structures support or fail to support them in those needs. In order to best support patient engagement in the hospital, we must deepen our understanding of what exactly patient engagement in the hospital consists of, from the patient perspective.

2.1.3 The Importance of Caregiver Participation

Much of the focus of the above literature is on patients. However, *caregivers*—friends and family members who help the patient manage their health and care—can play a vital role in care, and have the potential to assist patients in achieving good rapport and information exchanges with clinicians in clinic visits and encourage patients to participate in decision-making (Wolff & Roter, 2011). Researchers have found that patients with family caregivers are five times as likely to complete patient activation interventions after discharge from the hospital (Epstein-Lubow et al., 2014). Kaziunas et al. highlighted how in the context of bone marrow transplant, caregivers must not just accompany patients in clinical settings, but handle a large proportion of patient care after discharge (Kaziunas et al., 2015), while other researchers have emphasized how caregivers collaborate with patients in chronic condition management (Nunes & Fitzpatrick, 2015) and how these dyads navigate conflicting values (Berry et al., 2017).

These findings illustrate the importance of caregivers in a variety of health settings. In the hospital, where patients are away from their homes and may be unable to leave their beds, caregivers have the potential to take on an even greater role in care. Thus it is important to include caregivers when forming an understanding of patient engagement in the hospital. Indeed, some researchers have called for system designers to explicitly incorporate caregivers as stakeholders (Chen, Ngo, & Park, 2013). But examinations of technological support for patients have often centered on the home context, for instance by focusing on the collaboration between patients and caregivers in everyday care for Parkinson's Disease (Nunes & Fitzpatrick, 2015, 2018) and depression (Naomi Yamashita et al., 2018; Noami Yamashita et al., 2017). More work is needed to understand how best to support caregivers alongside patients in engaging with care in the hospital environment.

2.2 METHODS

To understand the roles patients and caregivers envision for themselves in the hospital, I interviewed 14 pediatric and 14 adult inpatients, together with their caregivers, at Seattle Children's Hospital (Site Y for youth) and Virginia Mason Hospital (an adult tertiary care hospital; Site A for adult). This work was done in collaboration with other members of the Patients as Safeguards research team. Both research sites are located in Seattle, Washington, and support patients from a wide, diverse geographic area. Each semi-structured interview lasted between 40-60 minutes. When a caregiver was available to be interviewed, two interviewers were present and the two interviews took place simultaneously in the same room. We conducted 60-90 minute bedside observations with each patient to understand their interactions with hospital staff. These observations occurred at different points in the day—in some cases we observed high-intensity interactions like rounds, and in others low-intensity interactions like routine check-ins with nurses. These observations formed the basis for many of our insights regarding interactions between the patient or their caregiver and the hospital team. The University of Washington Institutional Review Board and the hospital sites approved this project. Interviews included questions about how patients and caregivers sought, received, and managed information relating to their care. Bedside observation sessions were conducted by one of the interviewers and typically occurred directly after the interview, although we made exceptions to accommodate participants' scheduling constraints.

Forty-eight participants were recruited for our study, including 28 patients and 20 caregivers from the two hospital sites: 14 of the patients were from each site, and 16 of the caregivers were parents of patients from Site Y. Participants were recruited using a purposeful, maximally diverse sampling framework covering gender, age, ethnicity, medical service (medical or surgical), and complexity of medical condition. Adult participants ranged in age from 20 to 76, with a median age of 53. Pediatric participants ranged in age from 7 to 16, with a median age of 12.5. Because we interviewed only those who were in relatively stable condition, participants in our study tended to be close to the end of their stay.

While interviews were being conducted, the research group met regularly to discuss preliminary findings from the data and determine new avenues for exploration. After interviews were completed, five members of the research group coded the interview transcripts in an iterative coding process. Through several rounds of coding, the research team developed a list of tasks performed by interview participants during their stay. This list was then used by two members of the research team to code all the primary interview transcripts to explore what behaviors participants engaged in while they were hospitalized and what factors influenced their behavior. During the analysis, these two members iteratively discussed the task schema to determine how the various activities fit together into roles. Because we focused on the role of information and the informal care manager with respect to the hospital team, we analyzed patients and caregivers together because either of them could fill that manager role.

2.3 FINDINGS: PATIENT AND CAREGIVER TEAM ROLES

I organized the care-related behaviors of patients and their caregivers into five distinct roles that patients and caregivers assume when interacting with their hospital care team. These roles included **bedside monitor**, **apprentice**, **decision-maker**, **historian**, and **team manager**. Within each role, I illustrate the range of activities, contrasting participants who took a more active role in their care with those who took a less active role. I also describe the attitudes patients and caregivers expressed about their participation in their care.

2.3.1 Bedside Monitor

One way for patients and caregivers to engage with their care was to act as a bedside monitor by observing the patient's condition and reporting on it to clinicians. For most participants, clinicians coming by on rounds would ask them how they were feeling, or ask caregivers about the patient's physical symptoms like stool consistency and passing gas. Caregivers acting as a bedside monitor were able to report back. Sometimes clinicians asked caregivers and patients to keep track of particular things. For example, clinicians asked Y02's caregiver to let them know when the patient first passed gas. Y09 and his caregiver were asked to keep track of how often the patient walked around. Y13 and her caregiver had to keep track of how much water the patient was drinking to reach an ambitious goal of several liters a day. Y12's caregiver logged more than just what clinicians specifically asked for. She asserted her desire to maintain her own record of what was happening: "*If I'm in a hospital…I wouldn't rely on somebody else to keep track of things.*" Instead, she wrote down everything she needed to stay on top of the patient's care plan and progress updates:

> *"He gave us this pad when we came and I've been writing everything down - kept track of some of his vital signs, questions that I have, things that were provided to me, some lab results. So I write it down so I don't need to remember."—Y12, caregiver*

In contrast, some participants either did not keep track of what was going on with their care or logged only what they had to. For instance, A11 said, "*I can't even tell you what medicines I'm on, I just don't know*." Y02's caregiver tracked only what had specifically been requested, and relied on hospital processes for the rest:

> *"…they want to know if he passed gas so I wrote it on there at the time, the first time he did.… But if he goes to the bathroom, I don't tell them, because they just automatically know. So I haven't – I mean just the automatic things I haven't had to. But they're amazing."—Y02, caregiver*

2.3.2 Apprentice

Behaviors that patients and caregivers must learn to understand the patient's condition and administer their care comprise the apprentice role. All the patients and caregivers we spoke to had at least some interest in understanding their condition and treatment. To perform this role, patients and caregivers listened attentively to clinicians during rounds and other face-to-face interactions, actively sought out information, and took notes to track their questions and new information as needed. Some patients and caregivers did research on their own to understand the care plan and learned how to administer care to themselves or the patient.

Apprentice participants like Y04's caregiver prepared for leaving the hospital by learning how to administer the patient's care herself. Y04's caregiver, who identified herself as the patient's "*care provider"* as well as parent, asked nurses to teach her how to administer medication to the patient herself and working with them to find a routine that worked for her: *"Whoever the nurse [is] for him that day tells me their system and then helps me develop my own system."* Y07's caregiver also considered herself *"proactive in [her] kid's care"* and felt that understanding the patient's care was *"[her] responsibility.*" She involved herself in the process by doing outside research about the patient's condition:

> *"...I have pretty easy access to articles, so that is mostly how I do it. I will just Google things sometimes. But I'm a big believer in reading peer review information...."—Y07, caregiver*

Between her independent research and her understanding of the patient's treatment, Y01's caregiver became so much a part of the care team that the patient was released early:

> *"They told us to anticipate 4-6 weeks being in the hospital, so being in the hospital for 17 days is the first time they'd ever released somebody so early, but it's because they knew we knew the signs of rejection, we knew how to take care of her. They felt confident that we knew what we were doing because we'd taken an active role."—Y01, caregiver*

Y03's caregiver also described getting discharged earlier than was typical for patients in that situation because clinicians knew they could rely on her:

> *"We will be discharged – a patient gets discharged because it is an option, because they know that I'm capable. Otherwise, if you didn't know about it we would be stuck here for two weeks and it's very depressing."—Y03, caregiver*

Y12's caregiver contributed to the care team by leveraging her real-life medical training and sharing her diagnostic suspicions with clinicians:

> *"You know, because he didn't respond to antibiotics and because my husband works in a hospital ... and I'm a nursing student working in the [hospital], we thought we brought MRSA home so we were very worried about it and we were proactive in asking our questions to the intern - the rounding."—Y12, caregiver*

In contrast, some participants adopted a relatively passive approach to understanding their condition and treatment. A11, for example, was less interested in understanding his condition than in "*get[ting] done with all this and mov[ing] on with my life.*" Although he did want to understand what he needed to do for his care, "*just what I have to do to get better,*" he did not seek a deep understanding of what was happening:

> *"I like to know how my health condition is coming along over time…I just like to know what's going on at all times, even if I don't understand it. I just like to know what's going on."—A11*

A11 undertook relatively few information-seeking tasks himself, relying instead on his caregiver to seek out and track information for him:

> *"When I don't know, she's like "Well, what can you eat? What can you do?" I'm like, I don't know, Mom. She'll be like "Well, all right, I'll be back then." She'll go right out there, find a doctor or something, one of my nurses, and she'll ask them and see what's going on."—A11*

Similarly, Y02's caregiver valued clinicians' explanations of the patient's surgery for the peace of mind it gave her rather than because it felt incumbent upon her as a stakeholder: *"…it's important to understand because it takes away fear and concern."* Like A11, Y02's caregiver performed relatively few tasks related to understanding and participating in the patient's care. Although she demonstrated a stronger desire to understand what was happening than A11, she was content to leave administration of care to clinicians and not challenge it:

> *"And I'm never going to question the medications per se. I trust the doctor, but I want to understand, because there's a difference."—Y02, caregiver*

2.3.3 Decision Maker

Patients and caregivers also played a decision maker role by shaping the plan of care itself. They carried out this role to varying degrees. Participants informed clinicians about the patient's needs and customized the care plan for their time inside the hospital and after discharge. Some participants also expressed a desire to be the final decision-makers, rather than ceding control to clinicians.

Decision-maker patients like Y11 (age 12) strongly preferred to be involved in decisions about their care. As Y11 said, *"they're the doctors and stuff, but I am actually the one that's sick, so I want to have a role in it."* Other participants influenced decisions about their care by leveraging their own knowledge of the patient and working with clinicians to tailor the care plan to their needs. Y06 (age 13) and her caregiver, for instance, communicated with clinicians about how the patient's after school activities would affect the care plan, and A13 made arrangements with clinicians so that she could leave the hospital when a relative passed away. Some participants also performed outside research to inform themselves about treatment options. Y07's caregiver, for instance, read extensively about different treatment options before making a decision about her daughter's care:

> *"...a lot of parents were saying well, this is what I think, this is what I think, and I just asked our surgeon and then I also read some of the research that was mostly on the National Institutes of Health site, the pros and cons and what the research is happening around different types of procedures. So if we really wanted to, we could have flown to [city], but I just trusted that what was happening here after I talked to our surgeon was the right thing. I mean I just find what I can find online, but I try to look at things that are peer reviewed."—Y07, caregiver*

A05, a physician himself, took a leading role in all aspects of his care:

> *A05: "I looked at my CT scan before anyone else did and knew what was wrong with me before anyone else did, so kind of directed the way - I've never been not informed about what was going on. Like every time I get an X-ray, I look at it before the radiologist does."*
> *I: "How do you get access to that before they do?"*
> *A05: "I just stand up after and I look on the screen. And I talk to the techs and tell the techs what I see, if they're interested too."*

In contrast, A11, who took a less active approach to his care, stated his preference for leaving decisions about his medical care up to his physician, saying, *"Just my doctor know me and my body, so hopefully they'll take care of it. [sic]"* A02 seemed to view his admission to the hospital as a surrender in which he ceded control of his health temporarily over to others:

> *"Coming in this time, I was just really ready to listen to what they were telling me because I knew there was something that was out of my control, something that I needed to let somebody else take care of and listen to what they were saying ...."—A02*

A06 also viewed his time in the hospital as a time to yield decisions about his health to physicians:

> *"...after our discussion he determined that he'd like me to stick around for a while and be treated here, more closely monitored than leaving me to my own devices at home, which I felt was a really good decision on his part. I know what to do, but I don't always do what I'm told."—A06*

2.3.4 Historian

Another way for patients and caregivers to interact with the hospital care team was to assume the role of historian and act as a backup information repository for clinicians. Historians would provide information to clinicians when their own knowledge base fell short.

Active historian participants contributed information about the patient's history proactively, as when Y02's caregiver informed nurses about the patient's pain medication preferences. Y02's caregiver stressed her trust in clinicians while recognizing that her own knowledge of the patient would sometimes be relevant for his plan of care:

> *"I do trust what the doctors are deciding for him, but I need to understand and know what he's getting, because I also know previous history with him."—Y02, caregiver*

Y11's caregiver expressed a much more wary attitude towards clinicians, which seemed to lead her into this active historian role. When explaining that the patient had an allergy to a particular medication, she described her vigilance to clinicians' awareness of this reaction:

> *"So if we didn't hear like "oh, he has this going on," I try to keep them from giving him something we don't know why - maybe they just didn't communicate if something else is going on that needs treating that we don't know about."—Y11, caregiver*

At this highly engaged end of the spectrum, Y11's caregiver proactively monitored clinicians to make sure they had all the information they needed when constructing a plan of care.

In contrast, some participants adopted this role passively, contributing information only when explicitly asked. A11, for instance, received a heparin shot unnecessarily because he did not know what it was when it was administered, an error which could have been fatal. He reflected later that if he had known, he could have told the nurse that he did not need the shot:

> *"Like the heparin shot, I wish I would have known I was going to get that this morning, I would have told her 'I don't need it, I already have a drip, I don't need the shot,' for what reason. ... Well, I already knew I had the drip, that's why it was in my head, I'm thinking like, why did I just get a heparin shot when I had the drip? I just didn't understand at all. I asked the lady and my mom went out there, like 'why did he get the shot?' and they were like well, it was a mistake, he wasn't supposed to get it."—A11*

Another caregiver described having to provide information about the patient's medication to a clinician within the hospital. The clinician did not know what medication the patient needed, even though they had seen the patient previously:

> *"Yesterday one of therapists actually asked me how one of her inhaler medications worked which I thought was odd, we had him last year."—Y03, caregiver*

2.3.5 Team Manager

Patients and caregivers sometimes acted as team managers, both for clinicians and for their own party. Patients and caregivers acted as team managers when they helped operations run smoothly, communicated patient needs to clinicians to keep patients happy, and coordinated among clinicians. As discussed in other work (Miller, Mishra, et al., 2016), collaboration between patients and caregivers could be quite complex. Patients and caregivers had to find out each other's needs and limitations to form a functioning care team. Tasks related to improving life in the hospital comprised another aspect of this internal management. Patients and caregivers worked together to improve the patient's quality of life within the hospital, as when Y03's caregiver requested a day pass so that she and the patient, who was in isolation, could leave the *"depressing"* room for a time. In some cases, caregivers were more engaged with the care than the patients were, as in the case of A11, who relied on his caregivers to perform almost all the information management tasks for his care, saying, *“it’s always been better for me if somebody’s always there with me.....”* Caregivers acted as team managers for almost all juvenile patients. One exception to this was Y10, who declared that the responsibility of knowing about his care was *“100 percent mine and 100 percent theirs [his parents’].”*

On the adult side, participants like A01 saw it as his role to understand everything that happened, and was displeased when he felt that clinicians had not fully informed him of updates to his care plan:

> *“If you know something that has to happen or if you know something's happening, if you don't tell me, I have a real problem with that. This is my healthcare, not yours that you're talking about.”—A01*

A01 compared learning about his care to managing a team in the workforce:

> *“Having people work for you who are not straightforward with you is not really good. You've got to manage your team. If you don't manage your team, it can backfire real quickly. You can't have a loose cannon out there.”—A01*

With this attitude, A01 did extensive research on his clinicians as well as his condition before coming to the hospital, looking up their histories to assess their qualifications:

> *“I did a lot of research, which I think people should do. And he was surprised how much research I had done on him and the hospital. ... You need to know about your healthcare. Actually, when I explained about his life, he said, "Where did you get that from?" I was like, well, I got it. And how many surgeries .... being in the same hospital for 19 years shows he's stable which is a good sign too .... that's some things I take, I look at experience.”—A01*

A13, who also considered herself an active participant in her care, described her role as the nexus point between different clinicians who had to work with them all to put things together:

> *“Well, I’ve got nephrologists and gastroenterologists and a hematologist now and all of them kind of have a slightly differing opinion about kind of where I ought to be, and I know where I usually am, but we had the thyroid out and that’s going to change things around a little bit. ... and I have to figure out sort of the best logical progression to do that, and that’s going to be kind of a team thing too, between all the specialists and hopefully a new primary doctor that I’ll be getting lined up too. So it’ll be getting back on the rails, it’s just doing it in the right way.”—A13*

A13 also saw it as her role to learn enough about hospital structures to help things run smoothly and efficiently. She made a point of learning to navigate hospital structures and identify the different expertise areas of different clinicians so that she could help the process along by better targeting her questions:

> *"...because I know I'm not dealing with gods, they don't know everything, and everybody has their specialty and that's part of why they're here. They can't know everything. So if I can facilitate my care by knowing which question needs to land with who, that's always helpful."–A13*

At the low end of engagement, participants like Y02's caregiver were content to let clinicians run the show as they saw fit:

> *"I trust that they have systems and procedures and policies in place, that that's all taken care of. I don't need to know when that is. .... part of that is with me managing people in the business world, I don't micromanage so I just know people have their responsibilities and they do it. I think it would be time consumption for them to have to explain to me what each of their responsibilities are."—Y02, caregiver*

2.4 FINDINGS: FACTORS THAT INFLUENCE ENGAGEMENT IN THE HOSPITAL

This study illuminated several factors that influence patients' and caregivers' willingness to engage with their care in the hospital. Below I discuss how patients' and caregivers' attitudes towards partnership and their perceptions of their relationship with clinicians affected both their behavior and their understanding of medical terms. I also discuss barriers to engagement, such as lack of access to outside resources and clinicians who ignored information from patients and caregivers.

2.4.1 Patient and Caregiver Characteristics that Influence Engagement

Patients' and caregivers' engagement in their care varied. Below I discuss how patient and caregiver attitudes towards partnership, their relationship with their clinicians, and their understanding of medical jargon influenced their engagement in their care.

2.4.1.1 Attitudes Towards Partnership

Participants who were very active in their care viewed themselves as partners in delivery of their care and took more ownership of decisions than less active participants. Y12's caregiver described her stance on patient involvement, saying, *"...as a patient you're not just a receiver, you're part of the healthcare team, actively making a decision .... you're not receiving care, you're participating in it."* Similarly, Y14's caregiver expressed her desire to make decisions about her child's care by stating: *"I want to be able to take a pick and say this is what works for our lives and our family and her, what I feel she would do the best with, the best outcome."* Y01's caregiver stated that patients and caregivers sometimes had more authority than clinicians:

> *"Their [clinicians'] opinions are not always the most important. That our opinion as parents and knowing them out of the hospital setting is just as important as what their opinion is. On some matters. On some things, yes, they have the authority and we don't."—Y01, caregiver*

As previously described, A13 was proactive in learning who she should direct her questions towards because she knew that her clinicians had human limitations. She felt it was her responsibility to help out where she could.

By contrast, participants who took a less active role saw themselves as ceding control. For instance, as mentioned earlier, A02 saw his admission to the hospital as a surrender, stating that he *"felt it was time to, like they say, put the cotton in your mouth and open the ears.... I thought it* *was time to listen to others."* A11 distinguished between his personal values and what was needed for his care, and saw the former as irrelevant:

> *"See, to me it's a difference about what's most important to me and what I need. ...the doctors don't care about what's important to me, it's just what I need to go through, I need to do. ...what needs to happen is important instead of what I want or need."—A11*

In some cases A11 preferred to not even to know the details of what might happen:

> *"They didn't really give me a book, they just really told me everything, which I wish they wouldn't have. I feel like half the stuff they told me that was probably going to happen that I was so terrified about didn't happen, wasn't going to happen, probably. They told me my legs were going to swell up and stuff like that, and it never happened. So I'm just like whatever. I wish they just kept their mouth shut or be like "well, you're going to be sore," all right, I can deal with that."—A11*

For some participants, this cessation of control was based in absolute trust. Y02's caregiver, for example, described her tolerance when clinicians rescheduled her son's surgery without notifying her:

> *"...we thought we were going to go in and have surgery right away, but then we didn't - that's probably the only thing that communication wasn't really, we didn't know why we didn't have it but I trusted them .... I knew that they would never put him in harm. I truly felt that way. Otherwise I would have asked."—Y02, caregiver*

Many of our pediatric participants seemed content to rely on their caregivers. However, some felt equally responsible for their care: as described before, Y10 felt that the responsibility of knowing what was needed for his care belonged equally to him and to his parents.

2.4.1.2 Relationship with Clinicians

Participants were also influenced by how they perceived their relationship with their clinician. This finding echoes other findings in the literature suggesting that patients are reluctant to perform tasks they see as challenging the clinician's judgment or behavior (Hibbard, Peters, Slovic, & Tusler, 2005a). For example, A03 was concerned about appearing impolite to her clinicians when asking them questions:

> *"I usually think about it. ...is it that important to bother them? Or something that worries me, then I want to ask them and try to be polite as possible. If they look like they're too busy, they're walking fast or they're behind, I don't ask."—A03*

Another participant felt that she walked a narrow line in holding her ground with physicians without crossing social boundaries of good behavior, and rather than speaking up to her clinician, she switched physicians when she felt they were dismissing her:

> *"Like the one hospitalist – well, I guess a creatinine of 3 is your new normal. See ya. Check out. And I mean, I was actively vomiting and stuff, the nurse there wanted to keep me, but I didn't want her to get in trouble for countering the doctor, and so I went ahead and left and I wound up up here in worse shape than I left [other hospital] in..."—A13*

At times the patients' faith in their own ability to take care of themselves or their child influenced their relationship with their clinicians. As discussed earlier, A02 ceded control of decisions about his health over to physicians because he felt he had made bad decisions in the past. By contrast, Y14's caregiver described struggling with feeling less authoritative than clinicians, but decided that she needed to be involved nonetheless: *"Sometimes I have to remember this is my child, I need to be an advocate for her and speak up, because I always feel like well, maybe they went to school for longer..."* Y03's caregiver, on the other hand, felt confident in her ability to participate actively in creating a care plan:

> *"... I want to agree and say what I think, and be listened to because I have read up, I do know a lot about what's going on with my family and the primary care person..."—Y03, caregiver*

2.4.1.3 Understanding of Medical Jargon

Patients and caregivers struggled to understand their care when they could not understand medical jargon. Y13 commented that she wished she had *"a sheet with all the words and their meanings at the very beginning so that you'd know what they're talking about."* Y04's caregiver encountered difficulty learning about the patient's condition and treatment both from medical jargon and from her own feelings of being overwhelmed. In fact, Y04 burst out laughing at the idea of getting information only at a time when she could focus, explaining how clinicians over time developed the ability to tell if she could handle new information or not:

> *"...we've been here for so long, they've gotten to the point where they could tell if I was having a good day or a bad day. So on days where they could tell I was having an okay day, they knew they could cram a lot of information in (laughs) and then they knew there were days where I was more emotional and they probably weren't going to get anything past me."—Y04, caregiver*

2.4.2 Barriers to Patient and Caregiver Engagement

Patients and caregivers' ability to engage with their care was limited by several external factors. Scheduling constraints limited patient and caregiver ability to be present for interactions with clinicians. Paywalls limited their access to research in outside resources. Patients and caregivers were also stymied when clinicians ignored or lost the information they offered, or did not inform patients and caregivers of new developments at all.

2.4.2.1 Being Present

Simply being present for verbal interactions with clinicians was a challenge for some participants (see also (Miller, Mishra, et al., 2016)). Y06's caregiver, for example, described a time when they avoided leaving the room out of fear of missing an encounter with a clinician:

> *"Well, I think one time we were in class and the nurses came looking for her, but then they were like "Go for a walk!" and I thought okay, I'll take her for a walk, and then I thought what if someone's looking for her? Like we don't know when people are coming. So we just stayed."—Y06, caregiver*

2.4.2.2 Lack of Access to Outside Resources

Patients and caregivers encountered obstacles in doing outside research about the patient's condition. In some cases, this was because they needed highly personalized information, as in the case of Y06, who did not do much outside research because *"they said every diabetes is different* *for each person so you look it up, it's more general."* Other participants encountered obstacles in accessing high-quality sources. Y13's caregiver encountered difficulty trying to access information and was only able to get it with her clinician's help:

> *"It's not easy, it's almost like they're hidden or something, or they want you to jump through a bunch of hoops to get them. There's been a couple of articles where ... I want to read this article and I can't get my hands on it. ... her urologist gave me a big paper on reflux .... So yeah, he gave me a big stack of like three different ones that I asked him for and I got those from him."—Y13, caregiver*

2.4.2.3 Lost Information

Even proactive patients and caregivers were stymied when clinicians ignored them. One caregiver described noticing that the patient's temperature had risen and notifying the nurse that the patient had a fever. The nurse dismissed the caregiver's concerns, and the next morning the patient's temperature had risen by four degrees. Y08's caregiver had learned through experience that clinicians had to cause the patient discomfort to draw blood because the patient was such a *"hard stick"*, but that the patient could tolerate the pain. She described trying to tell this to clinicians who ignored her, saying, *"I don't think people believe me when I say she can tolerate a lot of pain..."* Similarly, A13 described how clinicians ignored her medical concerns and treated her as a drug seeker:

> *"At the risk of being a total cat here, it really didn't seem like it was being taken very seriously in [place], to be perfectly honest. They were just kind of treating me like a pill chaser and sending me back out the door when I would show up at the emergency room..."—A13*

Providing information to clinicians was also complicated when information that had previously been communicated was lost at shift changes, placing an extra burden on patients and caregivers to inform clinicians of their needs all over again. For instance, Y02's caregiver had specific requests for how to administer pain medication to her child, but a shift change occurred before it was time to give the patient his pain medication. Although the caregiver had made her request earlier, she did not remind the new clinician of her preferences, and the pain medication was administered contrary to her wishes.

Patients and caregivers also ran into difficulty when information was not passed on to them that they needed to respond to. As described earlier, A11 received an extra dose of a drug because of such a communication breakdown, an oversight that could have been fatal.

2.5 DESIGNING TO MOTIVATE AND SUPPORT PATIENTS AND CAREGIVERS IN THE HOSPITAL

These findings show that patients and caregivers possess a variety of attitudes towards participating in their care by performing different roles, encompassing different health behaviors. Because patients and caregivers have different levels of interest, designers seeking to engage inpatients in their care should explore ways to motivate patients as well as to support them in performing care-related tasks. Below I discuss how patient-facing systems can support patients in each of the roles I have identified above.

2.5.1 Supporting the Bedside Monitor Role

Patient-facing systems can support the bedside monitor role both by suggesting to patients what they can track and by facilitating the act of tracking. Previous outpatient research has suggested that setting actionable goals encourages behavior change (Medynskiy, Yarosh, & Mynatt, 2011). Previous work has also found that goals assigned by a system can be as effective as goals chosen with the patient's input, as long as the goals' purpose is clearly conveyed (Locke & Latham, 2002). Researchers have investigated the role of setting actionable goals in behavior change technologies for the wellness sphere (e.g. (Consolvo, Klasnja, McDonald, & Landay, 2014; Consolvo, Mcdonald, & Landay, 2009; Lau, Lau, Wong, & Ransdell, 2011; Munson & Consolvo, 2012)).

This technique could also be applied in the hospital context to motivate patients and caregivers to engage in the bedside monitor role. In the hospital, a system could prompt patients and caregivers to keep track of what medication the patient receives, the patient's vital signs, the consistency of the patient's stool, or other elements of the patient's condition or care. Suggestions should be customized to the patient's condition, so that patients and caregivers are only prompted to keep track of relevant symptoms.

Systems should also support patients and caregivers in performing these tracking activities. For example, systems could provide instructions on how to track an important clinical sign or symptom, such as stool consistency using the Bristol stool scale (Lewis & Heaton, 1997). Such a system would teach patients what to look for and give them language to describe the patient's output to clinicians (Riegler & Esposito, 2001). Systems should also physically facilitate logging. Data should be easy to enter and retrieve; the process should also be readily interruptible, because patients and caregivers could be distracted at any moment.

2.5.2 Supporting the Apprentice Role

Patient-facing systems should assist patients and caregivers in learning about the patient's condition and care, including general information about different procedures and statistics. For example, a system could show both lab results and explanations as to what is within a normal range, what would be expected for the patient based on their current condition, what the patient's levels mean, etc. The system could also help patients learn medical jargon, for example by offering a glossary like what Y13 requested.

As with the bedside monitor role, suggesting actionable goals to patients and caregivers could motivate them to perform specific tasks, in this case learning new behaviors. Although Y04's caregiver took it upon herself to learn how to administer the patient's medications, not all patients and caregivers were so proactive, as discussed above. A system that suggests specific goals like learning to administer medications or understanding particular procedures could motivate patients and caregivers to further their understanding of the patient's care. Such a system could also educate patients and caregivers about the potential benefits of increased patient engagement, such as better medical outcomes or early discharge date, to motivate them to learn more about their care.

To accommodate patients and caregivers with different levels of medical knowledge, systems should also offer graduated levels of information, or links to outside resources for users interested in gaining more in-depth knowledge. Although some resources still require payment for access, a curated list of reliable resources would help patients determine which resources are worth expending effort or money to reach.

2.5.3 Supporting the Decision-Maker Role

Recommendations to support the apprentice role would also apply for the decision-maker role, because a certain level of knowledge of the patient's condition and care is necessary for helping to make decisions. The decision-maker role builds on this knowledge to proactively work with clinicians in shaping the care plan. In order to support this role, systems need to encourage patients to think of themselves as active partners rather than passive recipients of care. Patient-facing systems can cultivate this attitude in a variety of ways, for example by reminding patients at key decision points that they ultimately have the final say in what happens to them. Systems should also remind patients that their own knowledge of their habits and environments outside the hospital could be important for shaping the care plan or recovery plan, and that discussing these topics with their hospital care team could improve their ability to adhere to the plan both inside and outside the hospital.

As discussed earlier, anxiety about offending clinicians can inhibit patients and caregivers from speaking up. Because of this possibility, clinicians should be involved in the design process. Their support for patient engagement in shaping the care plan could both encourage patients and caregivers to participate actively and reduce the potential for clinicians to ignore patient and caregiver input. One way to cultivate a sense of partnership in patients and caregivers is to place them on an equal footing with clinicians in their meetings. A shared space where patients and caregivers could set a shared agenda for their meeting times would indicate to patients that they too have control of the conversation, as suggested in Unruh et. al (Unruh, Skeels, Civan-Hartzler, & Pratt, 2010). Designers could also enable patients and caregivers to notify clinicians about blocks of time when they intend to be out of the room, giving them more control over when meetings happen and saving fruitless trips to empty rooms for clinicians.

Designing to allow for asynchronous communication and remote participation, suggested in other work as a solution to overreliance on verbal information transfer (Miller, Mishra, et al., 2016), could also help patients and caregivers feel less concerned about bothering their clinicians. A13 used email for this purpose:

> *"They have the [patient portal] with the email and stuff? And I love that, because I can hit them up with a question and they can kind of take their time getting back to me if they have ... something they need to deal with .... so I have a vehicle that I can do that with, with the email and things like that, and that's really helpful."—A13*

2.5.4 Supporting the Historian Role

Cultivating an attitude of partnership would also support the historian role, because it would remind patients and caregivers that they too have valuable information to contribute. However, designers could specifically support patients and caregivers in this role by educating them about how their contribution of information about the patient could help prevent medical errors. As with the decision- maker role, explicit clinician support could be invaluable in supporting active participation from patients and caregivers because anxiety about annoying clinicians can inhibit patients and caregivers from speaking up.

Designers should also consider ways to support patients and caregivers in proactively communicating with physicians about things pertinent to their care. For example, designers could provide templates for checklists of information that patients and caregivers would want to communicate to clinicians. These lists could be accompanied by notifications of clinician discontinuity to inform patients and caregivers when they need to be on the alert for potential information loss.

2.5.5 Supporting the Team Manager Role

Designers can support patients and caregivers in coordinating their care between clinicians by helping them understand the hospital structure. Patient-facing systems should include the names and roles of members of the hospital care team, together with enough information about the organizational structure to help patients understand how the team members interact. Systems could support patients even more by helping them identify which team members are best suited to answer their questions. In general the more patients and caregivers understand about how information flows between team members at the hospital and how decisions about care are made, the more able they will be to coordinate care between clinicians, be on the lookout for things that might go wrong, and identify the right person to ask their questions of.

2.6 LIMITATIONS AND FUTURE WORK

Communication and collaboration with clinicians is the heart of patient engagement, and no system can be complete without clinician involvement. Future work should explore the role of clinicians in supporting patient and caregiver engagement in the hospital. Because inpatients are heavily reliant on clinicians for even the most basic needs, clinician support for any patient engagement system is essential. Future work should also explore the limits of patient engagement. Relinquishing control can at times be beneficial for patients, comprising an important part of coming to terms with and managing illness (Aujoulat et al., 2008). Additional work is necessary to understand how best to support the full range of strategies patients and caregivers use to manage their health.

Although we sampled as broadly as possible with our interviews, we were limited to participants who agreed to speak with us. These participants could have been more engaged than average with their care. Additional research could uncover the motivations and behaviors associated with low patient engagement. This selection bias could have been especially pronounced at the children's hospital site because we only interviewed patients whose caregivers were there to give consent and participate in the interview.

2.7 CONTRIBUTION

In this chapter, I describe patient engagement in terms of the roles patients and caregivers assume in their care. Patient engagement in the hospital is presented as highly collaborative, as patients and caregivers essentially act as part of the care team. I illustrate how individual patients and caregivers can vary in the extent to which they engage with their care, and describe factors that influence engagement such as information loss and patients' and caregivers' attitudes towards partnership. I offer design recommendations to encourage patients and caregivers to take an active role in their care. In the next chapter, I will more deeply explore how the clinician-patient relationship influences patients' and caregivers' willingness to engage in their care—specifically, in their safety.

Chapter 3. THE CLINICIAN-PATIENT RELATIONSHIP AND PATIENT AND CAREGIVER ENGAGEMENT WITH SAFETY BEHAVIORS IN THE HOSPITAL

As reported in Chapter 2, patient and caregiver engagement is partially driven by concerns about how engaging with care will impact patients' and caregivers' relationship with their clinicians. In this chapter, I more deeply explore this dynamic to explore **RQ2: How does the clinician-patient relationship impact patients' and caregivers' willingness to engage in safety behaviors in the hospital?** To investigate this question, I conducted a series of interviews with patients and caregivers in the hospital, in both adult and pediatric settings. Below I describe how different aspects of the clinician-patient relationship inhibited or promoted patient and caregiver behavior in the hospital. In particular, I focus on behaviors related to patient safety. I count as related to safety any behavior related to information-seeking about care or care schedule, communicating problems to clinicians, and actively monitoring and involving oneself in care. I discuss the implications of my findings for the design of patient-facing safety technologies in the hospital. My findings suggest new possibilities for how patient-facing information technology can help patients prevent medical errors.

3.1 RELATED WORK

In this section I describe why and how patients have thus far been expected to engage in safety behaviors while in the hospital. I illustrate how the clinician-patient relationship influences safety behavior in patients, and explain why further study is needed to understand the complex influence of this relationship on patient and caregiver behavior.

3.1.1 Involving Patients in Safety

Since the publication of To Err is Human (Institute of Medicine, 1999) and Crossing the Quality Chasm (Institute of Medicine (US) Committee on Quality of Health Care in America, 2001), healthcare organizations and researchers have invested heavily in the prevention of medical errors. In addition to improvements in clinical structures and workflows, researchers have begun to investigate the role patients can play in preventing errors (David L.B. Schwappach, 2010; Unruh & Pratt, 2007). This movement has gained momentum in recent years as researchers have found that not only are patients willing to participate in their own safety (David L.B. Schwappach, 2010), but patient involvement in their safety is associated with fewer adverse events (Weingart et al., 2011), and fewer medication errors (Longtin et al., 2010). Patient engagement more broadly is associated with shorter lengths of inpatient stays (Charmel & Frampton, 2008) and better patient self-management (Mosen et al., 2007). Yet the prevalence of medical errors remains high—according to some estimates, the third leading cause of death in the United States (Makary & Daniel, 2016). Thus, we urgently need to understand how to develop new interventions that involve patients in their own safety.

To safeguard themselves against medical errors, patients are generally encouraged to engage in specific behaviors. First, patients are encouraged to make sure their health care institution is accredited (The Joint Commission, 2018b). Before and during hospitalization, safety initiatives typically suggest that patients seek out information about their care, including information about procedures and medications (AHRQ, 2017; Duckworth et al., 2017; The Joint Commission, 2018b). During hospitalization, patients have also been encouraged to make sure that information is properly communicated to and from providers (David L.B. Schwappach, Frank, & Davis, 2013), ask questions and speak up if they notice anything amiss (AHRQ, 2017; The Joint

Commission, 2018b), bring along an advocate (The Joint Commission, 2018b), participate in medical decisions (The Joint Commission, 2018b), attend to both clinicians' (nurses, doctors, or technicians) and their own hand hygiene (Landers, Abusalem, Coty, & Bingham, 2012), help mark the surgical site (DiGiovanni, Kang, & Manuel, 2003; David L.B. Schwappach, 2010; Weingart et al., 2011), and report errors (Couture et al., 2015; Weingart et al., 2011). Overall, these actions describe the patient role in safety as a "vigilant monitor" (Sutton, Eborall, & Martin, 2015), where patients in particular monitor communication with clinicians (David L.B. Schwappach, 2010) and compliance with easily understood hospital protocols such as hand hygiene (Landers et al., 2012).

To perform this role, patients need access to information about their care and the system that provides it. For this reason, patient information priorities for research in patient and family empowerment have been identified as an urgent research need in patient safety (Sarah Collins et al., 2017). Thus researchers have sought to understand what patients want to know about their care (Benham-Hutchins, Staggers, Mackert, Johnson, & DeBronkart, 2017; Miller, Pollack, et al., 2016; Park & Chen, 2016, 2017; Pollack et al., 2016) and have explored a variety of interventions to help hospitalized patients access and understand information about their care, including in-room paper-based displays mimicking the capabilities of large screens(Wilcox et al., 2010), mobile apps (Vardoulakis et al., 2012), inpatient portals (Dalal, Bates, & Collins, 2017; Dykes et al., 2012, 2017; Kelly et al., 2016; K. J. O'Leary et al., 2016; Vawdrey et al., 2011; Wilcox et al., 2016; Woollen et al., 2016), and virtual nurses (Bickmore et al., 2009), although the impact of personalized information about the care plan compared to generic safety recommendations remains unclear (David L.B. Schwappach, 2010; Weingart et al., 2004). Researchers have also explored interventions to involve patients in other aspects of their safety, including efforts to design technologies—such as patient-facing interfaces to encourage patients to report errors (S Collins et al., 2016; Couture et al., 2015), a visible fall risk plan by the patient's bedside (Dykes et al., 2010), a bedside screensaver featuring a patient safety plan dashboard (Duckworth et al., 2017), a tablet application including an interactive safety module (Greysen, Khanna, Jacolbia, Lee, & Auerbach, 2014), and a visual novel to increase patients' self-efficacy in managing their stay (Yin et al., 2012). Work in this field has also investigated the potential of social support from caregivers (Miller, Mishra, et al., 2016) and peers (Haldar, Mishra, Khelifi, Pollack, & Pratt, 2017) to help patients engage with their care and safety.

These interventions have focused on getting patients access to information about their own care, but generally do not attempt to influence the clinician-patient relationship. Yet the clinician-patient relationship influences patients' willingness to engage with their safety. I summarize related work on this phenomenon below.

3.1.2 The Clinician-Patient Relationship and Patient Safety

The clinician-patient relationship has been found to impact patient willingness to engage in safety behaviors. Patients have been found to be reluctant to engage in safety behaviors that appear confrontational or that require patients to digress from the traditional patient role by questioning or challenging clinicians' judgments (Doherty & Stavropoulou, 2012; Hibbard et al., 2005a; David L.B. Schwappach, 2010). For instance, patients are reluctant to ask clinicians if they have washed their hands (Landers et al., 2012), and less willing to check that they have received the correct medication than to seek information about their care plan (Weingart et al., 2011). Perceptions of staff time pressure (Mishra et al., 2016; D. L B Schwappach & Wernli, 2011), fear of negative reactions from clinicians (David L.B. Schwappach, Olga Frank, Möller, & Wasserfallen, 2011; Rainey, Ehrich, Mackintosh, & Sandall, 2015), and the fear of being seen as a "difficult" patient (V. A. Entwistle et al., 2010) have been found to inhibit patient engagement in safety.

Researchers have explored ways to influence patient-clinician communication to improve this relationship. For example, researchers have identified specific clinician communication behaviors linked to patient satisfaction (Finefrock et al., 2018), and devised interventions such as ambient and real-time displays to improve patient-clinician communication (Faucett, Lee, & Carter, 2017; R. Patel et al., 2013). Some work has also explored patient-facing interventions. For example, one study examined how patient-reported outcome measures (PROMs) affect patient-clinician communication, and found that while PROMs (Greenhalgh et al., 2018) gave patients “permission” to raise issues with clinicians, they could also constrain the conversation or become a substitute for rather than supplement to the verbal exchange of information.

Researchers have also examined how clinician behaviors can impact patient willingness to engage specifically in safety behaviors. Studies have found that overt encouragements or invitations to participate in safety from health care providers have the potential to increase patient performance of safety behaviors (Bernstein, Potvin, & Martin, 2004; Doherty & Stavropoulou, 2012; V. A. Entwistle et al., 2010; Longtin et al., 2010). Accordingly, researchers have thus suggested that clinicians should wear buttons encouraging patients to ask them about hand hygiene (Waterman et al., 2006a), and that clinicians should present themselves as caring and attentive, not act rushed, and legitimize patients’ input with appropriate responses (V. A. Entwistle et al., 2010).

However, there is some suggestion in the existing literature that the influence of this relationship is complex. A positive clinician-patient relationship may not invariably promote patient engagement. For example, while most researchers discussing the influence of the clinician-patient relationship on patient engagement in safety stress the need to maintain a positive relationship and not erode trust (V. A. Entwistle et al., 2010; David L.B. Schwappach, 2010; Waterman et al., 2006a), one study found that trust could act as a negative influence on patient engagement in safety (Scott, Dawson, & Jones, 2012), while another found an association between clinician humility and increased patient satisfaction (Huynh & Dicke-Bohmann, 2019).

Moreover, the clinician-patient relationship itself is multifaceted, and there is no generally accepted ontology describing what this relationship actually is. Researchers have examined the clinician-patient relationship from multiple angles, including investigating how conversational patterns can contribute to an empathetic relationship (Finset & Ørnes, 2017) or indicate implicit bias (W. J. Hall et al., 2015), and uncovering how small clinician behaviors like sitting down instead of standing can increase patient satisfaction (Orloski, Tabakin, Shofer, Myers, & Mills, 2019). Eveleigh et al., reviewing 19 instruments measuring the doctor-patient relationship, found very different conceptualizations of the nature of this relationship across instruments, with some frequently occurring themes like “alliance,” including shared goals and collaboration, “empathy,” “trust,” and “relational communication” (Eveleigh et al., 2012). Given patients’ dependence on clinicians in the hospital environment, we need clarity on how different aspects of the clinician-patient relationship influence patient engagement in safety, and how the design of patient safety interventions should support that relationship.

3.2 METHODS

To investigate how different aspects of the clinician-patient relationship might affect patient and caregiver willingness to engage in safety behaviors, I conducted two interview studies with hospitalized patients and their caregivers, at a children’s hospital and an adult-only hospital in an urban setting, to understand what kinds of tools could help hospitalized patients and their family members engage with their safety. I did this work in conjunction with other member of the Patients as Safeguards research team. I describe each study below. Both studies were approved by the

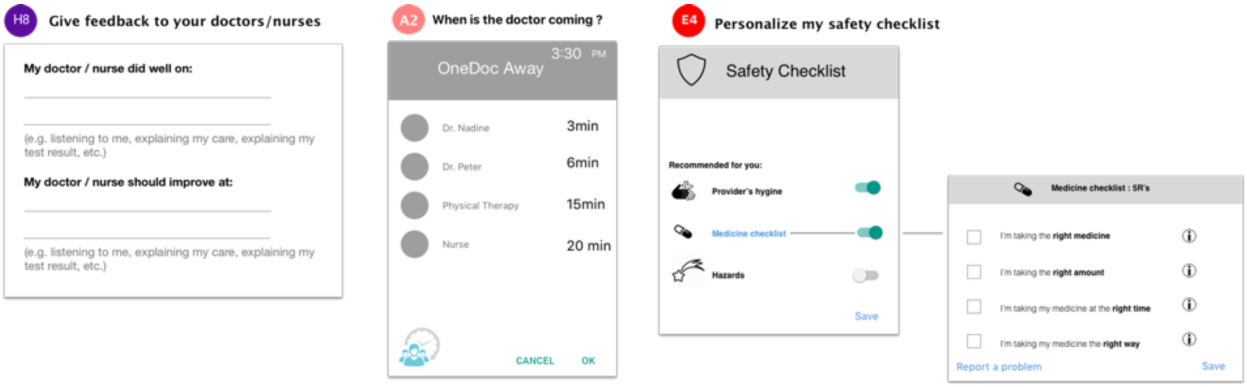
University of Washington Institutional Review Board, and in both studies, we employed a maximum variance sampling strategy to recruit patients and caregivers from different services and conditions.

3.2.1 Study 1: Low-Fidelity Prototype Interviews, “L-”

To understand how information technology could meet the needs of hospitalized patients and their caregivers, we conducted semi-structured interviews with patients and caregivers at both sites. In these interviews, we offered patients a set of “feature cards” depicting low-fidelity designs of different features that could be included in a patient-facing system. The features included communicating with clinicians, tracking the patient’s health status, and viewing information from the EHR (see Figure 3.1 for example cards). We asked patients about what features would be important, why they were important, and how they would use or change each feature. In both hospital settings, we conducted the interview with the patient, but invited caregivers present in the room to participate. In the children’s hospital setting, we also conducted 3 interviews with caregivers (L-Y13, L-Y14, L-Y15) to expand our sample. In all, we conducted 12 interviews with patients and 3 with caregivers at the children’s hospital, and 15 interviews with patients at the adult hospital, for a total of 30 interviews. Our pediatric patients’ ages ranged from 7 to 17 (mean and median age 10.5), and our adult patients’ ages ranged from 18-75 (mean 57.5, median 64). Across both groups, 15 participants were female and 15 male; 27 participants were White, 1 African-American, 1 Native Hawaiian, and 1 Asian. 3 additionally said their ethnicity was Hispanic/Latino. We did not collect information about participants’ specific conditions, but participants were recruited from a range of services including medical, hospitalist, surgery, hematology-oncology, and pulmonology. The interviews lasted 40-60 minutes each.

3.2.2 Study 2: Tracking Interviews, "T-"

To understand the needs of hospitalized patients and their caregivers to keep track of information about their care in the context of error prevention, we conducted another round of semi-structured interviews at the same two hospital sites. In Study 2, subjects participated in up to 2 interviews occurring during their stay and 1 follow up interview post- discharge. In Interview 1, we asked participants to sketch the ending to a story that starts by describing a hypothetical medical error, then we asked follow-up questions about the story they created. We also asked participants about who on their team made them feel safe and what information about their care they wanted to keep track of. If participants were still in the hospital more than 24 hours later, we invited them to participate in a second interview, where we asked follow-up questions about how their attitudes had changed since the previous interview. After participants were discharged, we contacted them by phone to conduct a brief follow-up interview, asking questions about their reflections on their stay, what information would have been useful for them to keep track of, and whether they had experienced any undesirable events during their stay. Interview 1 typically lasted 40-60 minutes; Interview 2 typically lasted 30-40, and Interview 3 typically lasted 10-20 minutes. As in Study 1, we focused our interview on the patient, but invited caregivers in the room to participate if they wanted to. We interviewed a total of 14 patients at the adult hospital and 13 patients at the children's hospital. Our pediatric participants' ages ranged from 9-17 (average age 12.9, median age 13), with 6 male and 7 female participants. Our adult participants' ages ranged from 34-78 (average age 61.9, median age 69), with 4 male and 10 female participants. Across both groups, 16 were White, 2 African- American, 2 Asian, 3 said they were another race, and 4 preferred not to answer. 3 participants additionally said their ethnicity was Hispanic/Latino. As before, we did not collection information about participants' specific conditions, but they were recruited from a range of services including medical, surgical, and rehab. Because not all participants were eligible for Interview 2 and some participants were lost to follow up, we conducted a total of 53 interviews in Study 2.



☐ I'm taking the **right medicine**
☐ I'm taking the **right amount**
☐ I'm taking my medicine at the **right time**
☐ I'm taking my medicine the **right way**

Figure 3.1. Example "feature cards" showing a way to give clinicians feedback (H8), the arrival time of the doctor to the patient's room (A2), and a personalized safety checklist (E4 and the card to its right).

3.2.3 Analysis

The interviews from Studies 1 and 2 were transcribed with identifiers removed. A member of the research team thematically coded the transcripts from both studies in an iterative process. Although the focus of these studies was initially on patients' information needs and the tools that could support them, themes relating to how patients and caregivers interacted with their clinicians arose from the data. As part of the analysis of these themes, a member of the research team held discussions with other members of the research team and iteratively coded the data to examine the role of the clinician-patient relationship in patient engagement.

3.3 FINDINGS

Overall, these studies revealed a population deeply invested in engaging with their care. However, different aspects of the clinician-patient relationship either promoted or inhibited participants' desire to engage in safety behaviors. This influence occurred even with safety behaviors that did not obviously deviate from the traditional patient role, and was exhibited by both patient and caregiver participants. Below I discuss how participants' desires to trust, keep the peace with, and protect their clinicians inhibited their engagement with their safety, while their desire to ease clinicians' burden and their sense of personal connection with their clinicians promoted their engagement. I count as safety behaviors any behavior related to information-seeking about care or care schedule, communicating problems to clinicians, and actively monitoring and involving oneself in care.

I refer to participants from Study 1 with an "L-" prefix, and participants from Study 2 with a "T-" prefix. Participants from the children's hospital are denoted with a "Y" and participants from the adult hospital with an "A". Caregiver participants are denoted with a "-C" suffix.

3.3.1 Aspects of the Clinician-Patient Relationship that Inhibited Safety Behaviors

I found that participants were discouraged from engaging with their safety due to several factors: trusting clinicians, keeping the peace, and protecting clinicians' feelings or professional interests. Sometimes these factors were powerful enough to stop participants from engaging with their safety at all; in other cases, participants reported the factor as a concern even if they acted anyway.

3.3.1.1 Trusting Clinicians

For some participants, trusting their clinicians demotivated them to perform safety behaviors. Several participants were reluctant to seek out information about their care because of their trust in clinicians. For example, T-A10 refused to look up information about his upcoming procedure online, saying, *"I didn't want to know too much and I trust the team .... that's just the way I decided to do it, because again, the bottom line is I trusted the team that they knew what they were doing."* Trust discouraged T-Y03 from tracking his medication schedule: he said, *"I don't keep track of* *too much because they do do their job around here [sic]"*. L-Y04, responding to a feature card depicting a "safety checklist" of actions patients can take to prevent medical errors, explained her lack of interest by saying, *"I feel like I trust my doctors and nurses to be taking care of that."* For one participant, trust was such a powerful influence that he said he would not act even if he had reason to suspect a medical error:

> *I: "So if you were suspecting that something is wrong and you're getting the wrong medication, what would you do to prevent that?"*
> *T-A14: "I'd just go – I mean, you've got to trust somebody. I mean certainly you and everybody that I know aren't pharmacists, so you've got to trust somebody. So yeah, I would end up primarily trusting what they said."*

My findings here illustrate how trust in clinicians, ostensibly part of a positive clinician-patient relationship, erodes patients' interest in performing safety behaviors. This influence is observed both before and during a hospitalization, and inhibits information seeking behavior, possibly the most fundamental act of patient engagement.

3.3.1.2 Keeping the Peace

Participants' desire to maintain a cordial relationship with their clinicians also discouraged or deterred action, even when the action was not obviously confrontational. In other words, participants worried about potential conflict or friction with clinicians even when the behavior was in line with the traditional patient role. For instance, T-Y08-C was so concerned about the possibility of conflict with his clinicians that he was willing to forego seeing specific information about his child's plan of care:

> *"So there's this path, there's this workflow which seems to be well documented ... . it would be nice to have that to be referred to, but I could also understand if the doctors don't want me to literally have that referred to, because at the end of the day, for them that's guidance. They still have to make their judgment based on reading the situation, and I'm sure they don't want to argue with me about like – hey, your procedure says this and why are we here? So I could also understand why it might be nice for me to know, but it doesn't necessarily change my outcome and it may end up generating more friction between me and [the clinician]."—T-Y08-C*

Participants' desires to avoid conflict with clinicians had physical and emotional impact. For example, T-A13 was so anxious to keep the peace between her and her nurse that she gave up on her own needs. Although she wanted anesthetic for a gastric tube, *"... it sounded like it was a major inconvenience. So I just figured oh, what the heck, I'll try it without. ... I didn't really want to go ahead and tick her off too much more than what I obviously did with my question."* As a result, *"I threw up a lot. It was very uncomfortable."* In another case, because of T-A12's equipment and fall risk, she and her caregiver were supposed to summon a nurse to help her go to the bathroom, but as T-A12-C said, *"I don't mind stepping in and helping them. I know it's a busy job...."* Although they knew what to do and made the trip on their own, they described significant anxiety about causing conflict with clinicians. T- A12 expressed her concern, saying, *"We're laughing, but if she'd have caught us, it wouldn't have been funny."* Both T-A12 and her caregiver felt ashamed of their own anxiety to please their clinicians, likening themselves to *"little bitty kids, afraid that Mommy and Daddy are [going to find out]"*, but nevertheless could not shake their worries about *"break[ing] their rules"* and causing conflict.

My findings here show that a reluctance to challenge or cause conflict with clinicians extends not just to more clearly confrontational behaviors like asking clinicians if they have washed their hands(3,14,49), but also to information seeking (in the case of T-Y08-C), incipient self-management (T-A12 and her caregiver), and requests for pain management support (T-A13). Additionally, patients and caregivers suffered considerable emotional and physical distress to maintain what they saw as a positive relationship with clinicians.

3.3.1.3 Protecting Clinicians

Participants also exhibited a desire to protect their clinicians' emotional or professional needs that at times interfered with their desire to engage with their own safety. Some participants were reluctant to seek out information because of these empathetic impulses. L-A02, responding to a feature card about getting second opinions while in the hospital, made a point of saying that even though he would be willing to seek out a second opinion, he would try *“[n]ot being rude or anything”*. L-A08, responding to a feature card that displayed when the doctor would visit their room, was concerned that her clinicians would be hampered in their job performance by such a tool because they *“don't ... have the flexibility to give other people more time when they need it.”* L-A04, responding to the same card, felt that although the information would be valuable to her, it would impose an undue burden on her clinicians. She voiced concern not just that her clinicians would be *“very busy”*, but that the clinician might feel uncomfortable if they could not show up as planned: *“And of course it would be awkward for him to say ‘I'm going to stop by in the morning’ because something might come up and he might not do it.”* Notably, L-A04 did desire such information about her clinicians’ whereabouts as long as it did not appear to constrain or burden them: when offered the alternative of a “marauder’s map” of the hospital—a map showing the location of everyone in the hospital—she responded positively: *“... that would answer your question and my question, like when is my doctor going to be in the area, and did he choose to come visit me during that time. That would work.”*

A couple of participants were reluctant to report undesirable events because of their concern over repercussions to hospital staff. L-A14 observed an aide not wearing gloves in a situation where he would be exposed to blood. Although she ultimately reported the incident, she *“really debated whether I should say anything because I didn't want to get him in trouble”*. Similarly, T-A12-C was reluctant to report his and his wife’s fear of clinicians’ wrath after the bathroom incident, because he *“didn't want to get any of the staff in trouble or have anybody imply that they weren't giving the care that they should be giving”*.

My findings here suggest that patients and caregivers feel so connected to their clinicians that they desire to protect them, and are at times willing to sacrifice their own information needs to do so. Moreover, patients' and caregivers' desire to protect the clinicians they work with opposes their desire to report undesirable events, meaning that problems observed by patients can go unaddressed, ultimately impacting the quality of care in the hospital.

3.3.2 Aspects of the Clinician-Patient Relationship that Encourage Safety Behaviors

By contrast, some aspects of the clinician-patient relationship encouraged participants to engage with their safety. Participants were motivated to engage with their safety by two factors: desiring to ease clinicians' burden, and feeling a personal connection to clinicians.

3.3.2.1 Easing Clinicians' Burden

Some participants engaged with their care and safety because they wanted to ease the burden on clinicians. As mentioned above, T-A12-C decided to help his wife go to the bathroom without clinician assistance because he felt they were busy and wanted to help them out by taking on a part of their duties. T-A13 likewise made a point of taking care of her own ileostomy bag, saying, *"I don't like ... causing grief for anybody, and I know that they go ahead and work hard, so if there's things that I can ... do to make their job easier, you know, I will ... do my best to do that."* Hearing a patient across the hall voicing his discontent, she took it upon herself to be an especially easy patient: *"...I ... listen to the gentleman across the hall, so I figure you've got to have somebody that's not quite that challenging."*

A couple of participants wished they could ease the burden on their clinicians by doing more research on their own but felt they did not have the resources. Responding to a feature card that would give them access to care-related information digitally in their room, both L-Y13 and L-A05 discussed how being able to look up information on their own would let them take up less of clinicians' time. As L-A05 put it, *"... I don't like bugging people all the time. I'd like a separate resource that I can look at that sort of reinforces what the staff is saying."*

My findings illustrate how patients' and caregivers' desire to help clinicians can motivate information-seeking about their hospital care and nudge patients towards greater self-management, both of which could improve patients' safety and health outcomes.

3.3.2.2 Feeling a Personal Connection

Feeling a personal connection to their clinicians enabled some participants to engage with their care. T-Y13 said they were more comfortable asking their nurses questions *"since I have known them for a few years."* T-Y02's sense of personal connection came from *"when the nurses care, like ask me questions about my life, like my siblings and stuff like that. It makes me feel more comfortable and actually want to ask them questions."* Another participant, L-A07, described how important it was to him to understand why his clinicians had decided to work in healthcare in the first place: *"to know that you have people who are just not here 8 to 5, but they're here because ... they feel good about helping. ... once you realize they are our family in a sense, these are my community, that ... would make me feel more comfortable."*

This sense of personal connection did not stem from a single source: amongst the participants it seemed to come from a sense of feeling cared for (T-Y02), a sense of clinicians as people (L-A07), or simply familiarity over time (T-Y13). Despite the elusive nature of this personal connection, these findings demonstrate its importance in patients' willingness to engage actively in safety-related behaviors.

3.4 DISCUSSION

My findings demonstrate that aspects of the clinician-patient relationship can either encourage or inhibit patient and caregiver engagement in safety. The clinician-patient relationship exists independently of technology, in the face-to- face encounters that lie at the core of medical practice. However, as information technology becomes increasingly central to the practice and consumption of medicine, designers of these technologies have the opportunity to advance the clinician-patient relationship to promote patient engagement, and to mitigate the influences that inhibit engagement. Below I discuss two ways patient-facing technologies could address these inhibiting factors and encourage patients to engage in safety behaviors by both supporting non-confrontational communication with clinicians, and framing safety behaviors as collaborative acts that reduce clinicians' burden.

3.4.1 Supporting Non-Confrontational Communication

I describe two ways to support patients in non-confrontational communication with clinicians: provision of health- and care-related information up front, and provision of alternate channels for reporting concerns and expressing needs.

3.4.1.1 Provision of Health- and Care- Related Information Upfront

Participants in these studies expressed worry about both real and potential conflict with clinicians. At times, this worry dissuaded them from seeking information about their care, even though having such information provides an important strategy in patient safety interventions. My findings suggest that patients would be more willing to learn information about their care if they felt that it was normal or that clinicians expected for them to know it. One way to set up that expectation would be for the healthcare organization to provide that information, rather than requiring patients to seek it elsewhere. For example, T-Y08-C, who was worried about conflict with his son's clinicians if he knew too much about the plan of care, might have been less worried if the hospital had provided him with information about clinical pathways directly, and thus implicitly endorsed his engagement efforts. In addition, the findings suggest that information should be provided in a way that does not appear to impose new burdens on clinicians. Just as L-A04's concern about clinicians being forced into a scheduled visit time was resolved by the "marauders' map", patients might be more accepting of new informational features if they do not feel that clinicians are being forced into anything. For example, when patients are granted access to traditionally inaccessible information, such as progress notes and other content from the EHR, patients could benefit from knowing when clinicians chose to share that information with them. If the system has an opt-out for clinicians so that they do not have to share information, like OpenNotes installations (Feldman, Walker, Li, & Delbanco, 2013), patients could be informed that clinicians have the ability to keep information private when they choose to do so, so that they know that their clinicians were not obliged or forced to reveal anything they did not feel comfortable sharing.

3.4.1.1 Provision of Alternate Channels for Reporting Concerns and Expressing Needs

My findings about participants' desire to keep the peace and their reluctance to report concerns point to the need for non-punitive communication channels. Patients should have ways to report concerns and communicate their needs where they feel confident that neither they nor the clinicians they rely on will suffer negative consequences.

This finding suggests a need for helping patients report undesirable events in a way that highlights their potential for helping clinicians improve their practice, rather than the potential for retribution. In other words, patient-facing reporting systems should stress the value of reporting to provide clinicians constructive feedback and improvement rather than punishing clinicians. One approach, adopted by Couture et al. in MySafeCare, is to allow patients to report concerns anonymously, coupled with the option to submit positive feedback (Couture et al., 2015). Another possibility is to enable patients to give private, electronic feedback, anonymous or otherwise, to the clinicians responsible for the concern. Thus, patients could give constructive feedback to clinicians without worrying about harming the clinicians professionally, and in a technology-mediated, non-confrontational way. Researchers should explore ways to support this feature while ensuring confidentiality, for instance by allowing patients to set a timer on the report, so that patients can describe the details in the moment but not submit the report until sufficient time has elapsed that they are not easily identifiable.

Patients and caregivers are sometimes concerned that voicing their needs will bring negative repercussions from the clinicians who care for them, as in the example of T-A13. To help patients and caregivers in this position, researchers should investigate whether helping patients switch providers within the hospital setting would empower them to communicate their needs without fear. Designers of patient-facing systems could set the expectation that it is ok for patients to request care from different clinicians, for instance to request a different clinician, or even to request a chance to speak with a different clinician, so that patients do not feel stuck with a clinician with whom they have a negative relationship. However, this strategy could also make patients feel as though they are going behind a clinician's back, or make them worry about harm to the clinician's professional reputation. Such strategies also impact the hospital's ability to provide efficient care. Thus, this strategy requires further investigation.

3.4.2 Framing Safety Behaviors as Collaborative Acts

I found that patients refrained from performing safety behaviors out of a desire to shield clinicians from emotional or professional injury, but that they were motivated to perform safety behaviors by a desire to collaborate with clinicians and share the load. These findings suggest that reframing safety behaviors as cooperative acts could promote patient engagement. One method I suggest exploring is to provide a shared checklist of safety-related behaviors with tasks assigned to both clinicians and patients. For example, patients could be tasked with confirming that their medication is correct or reading a brief passage about their care. Transparently assigning tasks to both parties could help cultivate a sense of teamwork between patients and clinicians, especially if participation is framed as helping clinicians and contributing to the team, rather than simply ensuring personal safety, and could facilitate conversations about safety between clinicians and patients. If self-management related tasks are included on the shared checklist, then this feature also has the potential to help clinicians monitor patients' progress towards building the self- management skills they will need when they are discharged, and to help patients build their self-efficacy for self-management. Building self-efficacy is an important part of preparing patients for discharge (Pollack et al., 2016).

Another challenge that arises from these findings is how to motivate patients to engage in their safety without damaging the trust in clinicians that discourages them from doing so. I suggest that researchers explore the potential of commitment statements to encourage patient engagement. Building on recommendations that clinicians invite patient participation and comment (V. A. Entwistle et al., 2010; Waterman et al., 2006a), I suggest framing patient engagement in care as a commitment that patients make to their care team, to engage with their safety to the extent they are able. Patients could be encouraged to commit to performing specific actions of their own choosing: for example, patients could pledge to speak up about their concerns or even commit to double-checking that they are receiving the correct medications. Researchers can use patient-facing systems both to ask patients to make these commitments and to remind them of their commitments throughout their stay. For example, patient-facing systems could send just-in-time reminders to patients of their commitments to double check that they are receiving the right medication just before medication administration time. Asking patients to commit to engaging in their safety may mitigate the discouraging influence of excessive trust in clinicians described in the findings without eroding that trust itself.

3.5 LIMITATIONS AND FUTURE WORK

Because the clinician-patient relationship influences patient engagement in complex ways, I caution that technologies built to support the motivating aspects of the clinician-patient relationship must be evaluated to ensure they do not cause new problems for people who are already engaged with their safety. In addition, I emphasize that that technologies should be used to supplement face-to-face communication, rather than completely replacing that communication.

In addition, although I describe how aspects of the clinician-patient relationship affect engagement, I do not offer a comprehensive model of the clinician-patient relationship. Future work should assess how other aspects of this relationship affect patient engagement in safety. A comprehensive model of how different aspects of clinician-patient relation affect safety behaviors in different healthcare contexts (e.g. both inpatient and outpatient settings) could be used to develop interventions to help patients participate more actively in their care. In addition, future work should evaluate the intervention techniques suggested in this chapter.

3.6 CONTRIBUTION

In this chapter, I explored RQ2: How does the clinician-patient relationship impact patients' and caregivers' willingness to engage in safety behaviors in the hospital? I found that patients were motivated to perform safety behaviors by feeling connected to their clinicians and by a desire to share workload with them, but were discouraged from performing safety behaviors by feelings of blind trust, concerns about conflict, and worries about professionally hurting their clinicians. These findings shed light on how patient-facing technologies could support the motivational aspects of this relationship while mitigating the inhibiting influence of other aspects of the clinician-patient relationship. I suggest that designing patient-facing technology to facilitate non-confrontational communication with clinicians and framing safety behaviors as collaborative acts could encourage safety engagement. These approaches have the potential to help patients to engage with their safety and prevent unnecessary harm in the hospital.

Chapter 4. SUPPORTING COLLABORATIVE HEALTH TRACKING IN THE HOSPITAL: PATIENTS' PERSPECTIVES

My final research question is **RQ3: How can we design technologies to help patients and caregivers engage with their care in the hospital?** I explore this question through two case studies. In this chapter, the first case study, I illustrate how technologies can support patients and caregivers in collaboratively tracking the patient's health and care in the hospital. As discussed in Chapter 2, patient and caregiver engagement in the hospital extends beyond receiving information about care, encompassing also activities related to communicating important facts about health and care to clinicians and making decisions about care—in other words, acting collaboratively with clinicians as part of the care team. Better technologies for patients and caregivers to keep track of their care could support patient engagement in at least some of the roles they assume as part of the care team. In this chapter, I investigate how tracking technologies should be designed to help patients collaborate with clinicians over their care, focusing on patients' and caregivers' perspectives.

As described in earlier chapters, patients who are engaged with their care have both better care experiences (Jessica Greene et al., 2013) and better health outcomes (J. Greene et al., 2015) than disengaged patients. Most definitions of patient engagement emphasize patients' awareness of their health status, understanding of their health care needs, or performance of particular behaviors (e.g. (Graffigna, Barello, Bonanomi, & Lozza, 2015; Gruman et al., 2010; Hibbard, Stockard, Mahoney, & Tusler, 2004; Mishra et al., 2016)). Thus, patient engagement necessitates patients engaging with information about their health status and treatment themselves, for example by tracking information about their care rather than relying on clinicians to track it for them.

However, in the hospital, clinicians are traditionally the only actors who collect, track, and reflect on data in the hospital. Recent work has demonstrated that patients in the hospital (inpatients) desire to stay informed about their care (e.g. (Kendall et al., 2015; Wilcox et al., 2010)), but often lack the tools to access this data to fully engage with their health information and treatment. Their inability to access this information limits their engagement in the care they receive (Benham-Hutchins et al., 2017; Irizarry et al., 2017; Mann, 2005).

Several barriers impact inpatients' access to this information. Much of the information transfer in hospitals continues to be verbal (Kendall et al., 2015), meaning patients' access to information depends on their alertness and ability to recall what was said. Inpatients also frequently face challenges in obtaining specific details about their care like their daily schedule (Kendall et al., 2015), or even who is coming into their room and when (Miller, Pollack, et al., 2016). Given the high number of hospitalizations occurring each year in the United States—more than 34 million in 2014 (Association, 2016)—it is urgent that researchers investigate how to design better tools to support patients in tracking their health and care information while in the hospital.

Many HCI researchers have studied the nature of health tracking and designed tools to support it. However, much of this work concerns everyday health and wellness. For example, researchers have examined the use of novel or commercially available systems for daily activity and dietary tracking (e.g., (Rooksby, Rost, Morrison, & Chalmers, 2014)) and tracking of daily or weekly physical activity goals (e.g., (Consolvo et al., 2008)), and health tracking in the context of chronic disease management (e.g., (Ayobi, Marshall, Cox, & Chen, 2017; Felipe, Singh, Bradley, Williams, & Bianchi-Berthouze, 2015; Mamykina & Miller, 2010)). In addition, models of personal informatics like the stage-based model (Li, Dey, & Forlizzi, 2010) and lived informatics model (Epstein, Ping, Fogarty, & Munson, 2015) have primarily been developed for an everyday context.

Yet the hospital environment differs substantially from the everyday context in which personal informatics has traditionally been studied. In the everyday context, people are largely in control of their own data and independently decide to set goals and track their personal progress towards them. In the hospital setting, patients surrender their bodies and health data to a host of doctors, nurses, technicians, and other health care providers whom they have likely never encountered before. With data locked in an electronic system that few have complete access to, patients have less access to their personal health data than they had with earlier paper-based systems (Kendall et al., 2015). In this vastly different context of control, how do personal informatics models hold up? How can we extend these models to apply in a context where the self that is being monitored might not be the self doing the monitoring?

To explore these questions, I worked with a research team to conduct 30 interviews with hospitalized patients and caregivers (e.g. parents, spouses, and other informal helpers) and engaged them in speculative design exercises. The study goal was to understand how patients in the hospital envisioned their role in monitoring their own health status and how we can design technologies to support them in tracking information about their care to support patient engagement. I found that patients desired support for collaborative tracking of their health and care in conjunction with clinicians. In this chapter, I:

- Illustrate how patients envisioned collaborating with clinicians to track their health and care through all stages of tracking (collaborative tracking);
- Discuss design implications for supporting patients in collaboratively tracking their health while in the hospital; and

- Reflect on how the stage-based model should be extended to describe collaborative tracking fully.

4.1 RELATED WORK

Here I summarize related work on information needs in the inpatient setting, and illustrate the need for better technologies to help patients and caregivers keep track of information about their care in order to engage with their care in the hospital. I also discuss work on clinician-patient interactions over health tracking outside the hospital, including the challenges that arise in clinician-patient collaboration over data and important findings in the literature about the design of technologies to support this collaboration.

4.1.1 Information Needs in the Inpatient Setting

Studies have shown that patients in the hospital essentially “want to know everything” (Benham-Hutchins et al., 2017) about their health status and care in the hospital. However, existing information sources often do not meet their information needs (Kendall et al., 2015; Park & Chen, 2017). Patients in the hospital get information about their care primarily from verbal encounters with clinicians and written notes on whiteboards. However, patients typically forget 40-80% of the information communicated in verbal encounters (Kessels, 2003), and this information cannot be reviewed. At the same time, information on whiteboards is often not up to date (Kendall et al., 2015; Sehgal, Green, Vidyarthi, Blegen, & Wachter, 2010) and only shows information that clinicians think patients ought to know, rather than information sought by patients themselves (Kendall et al., 2015). Compounding the problem, online information sources like patient portals that are frequently available outside the hospital are not always available in hospitals

(HealthIT.gov, 2015; Kelly et al., 2016), even though patients find them valuable (Kelly et al., 2016; K. J. O'Leary et al., 2016; Woollen et al., 2016).

Interventions offering patients personalized information about their care, as well as interventions supporting advanced modes of patient-clinician communication, have been identified as important areas of research in patient engagement (Prey et al., 2014). Researchers have begun to explore new techniques to inform hospital patients about their care and about what to expect in the hospital (Bickmore et al., 2009; Haldar et al., 2017; Miller, Pollack, et al., 2016; Prey et al., 2014; Skeels & Tan, 2010; Vardoulakis et al., 2012; Vawdrey et al., 2011; Wilcox et al., 2010), as well as exploring design requirements and strategies to help patients and caregivers work together to exchange care-related information (Hong, Wilcox, Machado, Olson, & Simoneaux, 2016; Miller, Mishra, et al., 2016). However, between receiving information and communicating about it lies a crucial step: tracking information. Valdez et al. recognize tracking as an important part of patient work (Valdez et al., 2015), and researchers have begun to explore the potential of tracking support tools in this space (e.g. (Wilcox et al., 2016) and others reviewed in the discussion section). However, tracking remains a difficult task for patients in the hospital. Kendall et al., surveying patients' and caregivers difficulties in tracking information in the hospital, found that members of both populations struggled with tracking changes in symptoms and questions for the care team (Kendall et al., 2015). Benham-Hutchins et al., looking at how patients with chronic illnesses kept track of health and care information both in and out of the hospital, found they relied on a mix of methods such as paper-based logs, memory, and electronic methods including "multiple patient portals," computer and phone applications, and digital notes (Benham-Hutchins et al., 2017). This scattershot approach to tracking implies a need for better tools to support patients and caregivers in tracking health and care in the hospital, so that they can better engage with their care.

4.1.2 Health Tracking and Patient-Clinician Interactions

As mentioned earlier, supporting tracking has the potential to be an important avenue for supporting patient engagement in the hospital. Yet most of the work about health tracking in HCI has been done outside the hospital, for wellness (Chung et al., 2017; Consolvo et al., 2008) or chronic conditions (Ayobi et al., 2017; Felipe et al., 2015; Mamykina & Miller, 2010). This tracking could be performed alone or in collaboration with family members (Pina et al., 2017). Rather than summarizing here the extensive body of literature about health tracking in general, we focus on health tracking in settings where patients are regularly interacting with clinicians about their health tracking.

Researchers have found that patients collect data outside the clinic both to develop self-awareness and to collaborate with clinicians in shaping their care plan (Zhu, Colgan, Reddy, & Choe, 2017). Some also collect it for curiosity (MacLeod, Tang, & Carpendale, 2013; Zhu et al., 2017). At the same time, clinicians can find patient-generated data overwhelming, unreliable, and clinically irrelevant (Zhu et al., 2017). Patients may collect data on different topics from what clinicians would prescribe (Rajabiyazdi et al., 2016), in part because the tools they use are not designed flexibly enough to support customized goals (Chung et al., 2016). Patients and clinicians may have misaligned goals, leading to frustration on both sides (Chung et al., 2016). Patients and clinicians may also approach the analysis of data in different ways (Mamykina et al., 2017). However, successful collaboration can be very rewarding: with the proper tools, discussing tracked data with clinician experts can increase patients' understanding of their health data, lead to more productive reflection, improve the clinician- patient relationship, and ultimately increase patients' ability to self-manage (Mamykina, Mynatt, Davidson, & Greenblatt, 2008; Piras & Miele, 2017;

Schroeder et al., 2017). Clinicians and patients can collaborate over data to jointly interpret it in and engage in shared decision-making (Mentis et al., 2017).

The design of the tracking tools themselves is very important. Chung et al. suggest that tracking tools be designed to more flexibly support collaboration and provide better visualizations (Chung et al., 2016), while West et al. suggest that tracking tools make it easier for clinicians to reason about the data they collect (West, Giordano, Van Kleek, & Shadbolt, 2016). Schroeder et al. suggest that tools support exploration through flexibility and simplicity, and emphasize the generation of actionable insights (Schroeder et al., 2017).

This work represents a valuable starting point in understanding patient-clinician interactions over health tracking. However, thus far researchers have largely focused on data collected by patients or their family members. Although researchers have begun to explore better ways to present data provided to patients by health care organizations (Hong et al., 2017; Zikmund-Fisher et al., 2017), much work remains to be done on how to support patient-provider collaboration in the hospital, where clinicians collect and control the bulk of patient data. Thus far, studies in this space have shown that hospitalized patients value the ability to ask their clinicians questions electronically (Wilcox et al., 2016), "triage" their inquiries (Wilcox et al., 2016), and set personalized health goals (Dalal et al., 2016). Studies of technology-mediated patient-clinician collaboration in the hospital (Dykes et al., 2017) and after discharge (Brennan et al., 2010) have shown improved outcomes as a result of this collaboration, underscoring the importance of properly supporting this collaboration. Research has further shown that hospitalized patients and clinicians place different values on specific types of information (Caligtan, Carroll, Hurley, Gersh-Zaremski, & Dykes, 2012), highlighting the importance of understanding both parties' needs for the design of tracking tools in the hospital. Because clinicians' workflows in the hospital environment are complex and constrained, we begin by investigating patients' perspectives: what process do hospitalized patients envision for collaboratively tracking with their clinicians, and what designs can support them in doing so?

4.2 METHODS

Since supporting tracking of health and care information in the hospital is an important avenue for supporting patient engagement, I used semi-structured interviews to explore how patients envision collaborating with clinicians to track their health and care. This was the same study described in Chapter 3 as Study 1; I describe the methods again here for reader convenience.

4.2.1 Procedures

I worked with the Patients as Safeguards research team to interview 30 patients and caregivers in two urban hospitals in the United States. We conducted these interviews with a speculative design probe to understand what kinds of tools could best support patients' health tracking needs. The design probe consisted of a series of "feature cards" (see Figure 4.1 for examples). Each card depicted a hypothetical tool or function to support tracking of health status or care, or facilitate communication with clinicians. For example, one feature card showed a generic line graph representing test results with an area labeled "Doctor's Notes" next to it; others contained features that would allow patients to take notes in various formats. During the interviews, participants described their thoughts about the feature, how it would or would not be valuable to them, and how they envisioned it working. Participants were encouraged to expand on each feature—including writing or drawing on it—to explain new ideas that the feature cards gave them.

The interviews lasted 30-60 minutes and were recorded, then transcribed. Members of the research team then analyzed the transcripts using an iterative, inductive coding process to identify different themes in the data. The project was approved by the researchers' institutional review board.

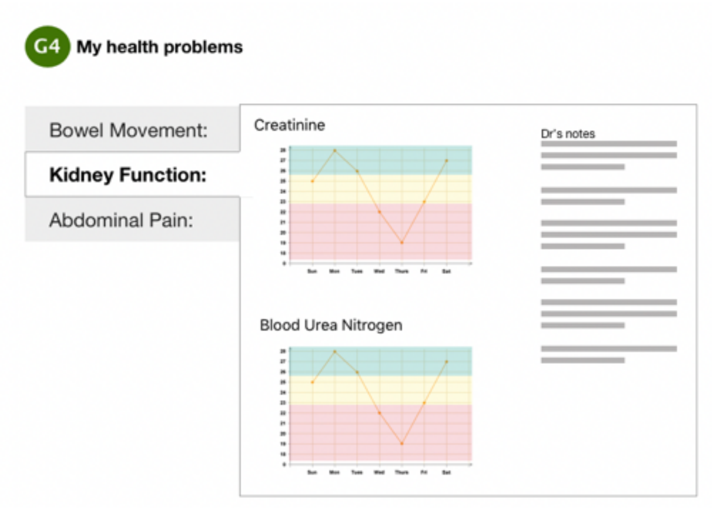


Figure 4.1. Example "feature card" showing generic graphs representing test results and doctor's notes to the side.

4.2.2 Research Sites and Participants

The research sites were Seattle Children's Hospital and Virginia Mason Hospital (a tertiary care hospital for adults) in Seattle, WA, United States. We identify participants from Seattle Children's Hospital with a Y (for youth) and participants from Virginia Mason Hospital with an A (for adults). From Seattle Children's, we recruited 12 pediatric patients. Because caregivers play a critical role in pediatric settings and our goal in this study was to get a broad sample rather than to distinguish patients from caregivers, we recruited 3 adult caregiver participants (Y13, Y14, and Y15). Five of the pediatric patients also had caregivers present during the interview. Pediatric patient participants ranged in age from 7 to 17 (mean and median age 10.5). At Virginia Mason, we recruited 15 patients, who ranged in age from 18-75 (mean age 57.5, median 64). Across both groups, 15 participants were male and 15 female. Participants were recruited across services and conditions to get a broad sample of experience.

4.3 FINDINGS: COLLABORATIVE HEALTH TRACKING IN THE HOSPITAL

Our participants described a vision of health tracking in the hospital in which neither patients nor clinicians were solely responsible for health tracking. Instead, participants envisioned a world where patients and clinicians could collaboratively track the patient's health. They described this vision in terms of both the tracking activities that they currently performed and the tracking activities that they wanted to perform. I illustrate participants' vision of collaborative tracking in the hospital and present the findings by the 5 stages of the personal informatics model (Li et al., 2010): preparation, collection, integration, reflection, and action. I use this model, rather than the lived informatics model (Epstein et al., 2015), because parts of the lived informatics model (e.g. selecting tools, lapsing) are rooted in the everyday tracking context, while the stage-based model's process-oriented focus generalizes more easily to different contexts. For brevity and because most of our participants were patients rather than caregivers, I refer to them as "patients" rather than "patients and caregivers," but include both patients and caregivers in that term.

4.3.1 Preparation Stage

In the preparation stage, users decide what data to collect and how (Li et al., 2010). In the hospital, these decisions are traditionally made by clinicians, who decide which tests to order and which biometrics to track. However, in addition to the existing standard in which clinicians collect data about patients, our participants envisioned a collaborative process for determining what data to collect, in which clinicians could request that patients collect data, and patients could also decide for themselves which data to collect, as well as request that clinicians collect data on their behalf. Participants also wanted to track important metadata regarding data collection.

4.3.1.1 Collaboratively Determining What Data to Track

Participants were happy to collect data about their health that had been requested by the care team. For instance, A05 had been asked by clinicians to record his urine output, and Y11 had checkboxes on the whiteboard in her room to mark how much water she drank. Participants also wanted to collect data about their health that clinicians were not already collecting. Often this data was about the patient's symptoms. Participants described wanting tools to support their data collection. For example, Y06 took it upon himself to photograph his surgery scar and track its healing progress, for his own sake rather than because clinicians had asked him to. Y04 wanted to take photos of *"a thing in my neck that's been changing in size.... It would be nice if we could keep [a photographic record] somewhere...."*. Clinicians had not requested that Y04 collect this data, but Y04 saw it as an important part of her health record. Moreover, she wanted to collect it to support discussion and collaboration between her and her care team.

In addition to data about themselves, participants thought it crucial to collect data from or about other people and processes in the hospital that were relevant to their care. One such data type was conversations with clinicians. Dialogue between patient and clinician was an important source of information about health status, but because it typically occurred verbally, participants were not able to retrieve the information later. As a result, some participants welcomed the idea of a notetaking tool or even an audiorecording of the conversation, like Y03, who said, *"if I wanted to remember something, I'd just ... go back over it and listen to it,"* and A11, who said, *"Recordings would be [helpful] because [my caregiver] tends to forget like what the doctor said, even though she wrote it down."*

When it was inconvenient for participants to collect data themselves, they also wanted to be able to ask clinicians to collect data for them. A09, for example, wanted pictures of how his wound was healing, but instead of taking the photos himself, he wanted someone from the hospital to take those photographs for him. Other participants envisioned clinicians tracking information for them about hospital processes and care administration, like shift changes and the medication schedule. For instance, Y15 wanted to know *"that Dr. [NAME] is here until 8 p.m. or 12 p.m .... That after 10 p.m. there is a handoff or something is going to happen."*

4.3.1.2 Collecting Metadata About Tracked Data

In addition to health data, participants wanted important metadata about tracked data to also be collected and shared with them. In particular, participants were interested in metadata about information provenance and the timing of information availability. Regarding information provenance, Y13 saw her care team members as distinct individuals. When describing how she wanted to hear about what her doctors were thinking (which we return to in the reflection section), she emphasized wanting to know what *each individual* doctor was thinking, especially as they changed shifts: she wanted *"to know one doctor's thinking to the next ... to keep track of that stuff."* Similarly, A09 wanted to have metadata about which doctor a given opinion came from, so that he could act based on that information: *"... I know that urology thinks I'm doing fine, but why does everybody else think I'm not doing fine? That way I can ask additional questions."*

A14 explained how metadata about both information provenance and the timing of information availability would help her keep track of her progress at the hospital. She said that because of *"the number of doctors or residents or interns coming in at different times and then the surgeon and the nurses and everything... it would be nice [if] you could just look it up on this date – Nurse Ratchet came in and told me .... A, B, and C ...."* Although A14 was describing performing a reflective activity (reviewing data), her statement implied the necessity of collecting metadata about information provenance and timing of information availability, i.e. who said what when. A14 focused on metadata about the timing of information availability in the past, but some participants revealed that they needed real- time updates and even forecasts about when information would become available to support later stages. Y04 wanted updates about when lab results would come, analogous to package tracking. She was waiting on lab results and wanted to know when information is *"coming out of the lab and when the information is coming to the hospital that you're in."* In other words, Y04 felt that in order to keep track of her health, she also needed to keep track of hospital activities that were completely out of her control.

Participants also frequently wanted to know when clinicians were coming to their rooms to give them updates, because clinician-patient patient conversations were one of the key ways in which participants received information about their care. Participants needed this metadata both to prepare themselves to engage with the information they would receive and to keep track of what was happening with their care. Y02, for example, wanted to know when the doctor was coming so that she could take steps independently to prepare herself for the clinical encounter: she wanted to *"be ready and have a plan when the doctor comes and when you meet with them, to .... have questions ready."*

In sum, participants envisioned not just collecting data when clinicians asked them to, but also independently deciding what data they would collect as well as what data clinicians would gather about or on behalf of them. They identified types of metadata—e.g., information provenance and timing of information availability—that would support them in later stages of tracking.

4.3.2 Collection

In the collection stage, users actually collect the data, and must navigate the weaknesses of their collection tool and any inherent ambiguity in the data to gather data and get it into the tracking system (Li et al., 2010). Our participants did not have good tools to support them in tracking their health, so instead of describing how they used tools to collect data, participants described characteristics of tools that they thought might meet their needs. Participants needed tools that would allow them to assert their own voice and offer flexible options for joint data collection.

4.3.2.1 Asserting Their Voice

Participants required tools that would let them collect data in their own words rather than relying on clinicians' language. For A09, using his own voice was essential for understanding. He preferred the notetaking feature card over the audiorecording card because notetaking let him *"put it in my own terms versus what they're saying might be in medical jargon that I don't necessarily understand."* Y04 saw the ability to use her own words as a form of empowerment. She wanted to express her symptoms as she experienced them instead of struggling to find the right medical words, and explained that patients should be able to *"....focus on just ... talking about how they feel instead of trying to put it into words for their mom to write down."*

4.3.2.2 Flexible Options for Joint Data Collection

A few participants addressed the role of caregivers in data collection, but expressed opposing views. Y04 wanted a tool that would support patients in collecting data independently from and unaided by caregivers. Implying that caregivers could corrupt the record, she said, *"...it'd be better to hear it from a kid what's going on with them .... because their mom might add to it, whatever, because my mom adds to it."* Y04 furthermore wanted a private chat with her doctors that her mother could not access, *"Like maybe something that you write down and then it goes away and just goes to your doctor. And you can't find it on your – it's just gone. ... that would be really helpful, like if you want to let them know something, and not whoever's in your room to know or whoever was using this to know."* By contrast, A06 depended on caregivers: she *"wasn't able to get photographs because ... I'm flat on my back and I couldn't even access my phone."* Note that both participants focused on the role of their caregiver rather than a clinician. No participants described wanting clinician help in recording data, nor did any participants want to maintain independent records of things clinicians were already tracking. We will return to this topic in the discussion.

4.3.3 Integration

Integration refers to bringing data that has been collected together so that it can reveal insights (Li et al., 2010). In collaborative tracking, integration means not just bringing different bits of data together, but bringing together data from different sources: from clinicians, patients, and caregivers. Our participants envisioned accessing clinicians' data, granting them access to data they collected themselves, and having data from both sources conjoined to support reflection.

4.3.3.1 Accessing Clinicians' Data

Participants wanted direct access to the same information their clinicians had. A05 wanted specifically to see laid out before him exactly what his doctors saw:

> *"I've had ... tumors that are visible, but they never give me the visual record, they always just give me the pathology interpretation. So the pathologist has a picture in front of him or her that they're describing...but they don't ever show the image so you can never correlate what they're [saying with] what's in the image. .... for the doctor looking at it, they're both reading and seeing, and so they're getting a hell of a lot more information [than I am]. So if my chest X- ray actually came up along with the medical report that describes the findings, I would be a lot more interested in that."— A05*

Other participants wanted tools that provided them information that clinicians might be expected to already know. For example, Y01 wanted to know not just what bacteria had caused his infection, but other information like how common it was and what cured it. Participants also wanted to understand the reasoning behind the care plan, which clinicians knew but did not always communicate to patients. For instance, Y04's caregiver wanted to know during blood draws *"[w]hat they're checking in your blood. Are they checking white blood cell count? Are they checking platelets? Are they checking iron?"* Y13, although a nurse herself, felt uncomfortable with her level of understanding of her child's treatment, and wanted more information to *"understand a little bit more as far as what they're watching and stuff.... he's on a certain medication that helps to potentiate one of the other medications, he doesn't necessarily need it by itself ... initially I didn't have a clue as to why he was on it other than for just getting rid of fluid...."* Y13 needed more detail about what function each medication served to understand the care plan she was looking at and to support reflective activities later on.

For their own purposes, participants wanted access to data tracked by clinicians about hospital processes and care administration, such as when shift change would happen and when medication would be administered. Access to this information would support participants in later-stage reflection on the care plan, to identify breaks in the care plan and the reasons for it. For instance, Y15 described how having access to information about the schedules and whereabouts of clinicians would enable her to notice if there was an irregularity in the care plan and to shape her actions in response: *"...if I'm waiting for my nurse, if it is a time to give Albuterol to my daughter ... I'd like to know where my nurse is, so that I know okay, she is attending someone critical, she's on lunch, something like that."*

In general participants wanted to know everything their doctors knew, but a few participants wanted clinicians to act as gatekeepers of negative news. For example, Y01, afraid of getting bad news from his doctors, preferred no news to the chance of bad news. However, most participants, like A11, wanted to know everything, good or bad: *"Let me know...if I got a month, do I have a year?"*

4.3.3.2 Granting Access to Patient-Collected Data

In addition to wanting access to clinicians' data, participants wanted clinicians to have real-time access to data patients could gather themselves. For example, the photos that Y04 wanted to take of her neck were something she wanted to *"keep ... archived in the app and go back and look at it and then like the doctor have access to it through their computers ...."* A10 and Y14 wanted tools to be able to communicate symptoms to clinicians, either to immediately get information about whether the symptoms were normal (Y14) or because otherwise they could forget when they experienced specific symptoms (A10). A12 wanted a way to share information about herself with clinicians to streamline communication. Annoyed with having to repeating information about herself to clinicians again and again, she said, *"...it should give you some centralized place ... so you don't have to continually do it over and over again...."*

The ability to share their data with clinicians was important to participants both because it would give clinicians a more complete picture of their health and because it would enable them to intervene in their treatment when needed. A06 wanted to send a photographic record of how her foot's condition was changing to send to clinicians because she felt that clinicians were not treating her correctly. As she put it, *"The purpose on that was to get the photo to my doctor because they were not transmitting it at [neighborhood]. The nurses were not getting the information to my doctor ...."*

4.3.3.3 Conjoining Data to Support Reflection

Having access to both their own data and clinicians' data was important to participants so that they could conjoin the two. Several participants commented positively along the lines of how *"hav[ing] like everything on the same app .... would be cool"* (A10). A05 spoke vehemently and at length about the benefits of a unified system that *"mak[es] the information useful so that the patient can* *interact with it"*. Others wanted to look at clinician-collected data about when medication was administered alongside patient- collected data about symptoms so that they could identify cause and effect patterns between medications and symptoms. We will discuss this in the reflection section.

With only a couple of exceptions around the delivery of bad news, participants desired to see the same data their clinicians see, and know the same things their clinicians knew. They also wanted the reverse: for clinicians to have instant access to patient-generated data about patients' symptoms and needs. Furthermore, participants wanted to conjoin clinician-generated and patient-generated data to support reflection.

4.3.4 Reflection

Li et al. define the reflection stage as "when the user reflects on their personal information". It includes both short- and long- term reflection, where short-term reflection informs the user about their current condition and long-term reflection uncovers patterns and trends over time (Li et al., 2010). In collaborative tracking in the hospital, reflection encompasses both patients reflecting on their data to make conclusions about their health themselves, and patients influencing clinicians' reflections. Participants described a number of types of tools that could support them in independent reflection, including information about clinicians' reflections and different types of contextualizing information. Additionally, some participants spoke about their desire to collaboratively reflect with clinicians.

4.3.4.1 Support for Independent Reflection

Participants discussed tracked health information with their clinicians face-to-face to understand their health status. During these conversations, clinicians would convey to patients their own reflections on the patient's health. Participants wanted access to these reflections *from clinicians*, to reflect on *themselves*. Participants wanted this information as a supplement to, rather than a substitute for, conversations with clinicians. Our "feature cards" contained two options for conveying clinicians' reflections: a card representing doctor's notes, and a card depicting emojis reflecting clinicians' attitudes about the patient's health. Although participants had mixed reactions to the specific format represented by the cards, they were extremely interested in accessing the content of clinicians' reflections because this information could support their own, independent reflective activities. A02 wanted to know *"how [the doctor] feels about my overall – how I'm doing. Because he's going to examine all my results and come to a conclusion."* A14 likewise wanted access to *"what you're [the doctor] thinking is happening here"*. Y13 emphasized that having access to information about clinician reflections was important for independent reflection: as she said, *"...people are busy, you know? It would be nice to just go look it up yourself and be done with it."* Y11 pointed out that forcing clinicians to enter information about their reflections in a tool might help her learn more than she would otherwise be able to find out through conversation with clinicians. One of the few participants who responded positively to the emojis, Y11 liked them because she felt that she could not trust her clinicians to be completely honest with her unless they were forced into a simple, emotive response. Worried that her doctors would not tell her the whole truth, she said, *"I mean, the doctors always tell you like 'oh, you're doing great,' but you never really get to see like what they mean by that, if they're telling the truth or not.... I want their emotion."*

In addition to information about their clinicians' reflections and conclusions, participants wanted information that would contextualize their health data and help them form their own conclusions. To contextualize their health data, participants wanted: (1) information to help them see the effects of the care plan, (2) benchmark ranges, (3) the patient's own history, and (4) the projected trajectory of the patient's care plan or hospital stay.

A couple participants wanted information that would help them see the effects of their care plan on their symptoms, to understand cause and effect. For instance, Y15 wanted to *"know exactly what has happened last time I visited and what time admitted, what was the observation, what kind of medications we're given on an hourly basis or something like that .... I can track, and if she's talking longer time this time to recover, then I can match exactly how much time last time she took to recover."* Y15 wanted to reflect on the patient's data herself, both to understand the patient's current health status (short-term reflection) and to find trends and understand patterns of cause and effect (long- term reflection).

Participants also wanted to see benchmark ranges. A14 wanted to see *"the margins that is best to be in for this particular lab that we had drawn"*. Y14 thought the benchmark range as an interpretative aid was more important than the results themselves, saying that *"it's fine if you have charts"* but that it was more important that patients *"have some sort of an explanation that [anyone] can understand and not spend so much time reading the actual results."*

Several participants felt that their own history would be useful in contextualizing their results. For example, Y04 (quoted earlier) wanted precise records of how her health issue was changing over time, and A03 wanted *"to know, it's my body, how things are going through this treatment, lymphoma, and how's the progress."*

Participants also wanted information about the trajectory of their care plan or hospital stay as a way to help them understand their health status. Y11 tracked her progress through her stay in context of how close she was to her discharge date. Y06's caregiver understood the patient's health status in terms of future care. She wanted results contextualized in terms of *"at what points you're* *going to need the transfusion so you can see oh, I'm getting close to like the red line ... critical values so that you know they're going to have to do something about it."* A14 similarly wanted a tool that would explain to her, *"if you're on the low side, this is what you could be expecting, or if you're on the high side and how to go about correcting that."*

4.3.4.2 Collaborating with Clinicians in the Reflection Stage

Collaboration with clinicians in the reflection stage was also important to our participants. A12 stressed the importance of engaging in dialogue with clinicians, saying, *"we have to be in charge of our own health, absolutely, but I also don't want [clinicians] to abdicate what they're responsible for, which is to keep me informed and make sure we've had this dialogue."* A couple of participants described how they proactively involve themselves as their clinicians formed impressions about their health and care. A09 felt that since each person is *"responsible for your health ultimately,"* it is their own responsibility to *"give them [clinicians] the most information in an easy to understand way,"* aiding not just with supplying information but with interpreting it for them. A09 felt that because clinicians' communication was necessarily imperfect, he needed to *"be his own advocate"*. Discussing the *"great variances in how people do things, and their interpretations of what heavy means and what light means,"* he felt that he was the failsafe to make sure the proper amount of lidocaine was applied. Similarly, A14 made a point of listening in to nurse handoffs *"because maybe I didn't explain something right, and now I'm hearing how she's presenting or he's presenting, and then I can interject something"*.

Our findings on the reflection stage suggest that patients desire tools that will support them in independently reflecting on and drawing conclusions about their health and care. However, participants also evinced desire to maintain a dialogue with clinicians and influence clinicians' reflections on patients' health data.

4.3.5 Action

Li et al. define the action stage as the time when people decide what to do about what they have learned through reflection. In some cases, action is about tracking progress towards goals, while in others it is about driving behavior (Li et al., 2010). In the hospital, participants wanted to be able to track their progress towards goals and modify their behavior to reach those goals, as well as collaborate with clinicians to set the goals. Participants also wanted to collaborate with clinicians to make changes to their care plans based on their reflections on information about their health and care.

4.3.5.1 Tracking and Collaborating Over Discharge Goals

Several participants wanted to track progress towards their discharge goals, i.e., goals set by clinicians that describe what needs to happen for the patient to go home. Participants wanted to know about their discharge goals so that they could act to meet them. For example, A10 said, *"It's just helpful to know like ... exactly what you have to ... complete each day .... if I'm missing something, I want to make sure that I get it done ...."* A14 lamented that her clinicians had not been clear about discharge goals with her. She knew her clinicians had been tracking her urine output, but did not know that she also had to reach a respiration goal. She said, *"... if I knew about that in the very beginning, that this was something that you really have to work on and work on breathing into this tube, I could have been maybe on it a little bit earlier and not just dismiss it."*

Although most participants took discharge goals as fixed criteria set by clinicians, a couple saw them as something that both parties should have input on. Y06 said that *"Sometimes we have to even convince our doctors"* that they were ready for discharge. A13 likewise expressed agency over his goals and goal achievement, joking about his ability to meet his discharge goals on his own timetable.

4.3.5.2 Collaborating with Clinicians to Change the Care Plan

Monitoring their health and care allowed participants not just to keep tabs on their health, but also to modify their care plan. A07, keeping track of his different therapies and his leg pain, drew a conclusion about how to improve his pain and suggested a change to the care plan. After a day with several back to back therapy sessions, A07 noticed that his legs hurt. To improve his symptoms, he suggested that he should be given pain medication before his therapy session and that there should be a change to the therapy schedule for the next day: *"...my suggestion was ... a bit more spacing in between my therapies so I can recover, you know, and it wouldn't have such a high impact."* Y13 used her knowledge of her child's needs and the care plan to coordinate with clinicians to *"customiz[e] [the care plan] for the day"*. She described working with clinicians to change medication administration times so that her child could sleep uninterrupted. A14 wanted to weigh in on her positioning on the table while under anesthesia. After a procedure, she felt *"tremendous pain across my upper back"*. Her discussion with clinicians yielded the insight that this pain could have been due to her positioning on table as well as the anesthesia, and she valued the ability to give *"input for the docs too, to say well, maybe we shouldn't have had her upside down, that caused some problems,"* so that in future this problem could be corrected. A09 similarly wanted to pass on to clinicians his evaluation of his care and the impact it had on him, so that clinicians could *"improve or in some cases stop doing something that you find annoying or not helpful."* Similarly, Y03 described how a tool to communicate evaluations of the care team would have been useful to him and his caregiver on a past occasion. At that time, his father had realized that the clinicians' assessments of the patient's status contradicted the patient's own description of his symptoms. He described how *"the nurses kept saying I was faking my pain, and then [my father] kind of went off on them."* He believed that better electronic communication support could have helped his father manage the conflict and secure him proper pain management.

Because any change to the care plan had to be made in conjunction with clinicians, participants also needed to know who was who on the care team to direct their communication. For instance, A08 wanted to be able to communicate directly with the hospitalist, *"Because the hospitalist is really the person that takes care of things ... it all has to go through the main hospitalist anyway."* A05 also evaluated clinicians by role: he valued his hematologist but said, *"... the other people that come in, the hospitalists and that sort of thing, really aren't that interesting"*.

In summary, participants demonstrated a desire not just to track their progress towards their goals, but in some cases to negotiate those goals. Participants also used their knowledge of their health, care plan, and care team to collaborate with clinicians to modify their care plans.

4.4 DISCUSSION

My findings yield insights into how we can design technologies to support patients and caregivers in tracking information about, and engaging with, their care. In addition, my findings illustrate how the stage-based model can be applied to a collaborative context. In what follows, I first reflect on the nature of collaborative tracking and discuss its implications for the stage-based model and for systems that support collaborative tracking. I then discuss implications of our findings for the design of patient-facing technologies in the hospital.

4.4.1 Adding Collaboration to the Stage-Based Model

Although my main purpose was to understand how tracking technologies should be designed to support patient engagement in the hospital, one of my goals was also to evaluate how well the stage-based model held up in the hospital context. I found that the model was overall robust to the change of context—my findings about health tracking neatly aligned themselves with Li et al.'s five stages, despite the shift in context to a short-term situation where the self being tracked (the patient) is not always in control of collecting, analyzing, reflecting, or acting on their data. My findings suggest that people engaged in collaborative tracking go through the five stages in parallel with their collaborators. I discuss barriers that arise in only the collaborative tracking setting, and additional considerations—the definition of collaborators and the importance of process-oriented metadata—associated with collaborative tracking that the stage-based model in its current form does not account for.

Based on these findings, collaborative tracking looks like a mix of independent and collaborative work. To the maximum extent possible, participants wanted to carry out tasks for each stage independently, then share the results with clinicians. Thus, in the collection stage, participants wanted to collect and contribute data but did not speak of needing clinician help. In the reflection stage, participants desired to reflect independently and form their own opinions to take action collaboratively with clinicians later on. Participants also generally did not speak of maintaining an independent record of things that clinicians were already keeping track of.

Thus, in terms of the stage based model for collaborative tracking, collaborators go through the same stages in parallel, touching base with each other in each stage. But in those touchpoints new barriers can arise that, in accordance with the stage-based model, can cascade to impede tracking activities later on. One such barrier is conflict amongst tracking collaborators. When they come into conflict in one stage, further stages are impacted, such as when Y03's father and the nurses disagreed about the patient's health status, which then made it difficult for Y03's father to take the action he thought necessary (getting more pain medication for Y03). Another such barrier is the potential for segregated knowledge. When knowledge is not shared among stakeholders the effects cascade, as when patients were unable to interpret their lab results (reflection) because they lacked access to contextualizing knowledge held by clinicians (integration).

Another consideration for modeling collaborative tracking is how the collaborators are defined. Chung et al. have already noted the need to extend the stage-based model to allow for the articulation of different roles in collaboration (Chung et al., 2016). However, Chung et al.'s study took place in the context of pair-wise interactions between clinicians and patients, outside the hospital. Our study took place inside the hospital, where patients interact with a multitude of clinicians, and might additionally be accompanied by caregivers. In this type of multi-agent setting, a tracking collaborator could be a single person (e.g. the hospitalist), a group of people (e.g. the whole care team), or even a role filled by different people at different times (e.g. the nurse on shift). A system that supports collaborative tracking must allow different kinds of collaborators to connect with each other as needed: individuals should be able to connect to individuals, groups, or roles, etc. Furthermore, these different types of collaborators stand in different relationships to each other. For example, a patient may have a very different relationship with a caregiver than they do with a clinician. Understanding what these different relationships mean for how collaborative tracking activities are conducted is a fertile new area of research for HCI.

Collaborative tracking also highlights the importance not just of data collection, but of process-oriented metadata collection. As shown in my findings, people engaged in collaborative tracking need metadata about information provenance and the timing of information availability. Although not explicitly discussed by participants, metadata about task assignment may also be important for supporting collaborative tracking. Metadata about information provenance is particularly important in settings where there are more than two people engaged in collaborative tracking. Collaborators touch base with each other throughout the tracking process. Without metadata about information provenance, this step cannot happen and later stages of tracking may be impossible. Metadata about the timing of information availability is necessary to inform people engaged in collaborative tracking about where their collaborators are in the process. Metadata about task assignment may also be necessary to inform collaborators about what information to expect and to make sure that collaborators are all on the same page about what data needs to be collected. Providing all three types of metadata will support people engaged in collaborative tracking in knowing what each collaborator is responsible for and where other collaborators are in their process.

4.4.2 Supporting Inpatients in Collaborative Tracking

I applied the stage-based model to these findings to see if findings from other research in personal informatics can help HCI researchers understand patients' needs in the hospital setting. Because the stage-based model held up well in this new context, I derive recommendations for supporting inpatients in collaborative tracking based on the personal informatics literature. For example, findings that systems should be designed to allow for flexibility of data collection (Chung et al., 2016; MacLeod et al., 2013) and integration (MacLeod et al., 2013) can be applied to this context, as can lessons about the questions people ask in discovery-phase tracking (Li, Dey, & Forlizzi, 2011). Adding to this literature, my findings shed light on how systems can be designed to support hospitalized patients in collaboratively tracking their care. Participants desired an equal, collaborative role throughout every stage of the personal informatics model. They envisioned a collaborative medical record, forged and used collaboratively by patients and clinicians. Building on existing avenues for electronic patient-clinician communication, like the ability for patients to electronically ask questions (Wilcox et al., 2016) or communicate health goals (Dalal et al., 2016), this transformed electronic health record would capture data from patients, caregivers, and clinicians to become a comprehensive record of the patient's health and care from multiple perspectives. Importantly, this record must support, rather than replace, communication between patients and clinicians. Below I discuss how this record should support different stages of tracking.

To support preparation, such a record should support requests for data collection from each party to each other and transparent delegation of tasks. Highlighting the role of the patient in particular could facilitate their participation (Benham-Hutchins et al., 2017; Larsson, Sahlsten, Segesten, & Plos, 2011; McMurray, Chaboyer, Wallis, Johnson, & Gehrke, 2011). To support collection, the record should support multiple kinds of data formats (e.g. text, photos, or recordings), and give patients flexible options for joint data collection (e.g. with or without caregiver help). Patients should be able to communicate with clinicians independently of caregivers, but also to grant caregivers editing privileges as needed, in compliance with hospital policies and laws. To support integration, the record must be accessible to and editable by patients, clinicians, and caregivers. Because information provenance is such crucial metadata in collaborative tracking and in the hospital, all users should be able to distinguish whether information came from a particular clinician, the patient, or a caregiver.

Permission management must be granular enough to distinguish when data is editable by a user and when the user can only annotate or comment on the data. Patients should furthermore be able to opt out of seeing data they do not want to see without clinician mediation, like bad news that they would prefer to receive only face to face.

Reflection support requires the inclusion of contextualizing information and support for communication about data. My findings uncovered several ways in which patients understand health data: by looking for cause and effect patterns, and by contextualizing health information against benchmarks, the patient's personal history, and the patient's care trajectory. Collaborative tracking systems should support all of the above means.

Regarding benchmarks, Zikmund-Fisher et al. demonstrated that visualizations of benchmark ranges for test results can help patients interpret data and distinguish near-normal from atypical results (Zikmund-Fisher et al., 2017). However, Wilcox et al. point out that clinicians sometimes object to the presentation of reference ranges because they are not appropriate in all cases (Wilcox et al., 2010). One technique to resolve these conflicting needs is to provide reference ranges that can be turned on and off, modified, or otherwise annotated by clinicians as appropriate for individual patients. For instance, a clinician could leave an explicit comment or a visual indicator that the reference range may not apply to the patient. Allowing clinicians to show or hide individual chunks of content has been used in other contexts. For example, clinicians using OpenNotes—an approach to allow patients to see all notes about their care, rather than the typical subset—can decide whether or not to share individual notes with a patient, and the function has not produced a significant increase in clinician workload (Delbanco, Walker, Bell, Darer, & Elmore, 2012). Nor is reflection support limited to test results—photographs of a surgical wound, for example, can be contextualized with past photographs to facilitate monitoring of progress. However, future research is needed to better understand how to communicate this information.

Support for the earlier stages of tracking—preparation, collection, integration, and reflection—should also entail support for action—for patients and caregivers to make decisions about their care, independently or in collaboration with clinicians. Supporting tracking thus can support engagement with care in multiple ways—for instance, both the bedside monitor role and decision-maker role, described in Chapter 2, could be supported with collaborative tracking technologies.

Note that some of the collaborative tracking activities described in this chapter are things that patients in theory already can do, but often don't (such as audiorecording conversations with clinicians), or are features that were not received well by patients in other studies (e.g. the less favorable responses towards features like sharing notes with clinicians that promoted active engagement in (Woollen et al., 2016)). My findings reaffirm that patients need better tools to support them in collaboratively tracking their health while in the hospital. The discrepancy between the need for tracking support uncovered in these findings and the cool reception of specific tracking tools suggests that HCI researchers must continue to explore this space to find the right designs and implementations to support hospitalized patients in actually performing collaborative tracking.

4.5 LIMITATIONS AND FUTURE WORK

The research team's broad sampling strategy, which enabled us to cut across conditions, was also a limitation: the strategy enabled us to cut across conditions, but also did not allow us to identify differences in tracking needs between patients with different conditions or provide deep insight into condition-specific tracking practices. Dykes et al. have demonstrated the potential of patient-clinician collaboration in the medical intensive care unit (Dykes et al., 2017), but it is unclear how well our findings on collaborative tracking apply in specific contexts, like mental health and trauma. More research is needed to understand how needs for collaborative tracking could change in different care contexts.

This work focused on understanding patients' needs for collaborative tracking. Because collaborative tracking is by definition about multiple agents, future work should also explore clinicians' and caregivers' needs and constraints in in this arena. Furthermore, our methods used simple, generic tracking prompts to elicit patient needs. Future work is needed to understand how to implement collaborative tracking systems given the large variety and amount of clinical data possible. Care must be taken to ensure that patients are not overwhelmed by the information they receive during their hospital stay. Rather than seeing collaborative tracking tools as sole information channels, they should be seen as a supplement to help patients be well informed when entering a dialogue with their clinicians.

4.6 CONTRIBUTION

In this chapter I investigated **RQ3: How can we design technologies to help patients and caregivers engage with their care in the hospital?** I explored inpatient needs for tracking their health and care, and found that inpatients envision collaboratively tracking their health and care plan with their clinical team in order to actively engage with their care. Collaborative tracking technologies could help patients and caregivers engage with their care in multiple ways, for instance by allowing them to contribute information about the patient's health status and make decisions about their care plan. I found that patients' and caregivers' tracking process follows the stage-based model of personal informatics, but that collaborative tracking introduces new barriers to and requirements for successful tracking. I provided insights about designing collaborative tracking systems to help hospitalized patients manage their health and care, reflections on how collaborative tracking extends the stage-based model of personal informatics, and suggestions for new research directions. In the next two chapters, I present the results of another study investigating RQ3, this time in the context of patients speaking up about their concerns.

Chapter 5. DESIGNING INTERVENTIONS TO ENCOURAGE PATIENTS TO SPEAK UP IN THE HOSPITAL: PERSPECTIVES ON THEORY-BASED INTERVENTIONS

In the last chapter, I presented findings related to the design of collaborative tracking tools, that can support patient engagement by enabling them to determine what data is collected about them by the hospital, to collaborate with clinicians in collecting that data, and to actively take part in reflecting and acting on that data. In the next two chapters, I explore the design of technologies to support patient engagement from a more internal perspective. I present the results of a low-fidelity study conducted with hospitalized patients, examining the design and reception of hypothetical interventions to encourage patients to speak up to clinicians about their concerns. This study tackles **RQ3: How can we design technologies to help patients and caregivers engage with their care?** As will be described in more detail below, the study had two parts: a validation step (Step 1) and interviews with patients about the final set of prototypes (Step 2). In this chapter (Chapter 5), I introduce the study as a whole, as well as related work, and present the results of Step 1 and relevant results from Step 2. I will present the bulk of the results of Step 2 in the following chapter (Chapter 6).

As mentioned earlier, medical errors in hospitals have been estimated to be a major cause of harm and death for patients nationwide (Makary & Daniel, 2016), and patients have the potential to help identify and prevent errors by engaging with their care, specifically by paying attention to their care and speaking up about their concerns (Kuo, Phillips, Graham, & Hickner, 2008; Longtin et al., 2010; David L.B. Schwappach, 2010; Unruh & Pratt, 2007; Weingart et al., 2005). However, patients are only able to prevent medical errors if they respond to them by intervening in some way (Haldar, Mishra, Pollack, & Pratt, n.d.), generally by “speaking up” to clinicians. Patients and clinicians can differ not just in their goals (Chung et al., 2016) and information priorities (Caligtan et al., 2012), but also in what they classify as errors or issues in their care (Bell et al., 2017; Etchegaray et al., 2016; Gillespie & Reader, 2018; Longtin et al., 2010; Weingart et al., 2005; Weissman et al., 2013), emphasizing the importance of patients speaking up about their concerns.

To encourage patients to speak up, in 2002 the Joint Commission launched its Speak Up campaign, consisting of a variety of brochures and videos for patients, aimed at encouraging them to speak up about their concerns. This campaign has earned feedback from a patient and family focus group that its messages and materials are valuable and effective at giving patients information they need (The Joint Commission, 2018a). In addition, researchers have developed interventions to inform patients about their care (Bickmore et al., 2009; Haldar et al., 2017; Miller, Pollack, et al., 2016; Prey et al., 2014; Skeels & Tan, 2010; Vardoulakis et al., 2012; Vawdrey et al., 2011; Wilcox et al., 2010) so that they can spot when something is wrong, as well as report errors after the fact (S Collins et al., 2016; Couture et al., 2015), and a variety of types of interventions to encourage patients to remind clinicians to wash their hands (R. Davis et al., 2015), as well as monitor and speak up about hospital acquired infections (Seale et al., 2015).

Yet researchers have continued to find that patients frequently do not report issues (Mazor et al., 2012; Mazor, Smith, Fisher, & Gallagher, 2016), and do not always feel comfortable speaking up about issues with their care (Bell et al., 2018; Fisher et al., 2019). Researchers have highlighted a variety of reasons why patients may feel uncomfortable or reluctant to speak up about their concerns, or otherwise actively participate in their care. Patients may worry about being perceived as ‘difficult’ (Frosch, May, Rendle, Tietbohl, & Elwyn, 2012), and worry about repercussions in their care (Delbanco & Bell, 2007; Mazor et al., 2016; Rainey et al., 2015). As also presented in an earlier chapter in this dissertation, researchers have found that the patient-clinician relationship also influences patient willingness to speak up (Rachel E. Davis, Jacklin, Sevdalis, & Vincent, 2007; V. A. Entwistle et al., 2010). Patients may also feel too sick to be able to speak up (Rachel E. Davis et al., 2007; Doherty & Stavropoulou, 2012; Mazor et al., 2016). In addition, patients may feel anxious about going beyond an accepted 'patient' role (Frosch et al., 2012). Indeed, Redley et al. (Redley et al., 2018), surveying inpatient medical wards for their control preferences, found a relatively even breakdown of control preferences, with a plurality of patients holding a low control preference (44.2%), meaning that they preferred their clinicians to assume more control of their care rather than themselves.

Because of this, some researchers have called for additional research into encouraging patients to speak up in the moment as well as to report events after they occur (Bell & Martinez, 2019). One way to answer these calls is research into the development of behavioral interventions that can motivate patients to change their ways and speak up more frequently about issues in their care. Theories of behavior have not often been applied in examining patient willingness to speak up about concerns. Luszczynska & Gunson (Luszczynska & Gunson, 2007) examined the impact of variables from the Theory of Planned Behavior (Ajzen, 1991) on patient willingness to ask providers about hand hygiene, and Schwappach et al., in a systematic review, devised their own conceptual model of patient willingness to engage in safety-related behaviors that incorporated some constructs from various behavioral models, such as self-efficacy, perceived subjective norms, and motivation (David L.B. Schwappach, 2010). In general, however, research dealing with patient comfort speaking up has often taken an inductive approach towards analysis (e.g., (Rachel E. Davis et al., 2007; V. A. Entwistle et al., 2010)). While this approach is extremely valuable—one I have used myself elsewhere in this dissertation—there may also be value in applying rigorously developed behavioral models to understand what kinds of factors can motivate patients to speak up about their care. In particular, the use of behavioral models can be used to guide the development of interventions to motivate patients to speak up, as has been done for other health behaviors in HCI literature.

The purpose of this study was to use the Integrated Behavioral Model (IBM, described below) (Montano & Kasprzyk, 2008) to understand patient and caregiver willingness to speak up in the hospital, and to explore how best to create a theory-based intervention for this context. In this chapter, I explore the question of what exactly it means for an intervention to be theory-based. I describe the process I used to validate that different intervention prototypes targeted specific IBM constructs, and present perspectives from researchers in HCI and related fields on the necessity and nature of validating the theoretical fidelity of interventions. I end with a discussion of the types of methods that can be used moving forward with behavior change research in HCI.

5.1 RELATED WORK

Because the focus of this chapter is on methodological considerations, in this section I will describe major behavioral models that have been used to guide behavior change research and the recent calls for changes to how those models are used and measured in HCI behavior change research. In the next chapter, I will include additional related work on patient safety and speaking up.

5.1.1 Definitions and Behavioral Models

I will begin this section with a few definitions. *Constructs* are defined by Hekler et al. as “the fundamental components or ‘building blocks’ of behavioral theory” (E B Hekler, Klasnja, Froehlich, & Buman, 2013). Behavioral models typically show the interrelationships of constructs and their effect on behavioral intention or behavior (see (E B Hekler et al., 2013) for more details on different types of behavioral models). A *mediator* or *mechanism* refers to how an intervention works (E B Hekler et al., 2013; Kraemer & Kupfer, 2012), e.g. what constructs an intervention targets in order to effect behavior change.

Behavioral scientists have come up with a variety of behavior change models, some of which depict behavior as the result of a variety of mediators. Some of the best known of these models are the Theory of Reasoned Action (TRA) and the Theory of Planned Behavior (TPB). The Theory of Reasoned Action, developed by Fishbein and Ajzen, posits that behavior is determined by behavioral intention, which in turn is mediated by an individual's attitude towards the behavior and their subjective norms about the behavior (Fishbein, 1967). Fishbein and Ajzen later expanded the TRA into the TPB, developing the model to add perceived control as an additional mediator of behavioral intention (Montano & Kasprzyk, 2008). These models suggest that to influence behavior, interventions should target the mediators of behavioral intention—in other words, that changing someone's attitude towards a behavior, their subjective norms about it, or their perceived control over the behavior can act as a mechanism for behavior change.

Building on the TRA and TPB, Montaño and Kasprzyk introduced the Integrated Behavioral Model (IBM) (see Figure 5.1) (Montano & Kasprzyk, 2008). The IBM follows the general model of the TPB, but breaks down each mediator into more granular constructs. Attitude becomes a combination of *experiential attitude* and *instrumental attitude*, where the former is defined as someone's affective feelings about a behavior (e.g., is it pleasant or unpleasant), whereas the latter is someone's cognitive attitude towards the behavior (e.g., is it a good idea or bad idea, what kinds of outcomes will result). Perceived Norm is a combination of *injunctive norms*—a person's beliefs about whether other people would approve of the behavior or think that the person *should* do the behavior—and *descriptive norms*—a person's beliefs about whether other people perform the behavior or not. And Personal Agency is both *self-efficacy*, meaning a person's confidence in their ability to carry out the behavior, and *perceived control*, meaning the degree to which a person believes carrying out the behavior is under their control at all. In addition, the IBM describes four factors that influence whether behavioral intention translates into actual behavior. First, a person needs the *knowledge and skills* necessary to perform the behavior. Second, the behavior must be *salient*, or relevant in the moment. Third, there cannot be any *environmental constraints* which prevent intention from being translated into behavior. And fourth, if a person has a *habit* of performing the behavior, they may be more likely to do it in the first place.

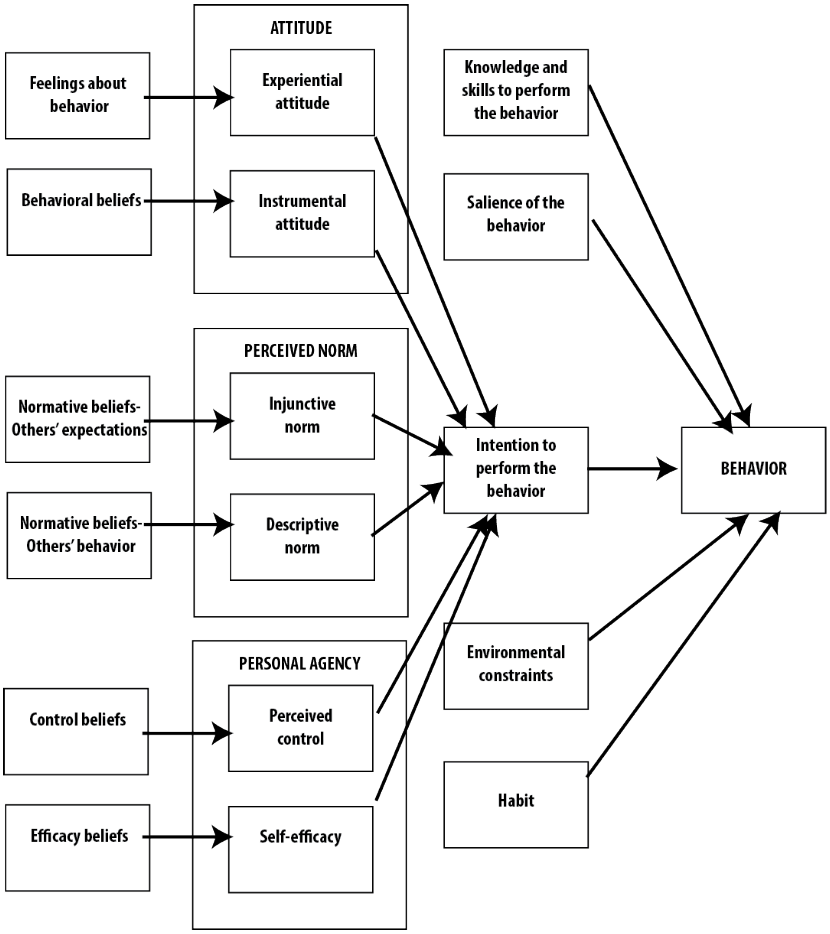


Figure 5.1. Depiction of the Integrated Behavioral Model, recreated based on original in Montaño & Kasprzyk, 2008.

The TRA, TPB, and IBM are hardly the only models of behavior change. For instance, researchers have also created the Trans-Theoretical Model to illustrate people's progress from not even contemplating behavior change to actually maintaining it (Prochaska, 1984); the social ecological model to describe how the layers of society in which a person exists, from the public policy level to the interpersonal and individual levels (McLeroy, Bibeau, Steckler, & Glanz, 1988); and the COM-B model and related Behavior Change Wheel, which depict behavior as the result of capability, motivation, and opportunity, and classify behavior change interventions both by function and by whether they relate to automatic or cognitive processes (Susan Michie, van Stralen, & West, 2011). While these models of behavior change are useful for identifying opportunities for intervention, the IBM (as well as the TRA and TPB) more directly links behavioral intention to specific mechanisms of change, offering guidance for the design of behavior change interventions.

However, as mentioned earlier, for the most part behavioral models have thus far not been applied to the act of speaking up while in the hospital. In addition, while models like the IBM can offer more guidance for design than models like the socioecological model, this guidance remains underspecified. By that, I mean that the model offers no guidance on exactly what an intervention targeting a mediator like descriptive norms or perceived control should look like. Research is needed to understand exactly what it means to design an intervention to influence a specific mediator as represented in a behavior change model.

5.1.2 Methodological Calls in HCI

As the research and development of novel technological behavior change interventions has grown in the last 15 years (E B Hekler et al., 2013), researchers in HCI and behavioral science have begun to call for improvements to the evaluation of behavior change interventions. Some of these calls have promoted the use of methods that can test individual components of interventions rather than complex interventions as a unit, such as fractional factorial experimental designs (Chakraborty, Collins, Strecher, & Murphy, 2010), Collins's multiphase optimization strategy and sequential multiple assignment randomized trial methods (L. M. Collins, Murphy, Nair, & Strecher, 2005; L. M. Collins, Murphy, & Strecher, 2007), and micro-randomized trials (Klasnja et al., 2015).

Researchers have called not just for individual components to be evaluated for their efficacy, but also on *how* they worked—in other words, what impact they had on the intended mechanisms. For instance, in 2011, Klasnja et al. (Klasnja, Consolvo, & Pratt, 2011) called for researchers to focus on how interventions worked rather than evaluating their overall efficacy in achieving change. More recently, Hekler et al. (E B Hekler et al., 2013; Eric B. Hekler et al., 2016) and Klasnja et al. (Klasnja, Hekler, Korinek, Harlow, & Mishra, 2017) have written about the importance of proximal outcomes as evaluation measures in order to aggregate data about the efficacy of different design techniques and the mechanisms through which they operate, and Kay et al. (Kay, Nelson, & Hekler, 2016) have proposed the use of Bayesian statistics to aggregate data from small-scale early prototype studies. Researchers have also developed protocols for intervention designers to choose an appropriate theory or theories to apply, and on which to base their intervention and evaluation (Bartholomew, Parcel, & Kok, 1998; Kok, Schaalma, Ruiter, van Empelen, & Brug, 2004).

In support of these calls, researchers have reviewed past research to evaluate what mechanisms have been used in past literature (Caraban, Karapanos, Gonçalves, & Campos, 2019), to analyze what kinds of evaluations have been conducted in past work (McCallum, Rooksby, & Gray, 2018), and even to examine how academic findings can be translated into practice and vice versa (Colusso, Bennett, Hsieh, & Munson, 2017; Colusso, Munson, Jones, & Hsieh, 2019).

These calls have been issued both to support knowledge aggregation and to understand why interventions fail—since behavior change is an extraordinarily complex process, interventions can fail for reasons that have nothing to do with the intervention itself (Klasnja et al., 2011). However, thus far work calling for behavior change interventions to be evaluated based on their impact on the mechanism of change have largely focused on the *intended* mechanism. But before evaluating whether an intervention works, how can we tell if it successfully implemented the intended mechanism in the first place—i.e., how can we validate that the intervention has theoretical fidelity, and works the way it is expected to?

Researchers have just begun to tackle this question by trying to map behavior change intervention techniques (Abraham & Michie, 2008; S Michie et al., 2011) onto theoretical mechanisms of change via expert consensus (Connell et al., 2018). These behavior change techniques are organized into a taxonomy which is intended to be a relatively comprehensive catalogue of possible types of behavior change interventions (S Michie et al., 2011). However, even in Connell et al.'s study, not all behavior change techniques have been successfully mapped to an intervention by expert consensus, and more than half of all possible links between behavior change techniques and mechanisms of change were rated by experts in Connell et al.'s study as "possible" or "unsure". In addition, many behavior change techniques were linked to more than one mechanism (Connell et al., 2018). These results suggest some internal disparity in how experts interpret how behavior change interventions are supposed to work, and completely leave out the perspectives of end users, who may respond differently from experts to behavior change interventions. Moreover, there are infinite potential implementations of each technique, and as technology progresses, new techniques may evolve. Thus even if any given intervention can be counted as an example of one of the behavior change techniques mapped to a mechanism in Michie et al.'s taxonomy (S Michie et al., 2011), it is not clear that it should therefore be assumed to operate through a particular mechanism. Much work thus remains to be done in exploring the means and meaning of validation of behavior change interventions.

5.2 METHODS

As mentioned earlier, my ultimate goal was to explore what kinds of theory-driven interventions might motivate patients to speak up about their concerns in the hospital, and what kinds of design guidelines should be incorporated in the creation of such interventions. To do this, I conducted an iterative process of prototype design and validation involving a combination of surveys and expert interviews (Step 1), followed by semi-structured interviews with hospitalized patients using low-fidelity intervention prototypes (Step 2). Each step is described in more detail below. All study procedures were approved by the researchers' Institutional Review Board.

5.2.1 Step 1: Prototype Development and Validation

I developed 12 prototypes over two iterations of design and validation. The prototypes were based on the 6 mediators in the Integrated Behavioral Model (Montano & Kasprzyk, 2008) that contribute to behavioral intention: experiential attitudes, instrumental attitudes, descriptive norms, injunctive norms, perceived behavioral control, and self-efficacy. The IBM was used because of its granular breakdown of individuals' attitudes and beliefs. Validation was achieved by asking experts (people with an advanced degree in a field pertaining to HCI or behavioral science) to complete a survey mapping each prototype to the IBM construct(s) through which they thought it would operate. After two rounds of this design and validation process, I conducted interviews with survey takers and people who had piloted the survey to evaluate the validation method. This process is described in more detail below.

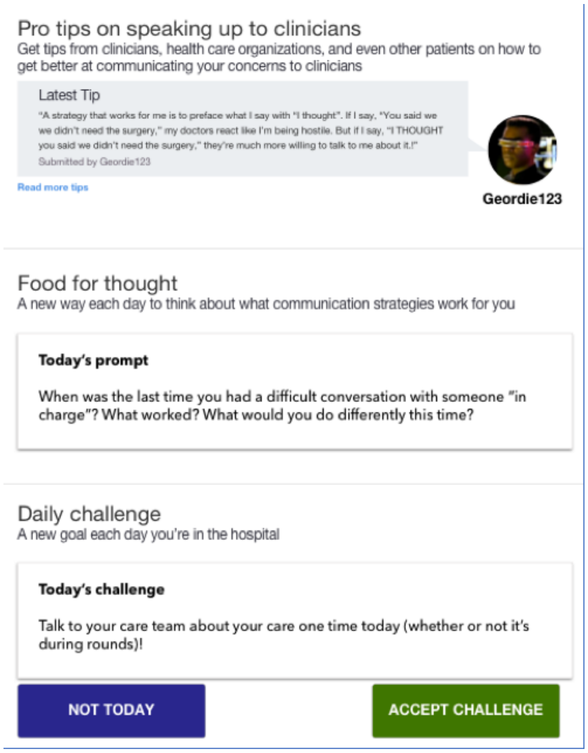
5.2.1.1 Validation Surveys

To explore how different design strategies could be used to target different mediators in the IBM, I prototyped 2-3 different interventions for each mediator. For example, as potential interventions for ‘self-efficacy,’ I created three prototypes: 1) a “pro tips” intervention containing suggestions on strategies for having difficult conversations with clinicians; 2) a daily prompt asking users to reflect on past times they had difficult conversations with authority figures; and 3) a daily challenge that users could accept or decline, challenging them to talk to their care team one time today (see Figure 5.2). I then asked to map each prototype onto constructs in the IBM. Experts were recruited through a combination of personal and professional networks, via word of mouth. In the survey, respondents were asked how familiar they were with the IBM, and quizzed on IBM constructs to verify their knowledge of the model. Respondents were then asked to select which construct(s) the prototype operated through (see Figure 5.3 for example survey question). Prototypes were considered validated for a particular mechanism if a simple majority of experts said that the prototype operated through a particular mechanism. (Note that as will be discussed in the findings, average Cohen’s Kappa values were considered and rejected as a validation threshold.) The survey was conducted in two rounds, until all 6 mediators had validated intervention cards associated with them. A total of 24 prototypes were tested, out of which 15 validated.

Because it would be difficult to adequately discuss 15 prototypes in patient interviews, I narrowed the final set of prototypes to 11 validated prototypes. I chose this set have every mediator represented in the final set and, where possible, have more than one prototype per mediator. Where mediators had multiple validated prototypes associated with them, I chose prototypes that had achieved higher levels of agreement.

5.2.1.2 Expert Interviews

To investigate the validation method and make sure the results were reliable, I asked survey takers to participate in brief, semi-structured interviews about their experience taking the survey. The interviews lasted 30-40 minutes, during which time I asked respondents about what they found challenging about the survey, their comfort with the IBM, and their own attitudes towards theoretical design and validation.



Pro tips on speaking up to clinicians

Get tips from clinicians, health care organizations, and even other patients on how to get better at communicating your concerns to clinicians

Latest Tip

"A strategy that works for me is to preface what I say with "I thought". If I say, "You said we we didn't need the surgery," my doctors react like I'm being hostile. But if I say, "I THOUGHT you said we didn't need the surgery," they're much more willing to talk to me about it.!"

Submitted by Geordie123

Food for thought

A new way each day to think about what communication strategies work for you

Today's prompt

When was the last time you had a difficult conversation with someone "in charge"? What worked? What would you do differently this time?

Daily challenge

A new goal each day you're in the hospital

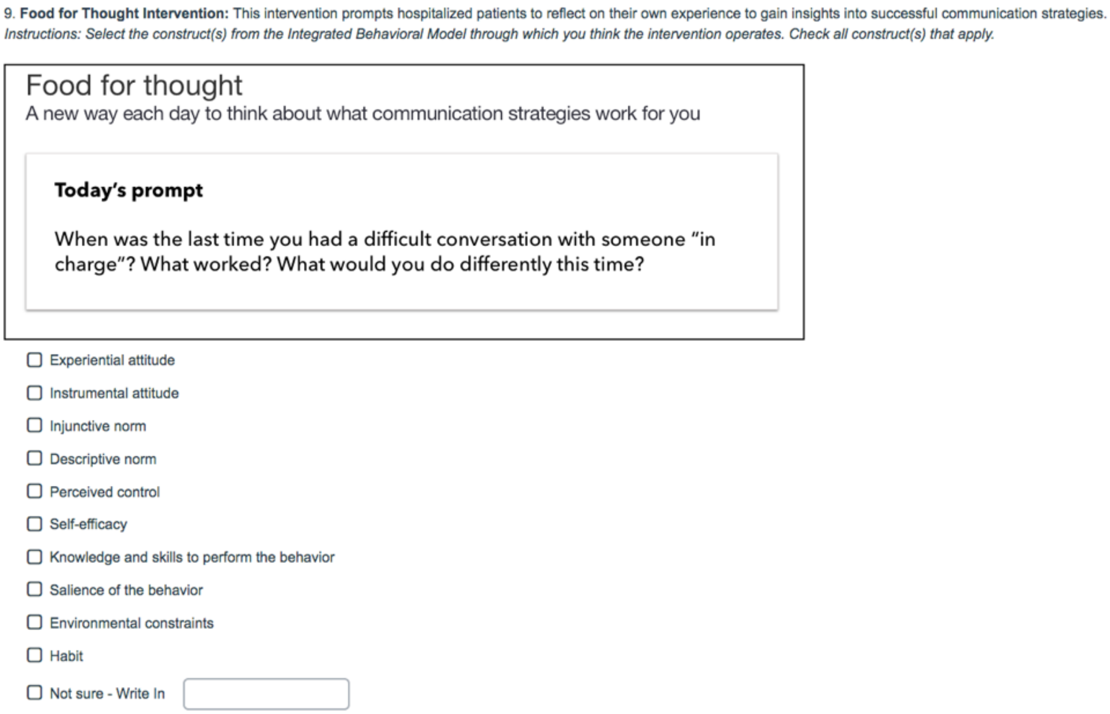
Today's challenge

Talk to your care team about your care one time today (whether or not it's during rounds)!

Figure 5.2. Initial prototypes for self-efficacy.

5.2.1.3 Validation Survey and Expert Interview Respondents

In all I had 7 respondents to the two rounds of surveys. No respondents participated in both rounds. Three of these respondents participated in the expert interviews. To preserve the anonymity of my respondents, who are researchers in HCI and adjacent fields, I report only high-level information about the respondents' positions and backgrounds. Of the 7 respondents, 3 were post-docs, 3 faculty, and 1 a researcher working in industry. Respondents had earned their degrees in such fields as information science, health behavior or behavioral medicine, computer science, and nutrition. A few people also piloted the survey, including several graduate students in HCI, computer science, and information science. The results of these pilot tests are not reported as survey findings, but one of these survey piloters, a graduate student in HCI, was interviewed, and their results are included in the expert interview findings, for a total of 4 expert interview participants. In the findings, expert interview participants are identified as “E##” (e.g., E01) for “expert”.



9. **Food for Thought Intervention:** This intervention prompts hospitalized patients to reflect on their own experience to gain insights into successful communication strategies.
Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.

Food for thought
A new way each day to think about what communication strategies work for you

Today’s prompt

When was the last time you had a difficult conversation with someone “in charge”? What worked? What would you do differently this time?

☐ Experiential attitude
☐ Instrumental attitude
☐ Injunctive norm
☐ Descriptive norm
☐ Perceived control
☐ Self-efficacy
☐ Knowledge and skills to perform the behavior
☐ Salience of the behavior
☐ Environmental constraints
☐ Habit
☐ Not sure - Write In

Figure 5.3. Example survey question.

5.2.2 Step 2: Semi-Structured Interviews with Patients and Caregivers

To understand what IBM mediators played a role in motivating or inhibiting people from speaking up to clinicians about concerns they might have about their care, I conducted interviews with hospitalized patients and caregivers. The interviews occurred at Virginia Mason Hospital, which only treats adults (participants denoted with A for “adult”), and Seattle Children’s Hospital (participants denoted with Y for “youth”). From Virginia Mason, I recruited 15 participants, ranging in age from 26 to 79 (mean 56.8, median 57). Of these, 9 participants identified as female and 6 identified as male. 9 participants identified as White, 1 as biracially White and Native Hawaiian, 2 as Black, 1 as Asian, and 1 as both Asian and Latino. In addition, one caregiver, the patient’s spouse, desired to participate in the interview. 4 of the Virginia Mason participants were on a surgical service, and the rest on a medical service. From Seattle Children’s Hospital, I recruited 7 patients and 3 patient-caregiver pairs. Patient participants ranged in age from 13-21 (mean 16.1, median 16), and caregiver participants were aged 37, 55, and one not collected. 8 participants were female and 5 male. 8 participants identified as White, 2 as Latino, 2 as Asian, and 1 as both Asian and White. 4 patient participants were on a surgical service, and 4 on a medical service, and 2 on a cancer service. Participants are identified with A## or Y##, with caregiver participants identified with an appended -C (e.g., A05, A05-C).

Patients and caregivers were eligible to participate in the interviews only if they had experienced an undesirable event, meaning events big or small that occurred in a hospital, resulted in major or minor harm or discomfort, and could have been avoided. In the interviews, I asked participants about their experiences with undesirable events, including what had happened and whether or not they had spoken up to clinicians about it. I asked participants about what kinds of factors had influenced their decision to speak up or not speak up, including whether they had received support from anyone else, what they saw as the pros and cons of speaking up, etc. After this discussion, I showed participants the prototypes. I asked probing questions about their responses to understand how valuable the information or function in the prototype was to them, how the information presented in the prototype compared to their actual beliefs, and how the prototypes compared to each other in relative value. After the first 4 interviews, I introduced an additional prototype which had not passed validation. This prototype (a pie chart showing the results of a hypothetical poll of patients, in which most patients indicated that they thought patients should speak up about their concerns) had missed validation by one vote, but directly paralleled another prototype which had passed validation, for injunctive norms (a pie chart showing the results of a hypothetical poll in which most *clinicians* said they thought patients should speak up about their concerns). I used this non-validated prototype in interviews in order to help focus discussions with patients and caregivers about differing injunctive norms between patients and clinicians (as will be discussed in Chapter 6). Thus the final prototype set used in most interviews thus included 12 prototypes, 11 of which were validated.

The interviews were transcribed and analyzed with a codebook derived from constructs from the IBM. Code definitions were based on construct definitions (Montano & Kasprzyk, 2008). I collaborated with another member of the research team to code overlapping transcripts, first jointly and then independently. We met several times to iteratively refine the code definitions and how they applied to the data. After each meeting, each coder coded another subset of data, after which we met again to review where we converged or diverged on codes, coming to mutual agreement on each coded passage and refining the code definitions until each coder agreed the codebook was complete (meaning, the codes were well-defined, with examples, and it was clear how to apply them to the data). Together, we coded six transcripts, or 24% of the total data set. After the codebook was complete, I coded the remaining transcripts.

5.3 STEP 1 FINDINGS: PROTOTYPE VALIDATION AND EXPERT INTERVIEWS

In this section, I report on the results of the expert validation surveys and interviews (Step 1). Overall, experts reached low consensus on how each prototype was supposed to work. Interviews revealed that while experts did feel some discomfort with the IBM model, much of the divergence was due to differing interpretations of both elements of the design of the prototype and assumptions about the mechanisms themselves.

5.3.1 Validation Survey Findings: Low Consensus for Validation

My original goal for validation was to use average values of Cohen's kappa to test for validation. However, getting agreement between our experts on how prototypes were supposed to function proved difficult. Out of the 17 prototypes presented in the first round validation survey, only 6—less than half—achieved an average kappa value of .41 or more (moderate agreement according to Cohen (McHugh, 2012)). In the second round validation survey, none of the 7 prototypes achieved an average kappa value of .41 or more.

Moreover, interventions did not always validate for the construct for which they had been intended. For instance, one potential intervention, the Prevented Error Tracker, had been intended to target instrumental attitudes by tracking the efficacy of speaking up in preventing medical errors – in other words, by shaping outcome expectations. Instead, this intervention was unanimously perceived as targeting descriptive norms, by showing that patients *were* speaking up (average kappa value of 1, as there was perfect agreement among all respondents that this intervention operated only through descriptive norms and not through any additional mechanism).

Because I revised the validation threshold to be a simple majority, I ultimately validated 11 out of 17 candidate interventions in Round 1, and 4 out of 7 candidate interventions in Round 2.

5.3.2 Expert Interview Findings

Expert comments about the validation method surfaced one weakness of the validation method, namely difficulty with the model. However, expert comments also highlighted the inherent difficulty of mapping design interventions onto specific mediators of behavior, due to the inherent inseparability of constructs. The interviews also yielded insights into different researchers' attitudes towards validation of theoretical fidelity, specifically towards the necessity or even possibility of validating designs.

5.3.2.1 Difficulty with the Model

Although all survey respondents were familiar with behavioral models and HCI behavioral interventions in general, they were not all familiar with the IBM prior to the survey. All respondents passed the IBM quiz with either 92% accuracy (1 respondent) or 100% accuracy (5 respondents), or indicated they were already extremely familiar with the model (1 respondent). Nonetheless, some respondents struggled to keep terms straight when trying to map interventions onto constructs. For instance, E01, who had piloted the survey, commented that while taking the survey she *"always kind of [had] to go look back at the model to kind of distinguish between some things"* (the survey permitted respondents to move back and forth between the model overview and the potential interventions). E02 explained his concern that his doubts about the model affected how he mapped interventions onto it, saying, *"the more familiar I was with the concept the more … comfortable I was applying it. But for some of these newer concepts to me, or concepts which I was still piecing through … I had a little bit more trouble mapping those onto [interventions]."* Notably, not all respondents struggled with the model—E03, for instance, described himself as less familiar with the IBM, but extremely familiar with many other behavioral models, and found it easy to grasp the definitions of the IBM's unique constructs.

5.3.2.1 Inseparability of mediators from the expert perspective

Respondents also found the act of mapping interventions to the model taxing because they wanted to not just choose the most direct mediator through which the potential intervention would operate, but also any other mediators which could indirectly be invoked. As E04 put it, *"…I [marked]* *multiple constructs, if I thought that particular intervention might be relevant to multiple ones."* Although my goal was to target interventions to particular mediators, respondents often felt interventions touched on more than one mediator, either because of something inherent to the design of the intervention or because they saw mediators as inherently interrelated, for example in a causal chain, even though this was not how the mediators were depicted in the IBM.

In some cases, respondents found that the interventions were too complex to be mapped to only a single mediator. For instance, one of the potential interventions in Round 2 was a three-part intervention intended to target self-efficacy. Drawing on Bandura (Bandura, 1995), I had included three components to the intervention: a prompt for patients to reflect on past times they'd had difficult conversations with authority figures, a prompt for patients to imagine how the conversation might go, and a prompt for patients to look at fictional example conversations to help them prepare for speaking up to their clinicians. E01 and E02, who both had deep knowledge of self-efficacy in the context of behavior change interventions, found this intervention too complex to function through a single mediator. E02 commented, *"...there's kind of this main concept [self-efficacy] which it feels like is being brought up, but there are all these other components."* E01 broke down the intervention in more detail:

> *"I mean for example this one has like three things. So, and like 'see some examples of how other people can speak up about their concerns', I know that's one of the constructs, it's like seeing other people performing the behavior affects whether you yourself will perform the behavior, so I know that that's one of them, that's, which one is it, the descriptive norm? But the other two are. 'imagine how the conversation might go,' 'reflect on your skills' ... those are about you doing some form of reflection ... but one of them relates to this descriptive norm. And so ... the reason why it's more complicated, this one, is because it was three things, and I can see ... and I need to ... make sure they're all about ... the same construct or different [constructs]."—E01*

However, the inseparability of mediators invoked by the designs was not limited to complex designs. One potential intervention consisted of a pie graph showing poll results, stating that 99%

of patients think it is important for patients to speak up. E01 found that even this apparently simple intervention was more complex than it seemed:

> *I: I mean, maybe, but literally one of those things, the first one that we looked at is literally a pie graph. Representing a poll result. What's simpler than that?*
> *E01: Well, a pie graph where 99% of patients think that patients should speak up. Yeah. Right? That's also related to attitude. You could map it to attitude if you really want to.*

Similarly, E04 felt that a similar graph showing that 95% of clinicians thought that patients should speak up about issues in their care mapped both injunctive and descriptive norms. In E04's mind, the graph appealed to injunctive norms because *"this is about how other people expect me to behave".* However, E04 also mapped this intervention to descriptive norms because *"95% is pretty high number in my mind,"* and the high number of clinician support for patients speaking up suggested something about descriptive norms—about what patients and clinicians were actually doing.

E03, who worked extensively with behavioral models in his work, found connections between mediators not just inherent in the design, but also in how the mediator would operate. For instance, looking at an intervention consisting of a graph showing how often patients speak up in the hospital, E03 matched the intervention with "*descriptive norm as a first instance and maybe self-efficacy if some patients see other patient that are used to tell other clinicians about their problems, maybe they can feel more confident to share their problem.*" Thus in E03's estimation, an intervention directly targeting one mediator (descriptive norms) would indirectly invoke another mediator (self-efficacy), even though those two mediators are not causally connected in the IBM.

5.3.2.2 Necessity of validation of theoretical fidelity

My respondents split on whether they themselves made a practice of validating their designs. One respondent, E03, was unfazed by the prospect of validation and felt the easiest part of building a behavioral intervention was coming up with a validation and evaluation plan, *"to build a model, to identify in theory what could predict a certain behavior and also to design ... the evaluation plan. So for example, like, when do we have to measure each specific determinant or the behavior, these kind of things."* Although he said he did not validate his interventions, he described a project including a validation step that involved using participant ratings to make sure the proposed intervention was perceived by participants as he intended. E04 used manipulation checks in at least some of their work. E01 measured some intermediate constructs in her work, but was more focused on behavioral outcomes; and E02 expressed regret that he had not validated his designs, focusing instead on distal outcomes.

Respondents also differed on whether they saw validation as an essential part of their research. All respondents did research involving the development of interventions to accomplish behavior change. While E03 seemed to view validation as part of the process of model and intervention building and evaluation, other respondents felt more conflicted about the value of validating whether their interventions operated through a specific mechanism. E04 did sometimes include manipulation checks, but still felt that validation was not always the most important step in designing and evaluating behavioral interventions. As E04 put it, *"I think from the science perspective it's important to know what made the difference so that we can contribute to the theoretical aspect. So from the scientific point of view it's important. But from the practical point of view, is it important enough?"* Speaking of a hypothetical intervention that would work by building self-efficacy, E04 said, *"...if you can deploy something for a long term you don't have to measure self-efficacy. Or you can, like pre- post. But what would be more interesting and* *important would be the actual behavior change which is the whole purpose of the deployment study."* E02 and E01 felt that validation was important, but were more interested in behavioral outcomes than in validation. E02 wondered if his role was really to translate existing constructs into behavioral interventions rather than starting from the ground up with an atheoretical perspective. As he put it, *"…oftentimes I would classify myself a little more as a human-centered design researcher, and so … I'm building from … a need finding and that sort of thing rather than from theoretical interventions. …. Kind of like a building of theory through understanding people's preferences."* E01 also felt that divining how best to validate how well specific constructs were achieved by a design was not necessarily her role. For instance, speaking of measuring goal specificity, she described how defining goal specificity was not her role, saying, *"And there are other people who probably would study what's the right level of specificity, but I wouldn't necessarily. Not in the same way that a psychologist would."* E01 further speculated about the actual possibility of validation for every construct used in behavior change interventions. Speaking of an intervention that asked participants to create "specific" goals, she said, *"Like the level of granularity of what does it mean to be specific … varies a lot. I don't know what would be the consensus of what's specific enough. …. I guess I made some decisions, but I could have done it differently and it would still be specific."* E01 moreover pointed out that these difficulties extended to many constructs used freely in HCI interventions, *"[l]ike social support. What is social support? It's instantiated in so many ways."* E04, describing design problems as *"wicked problems"* (referring to (Rittel & Webber, 1973)), commented that it did not make sense to think about design in terms of right and wrong at all, but only in terms of better or worse, saying, *"…Design A might convey a particular construct better than Design B in a relative sense … there's no absolute answer but [a] relative answer".*

Overall, experts often disagreed about what mechanisms the intervention prototypes were likely to reach. This disagreement stemmed largely from both design elements of the interventions and from differing ideas about how constructs in the IBM inherently affect each other. In addition, experts disagreed about the degree to which HCI researchers should be concerned about validating behavior change interventions in the first place.

5.4 STEP 2 FINDINGS: INTERVIEWS WITH HOSPITALIZED PATIENTS

My focus in this paper is on presenting the findings of Step 1 and discussing methods of validation in HCI, rather than on presenting results about the needs of hospitalized patients. However, in my interviews with patients, some themes emerged which were similar to themes that had arisen in the interviews with experts. In particular, patients diverged in their interpretations of validated interventions, and their comments pointed to the same inseparability of constructs that was discussed in the expert interviews. I describe both sets of findings in more detail below.

5.4.1 Patient vs. expert assessments

Patients at times different from experts in how they responded to interventions. For instance, experts agreed unanimously that two prototypes acted only through descriptive norms. These were a graph tracking how often patients spoke up, and a graph tracking how many errors patients had prevented by speaking up. Yet patient and caregiver comments sometimes suggested that these prototypes could function as interventions on different mechanisms of change. Y01-C enthused about the prevented error tracker, not because it illustrated that patients were speaking up, but because it highlighted both the potential for errors and the potential of speaking up to prevent those errors—in other words, because it impacted outcome expectations (a component of instrumental attitudes). Y01-C described this as her "*favorite*" intervention because of its impact on patient attitudes, saying, *"If you don't speak up and there could be an error that's happening, are you really safe? Kind of like the medicine. When you're in the hospital and you're here getting care, should you always be safe?"* A06 likewise praised the error tracker prototype for its focus on outcomes and its illustration of the fact that *"people actually hear you"* and *"your speaking up makes a difference"*. The prototype that tracked how often patients spoke up likewise was interpreted in more than one way by participants. For instance, A14 interpreted this graph as being about outcomes as well, on the grounds that people would only speak up if it made a difference. As she put it, *"... to see how much of us speak up and how much of us don't. It's kind of helpful to see that. ... Because then we know if we should – if speaking up actually works and helps us in the long run, or if it doesn't."*

5.4.2 Inseparability of mediators from the patient perspective

Patient responses to intervention cards demonstrated a similar theme of the inseparability of mediators. As was discussed in the expert interviews, this inseparability resulted both from the design of interventions and from inherent links between mediators. For instance, one intervention card that showed a graph of how often patients at the hospital spoke up. This intervention card had been intended to target descriptive norms, and experts had unanimously rated it as targeting only descriptive norms. Looking at this intervention card, A01 read into it both descriptive norms, injunctive norms, and instrumental attitudes. She thought it *"great to see the number of patients that do it,"* and commented that the graph made her feel like speaking up is *"normal and it's a good thing to do and people are doing it,"* demonstrating both an impact on her belief about descriptive norms and an impact on her instrumental attitudes (that the behavior was generally a "good thing to do"). In addition, A01 commented that looking at the graph, *"So that just occurred to me, it's like people have your back."* In other words, seeing a graph that showed simply the number of people speaking up implicitly suggested to her that all those people speaking up would also approve of her speaking up, and that it must be a good thing to do because so many other people were doing it. Although the design of the intervention card was extremely targeted, for A01, it touched implicitly on multiple other mediators of behavior.

As with experts, patients' comments also revealed how mediators could causally influence each other. Looking at a graph of how many errors patients had prevented, A07 illustrated how belief that other patients were speaking up (belief about descriptive norms) could increase her self-efficacy. As she put it, *"If everybody else is speaking up, why can't I? I can just be more brave and say something. ... Sometimes I had a tendency to not be very brave, so knowing that other people are speaking up makes it easier."*

Overall, patients and experts did not always respond in the same ways to intervention prototypes. However, similar themes emerged among patients and experts, in the sense that patients, just like experts, felt that some mechanisms of change were inherently related to each other, as well as that the design of interventions often called on more than one mechanism, even when it had ostensibly been targeted at a single mechanism.

5.5 DISCUSSION

As mentioned in the findings, the results of the expert surveys were sometimes unexpected. In what follows, I discuss possible reasons for the low consensus among participants about how prototypes were supposed to work. I also discuss experts' differing stances on the role of HCI research in designing behavior change applications, and the kinds of methods HCI researchers can use in future to gain information about how an intervention is working.

5.5.1 Possible reasons for low consensus

There are four possible reasons for the low consensus among experts on how the prototypes operated. First, it is possible that the experts were simply not comfortable with the model. Second, it could be that the model's constructs are simply too poorly defined to be used for this purpose. Third, the prototypes could simply be too messy or complex to be cleanly mapped onto the model. Fourth, it could be that it is inherently difficult, if not impossible, to cleanly map interventions onto a model in the minds of all users of the prototype.

With regards to expert comfort with the model, my expert interview findings suggest that the "experts" did not always feel comfortable with individual constructs from the IBM. A related concern is with the quality of the IBM's construct delineations. It is possible that there is something about the IBM which is uniquely confusing and difficult for people to work with, especially as it makes distinctions between constructs that not all experts agree are distinct (for example, Hekler et al. state that many behavioral scientists consider self-efficacy and perceived control to be essentially the same thing, even though they are distinct from each other in the IBM (E B Hekler et al., 2013)). Poor definition of model constructs could have contributed to expert confusion, and could mean that survey respondents lacked a shared understanding of construct definitions. However, expert interviews revealed that survey respondents were able to move back and forth between construct definitions and interventions. Thus, interview findings suggest that survey respondents were likely able to compensate for lack of familiarity with the model as they went through the survey. Survey respondents' high performance on the quiz built into the survey also suggests that they understood the construct definitions given in the survey. Issues with expert clarity on model constructs could still have contributed to low consensus; however, the interview findings and quiz results suggest that they are not the only or even necessarily major contributors.

Nevertheless, this concern could be explored more fully with additional study focusing on other models. If interventions based on other models achieved greater consensus, then it would suggest that issues with either the model or experts' knowledge of it was partially to blame for the low consensus on the prototypes. In future work, researchers should more fully explore what characteristics of behavioral models are more likely to achieve expert consensus. For instance, I chose the IBM because of its granularity of construct definition (e.g., breaking up 'norms' into subjective and descriptive norms). But could that very granularity have contributed to a lack of consensus, because the lines between constructs are too thin? Additional exploration is needed to determine if, for instance, there is higher or comparably low consensus if interventions are instead based on and mapped to a model like the TPB, which is simpler than the IBM.

The other possibilities for low consensus were that the prototypes were inherently flawed, or that consensus is simply difficult because of individual variability. The interview findings presented in this chapter suggest that low consensus was likely due in large part to individual variability, and that the prototypes were not necessarily flawed, but rather subject to that same variability in individual interpretation. Theory is in the eye of the beholder in the sense that individuals find different meanings in the same intervention. Individual variation also accounts for the variation observed in patient participants, and the disagreements between patients and experts.

5.5.2 Role of HCI

Our expert participants had varying opinions about the goals of HCI research in behavior change interventions. Specifically, experts felt unsure about whether HCI should focus on whether the intervention works or on ensuring theoretical fidelity; about to what degree it is the role of HCI to create design specifications for theoretical constructs that are underspecified for design; and about whether HCI research is about translating theory into design, or rather taking a ground-up, user needs-based approach rooted in empirical findings rather than abstract theories. As described earlier, other researchers in HCI have argued that it is critical for HCI researchers to measure the impact of an intervention on its purported mechanism of change, in order to facilitate the aggregation of knowledge that can be transferred to future interventions (E B Hekler et al., 2013; Kay et al., 2016; Klasnja et al., 2017) and aid with knowledge-sharing between fields (Erik B. Hekler, Klasnja, Traver, & Hendriks, 2013). Our findings suggest that for other researchers in the field, this is still an open question. E04's comment about whether evaluating an intervention's impact on mechanisms is "*important enough*" suggests that this disagreement stems partially from concern over resource limitations. As will be discussed in more detail in the next discussion section, designing a study to evaluate mechanisms impacts both researchers and users, since researchers must put in the time to properly map their proposed interventions onto an appropriate theory (Bartholomew et al., 1998; Klasnja et al., 2017; Kok et al., 2004), any method of data collection on mechanisms of change is likely to require direct input from users of the system.

However, our expert participants' comments suggest another level to this disagreement, namely questions over the role HCI researchers should take in translating theoretical constructs into design. Constructs from behavior change theories are generally underspecified for design, and the well-known taxonomy of behavior change techniques from Michie et al. (S Michie et al., 2011) is largely atheoretical (E B Hekler et al., 2013), although there has been some work to map these techniques onto mechanisms of change via expert consensus (Connell et al., 2018). As several of our experts pointed out, this leaves designers hanging to some extent, as they must figure out on their own exactly what it means to instantiate a construct into design. To what degree is it the role of HCI researchers to gather data about exactly what ways are better or worse to instantiate constructs, and in what contexts? While some expert participants (like E01 and E04) felt that this was not necessarily the job of HCI researchers, it is a necessary step to obey calls from others in the field for supporting better aggregation of knowledge. In addition, one participant argued that instead of translating theory into design, HCI researchers can and should at times adopt a ground-up, user needs-based approach to design, starting with identifying user needs and then creating systems to meet those needs.

Wobbrock and Kientz list empirical contributions as one of seven types of contributions in HCI (Wobbrock & Kientz, 2016). Identifying user needs falls solidly into this contribution type, and creating systems to meet and further explore those needs is valuable work. When the goal is behavior change, however, building interventions off of behavior change theories gives HCI researchers a scaffold on which to understand their results. This is not to say that, for instance, a grounded theory (Corbin & Strauss, 1990) approach to qualitative data about user needs and user interaction with new technologies is not useful. Approaching qualitative data without an explicit theoretical lens can allow researchers to stay close to themes in the data and design interventions responsive to those themes, and to identify opportunities for where theory can be usefully applied. For example, researchers have found that interventions not initially designed for identity construction have been adapted to that purpose by end users, revealing unexpected avenues for supporting people living with chronic illness (Mamykina & Miller, 2010). However, designing behavior change interventions rooted in theory, and evaluating those interventions both for efficacy and for details about how and in what contextual circumstances they succeed or fail, is vital for advancing the science of behavior change (E B Hekler et al., 2013).

5.5.3 Methods to Examine How an Intervention Is Working

Thus far, calls for directly measuring the impact of interventions on mechanisms of change (E B Hekler et al., 2013; Klasnja et al., 2017) have been concerned with the risk of missing a real effect if an intervention fails, and the risk of not accurately testing the hypothesis in the first place. For this reason, these calls have focused on anticipated mechanisms. Our findings demonstrate that anticipated mechanisms may not capture the whole truth of an intervention—that interventions can work in unexpected ways. The issues of validation and theoretical fidelity raised in our results are relevant in two cases. First, if the intervention fails, it might still have a real effect—but that real effect might be via an unexpected mechanism, meaning researchers would be missing that real effect. In this case, gathering data about which, if any, mechanisms of change the intervention impacted is useful for the same reasons gathering data about anticipated pathways is useful—understanding whether the intervention actually impacted any mechanisms of behavior change, even if it failed due to outside factors, can yield knowledge to guide the design of future interventions. Second, if the intervention works, it might work for reasons that are not the anticipated ones—it might work via an unanticipated mechanism or mechanisms. In this case, gathering data about how the intervention actually worked is still important, in order to add to scientific knowledge of the mechanisms of behavior change that are effective in particular contexts.

But how can we measure what mechanisms an intervention impacts if we do not expect them to be impacted in the first place? I acknowledge that evaluating proximal outcomes for multiple possible mechanisms is difficult, as it adds to the complexity of the study plan and to the user burden. In addition, fully evaluating an intervention involves not just understanding whether it worked and what mechanisms were impacted, but also such criteria as user acceptability and engagement. Evaluating all three aspects of interventions is burdensome enough that one review found that less than a third of studies evaluated behavior change applications on all three counts (McCallum et al., 2018). However, it is asking much to ask researchers to evaluate an intervention on every possible mechanism devised by psychologists and behavioral scientists. Instead, I suggest following recommendations from Hekler et al. (E B Hekler et al., 2013) and using the *entirety* of the model the intervention is based on as a guide – in other words, evaluating whether the intervention is working by any of the constructs in the model, rather than only the intended mechanism, and without measuring every construct ever described in literature. This goal can be approached in two ways: either by a comprehensive battery of assessments, for instance psychometric questionnaires, meant to measure each individual construct, or by semi-structured qualitative interviews with users. While the first means can provide comprehensive data for each individual user, qualitative interviews offer other advantages. In particular, interviews or another form of qualitative data is necessary for disambiguating whether it is the *design* that touches on multiple mechanisms, or whether the mechanisms in question are inherently connected for a particular user. As Hekler et al. point out, one of the goals of behavioral science is to understand the interrelationships between the constructs in behavioral models, and behavioral interventions should be designed to facilitate a trial of principles (Eric B. Hekler et al., 2016), meaning to shed light on how different mechanisms of behavior change operate in the real world. HCI research adds onto this a layer of design – our goal is to understand not just the interrelationship between mechanisms of behavior change, but also the interrelationship between those mechanisms and the design of interventions (E B Hekler et al., 2013; Klasnja et al., 2017).

One concern of using qualitative data in this context is the risk of allowing confirmation bias to help us see things that are not there (E B Hekler et al., 2013). Hekler et al. suggest that qualitative researchers preregister their hypotheses or establish set phrases to define codes before analyzing their data to mitigate this risk (E B Hekler et al., 2013); however, this may not always be possible, given that much of the goal of qualitative research is to learn more about users' experiences and perspectives of a situation, which may not be predictable in advance. To mitigate this risk therefore, I suggest iterative study—after affected mechanisms have been identified through qualitative work, succeeding rounds of research can then use quantitative methods like psychometric questionnaires to verify the activation of different mechanisms of behavior change.

Additionally, these findings suggest that the interrelationships of design and mechanisms of behavior change may vary substantially between individuals. Whether qualitative or quantitative data collection is used to the measure the impact of interventions on mechanisms of behavior change, our findings suggest that researchers must analyze this data not just for overall trends, but also for patterns between individuals. Ideally, in the long run we will be able to find patterns in the variation of how individuals interpret designs and what mechanisms those designs trigger, and can use that knowledge to better understand how to design highly personalized, idiographic interventions (Martín, Rivera, & Hekler, 2017; Phatak et al., 2018), including interventions that adapt to users' changing needs over time (Kumar et al., 2013).

5.6 LIMITATIONS AND FUTURE WORK

There are several limitations on this work. To begin with, the sample of experts is quite small, and may not represent the full spectrum of views within the HCI community on validation. In addition, as described in the discussion, within the bounds of the current study it is not possible to tell if the results I found were the result of issues with the model, or expert familiarity with it, or whether the low consensus I observed reflects inherent difficulty in targeting interventions to specific mediators. Another potential contributing factor, which could not be explored in this study given the small sample size, is the background of expert participants. For instance, researchers trained in behavioral science may have a different perspective from researchers changed in HCI. More work is needed to more fully explore the reasons for this low consensus between experts. In addition, researchers should more fully explore how expert and end-user perspectives align or diverge on the interpretation of interventions and what behavior change mediators they touch upon. Further insight into how well experts can actually predict how behavior change interventions operate is needed in order to inform how behavior change research should be conducted in future.

5.7 CONTRIBUTION

In this chapter, I contribute empirical findings from a small-scale validation study of potential interventions encouraging hospitalized patients to speak up about issues in their care, as well as findings about how expert perspectives lined up with or diverged from end-user perspectives on behavior change interventions. I also contribute suggestions for the kinds of methods researchers should use to evaluate their behavior change interventions.

Chapter 6. DESIGNING MOTIVATIONAL INTERVENTIONS TO ENCOURAGE PATIENTS TO SPEAK UP IN THE HOSPITAL

As mentioned in the previous chapter, in this chapter I discuss findings from the patient and caregiver interviews, exploring **RQ3: How we can design technologies to help patients and caregivers in the hospital engage with their care and safety?** Before delving into the findings, I summarize some of the existing work on interventions to encourage speaking up to promote patient safety. Although the methods of this study were presented in the last chapter, I offer more detail on the protocol and prototypes used in the interviews. I then present findings relating to patients' attitudes towards different mechanisms of change and the design of interventions targeting those mechanisms of change. I discuss the implications of these findings for the design of patient-facing interventions to encourage speaking up.

6.1 RELATED WORK

In this section, I describe related work on speaking up, including work done to promote both clinician and patient speaking up behavior. I describe factors that have been found to be relevant to patients' willingness to speak up, and existing interventions designed to encourage this behavior. I highlight the need for additional work examining both the specific behavioral mechanisms which influence speaking up, and the design of interventions to affect those mechanisms.

Much of the work focusing on speaking up has actually focused on encouraging clinicians to speak up about issues in care delivery and quality that they observe (Bell & Martinez, 2019). For example, researchers have examined differences in speaking up culture between nonacademic and academic hospitals, and between clinicians of different roles like nurses and doctors (D.

Schwappach & Sendlhofer, 2018). Multiple studies have found that health care providers frequently do not report incidents that they observe (Martinez et al., 2015; D. Schwappach et al., 2018; D. L.B. Schwappach & Gehring, 2015), for a variety of reasons. For instance, clinician willingness to speak up is affected by perceptions of harm to reputation, harm to patients, and individual factors such as confidence and communication skills (Lyndon et al., 2012; Okuyama, Wagner, & Bijnen, 2014; Voogt et al., 2019). Researchers have also devoted attention to the development of scales to measure clinician willingness to speak up about concerns and unprofessional behavior (Martinez et al., 2015), and what kinds of interventions can encourage clinicians not just to report issues to the hospital, but to disclose errors to patients and families as well (Langer et al., 2016; Martinez, Browning, Varrin, Sarnoff Lee, & Bell, 2017).

Researchers have also called for greater exploration into ways to encourage patients to speak (Bell & Martinez, 2019). Thus far, much of the work in this space has examined what kinds of factors affect patients' willingness to speak up. As discussed in Chapter X of this thesis and noted by other researchers, patients' willingness to speak up about important health or safety issues, and to engage in safety-related behaviors, is affected by their trust in and relationship with clinicians (Rachel E. Davis et al., 2007; Doherty & Stavropoulou, 2012; V. A. Entwistle et al., 2010; Rainey et al., 2015), and fears of getting a poor response from clinicians (Delbanco & Bell, 2007; V. A. Entwistle et al., 2010; Frosch et al., 2012; Mazor et al., 2016; Rainey et al., 2015). Patients are less willing to perform behaviors seen as challenging clinicians (David L.B. Schwappach, 2010) or ask challenging rather than factual questions (R. E. Davis, Koutantji, & Vincent, 2008; David L.B. Schwappach, 2010), and they need clinicians to be willing to listen (Rachel E. Davis et al., 2007; Waterman et al., 2006a), approachable and responsive (Lyndon, Wisner, Holschuh, Fagan, & Franck, 2017). Clinician attitudes can influence patient autonomy in the hospital (Vikki A. Entwistle et al., 2010), another attribute that is thought to influence patients' willingness to speak up (Buetow, Davis, Callaghan, & Dovey, 2013). Indeed, one study found that clinician initiative to include patients drove much patient participation in the hospital (Redley et al., 2018). However, clinicians are not solely responsible for patients' willingness to speak up. Researchers have identified other patient attributes, such as conscientiousness and the patient's knowledge that can influence patients' willingness to speak up (Buetow et al., 2013; Longtin et al., 2010). Patients are also influenced by experience with medical errors, whether their own or someone else's, and fears of getting a poor response from clinicians (Nau & Erickson, 2005; David L.B. Schwappach, 2010). Patient's emotional worry about errors also influence their willingness to speak up (Peters, Slovic, Hibbard, & Tusler, 2006), as well as their physical state (Rachel E. Davis et al., 2007; Doherty & Stavropoulou, 2012; Mazor et al., 2016).

A few researchers have analyzed the factors associated with speaking up from a more behaviorist perspective. As mentioned in the last chapter, Luszczynska & Gunson (Luszczynska & Gunson, 2007) examined the impact of variables from the Theory of Planned Behavior (Ajzen, 1991) on patient willingness to ask providers about hand hygiene, and found control beliefs to be a relevant factor for predicting people's willingness to speak up. Hibbard et al. (Hibbard, Peters, Slovic, & Tusler, 2005b) analyzed the role of self-efficacy as well as patient beliefs about the efficacy of specific action items, and found that both mattered to patients' willingness to speak up or take action to ensure their safety. Schwappach et al. conducted a systematic review and created a conceptual model of patient willingness to engage in safety-related behaviors such as speaking up that incorporated some constructs from various behavioral models, such as self-efficacy, perceived subjective norms, and motivation (David L.B. Schwappach, 2010). However, more work is needed to understand both how different mechanisms can influence patient speaking up behavior, and how to design interventions to affect those mechanisms.

Researchers have devised a variety of interventions to encourage patients to speak up. Some of these interventions take the form of educational materials like videos and brochures designed to encourage patients to speak up (David L.B. Schwappach, 2010). For example, the Joint Commission's Speak Up campaign utilizes videos and brochures, which patients and their families have found informative (The Joint Commission, 2018a). Patient feedback on educational videos to promote patient safety has found that while patients appreciate the efforts to raise awareness of the necessity of patient engagement, a 'one-size-fits-all' approach is inadequate (Pinto, Vincent, Darzi, & Davis, 2013). A variety of health organizations, such as AHRQ (AHRQ, 2017), offer tips for patients and their families to participate in their care and improve their safety, although these recommendations may vary substantially between organizations and are often seen as being of little value (Weingart, 2009). Researchers have explored making portals (Grossman et al., 2019, 2017; Schnock et al., 2019), doctors' notes (Bell et al., 2017), and medication trackers (Wilcox et al., 2016) available for patients to give feedback and voice concerns, designed a variety of interventions for patients to stay informed about their care (Bickmore et al., 2009; Haldar et al., 2017; Miller, Pollack, et al., 2016; Prey et al., 2014; Skeels & Tan, 2010; Vardoulakis et al., 2012; Vawdrey et al., 2011; Wilcox et al., 2010), which can make patients more willing and able to act (Doherty & Stavropoulou, 2012; David L.B. Schwappach & Wernli, 2010). Indeed, one study found that a multipronged intervention including patient participation components like an inpatient portal substantially reduced adverse events (Dykes et al., 2017). Researchers have also explored ways to give patients alternative communication channels and personalized decision-support (Prey et al., 2014), which can help provide patients opportunities to speak up. Some researchers have also developed more targeted interventions. For instance, researchers have developed a variety of interventions to encourage patients to remind clinicians about hand hygiene (R. Davis et al., 2015), as well as to monitor and speak up about hospital acquired infections (Seale et al., 2015). Researchers have also explored ways to encourage patients to report incidents after they have occurred (S Collins et al., 2016; Couture et al., 2015). This body of work gives extremely valuable insight into how we can support patients in speaking up about issues in their care. However, intervention studies to promote patient engagement and speaking up thus far generally have not focused on understanding mapping intervention components to behavioral models to understand exactly *how* they work, in the sense of what motivators or mechanisms of behavior change they operate through.

Understanding this point is vital because despite efforts to promote speaking up and patient engagement, patients do not always voice their concerns (Mazor et al., 2012, 2016), and do not always feel comfortable speaking up about issues with their care (Bell et al., 2018; Fisher et al., 2019). One study found that nearly half of their participants did not speak up about issues they encountered in their care (Rance et al., 2013). Family caregivers, too, do not always speak up about concerns, and may feel guilty for failing to prevent medical errors from occurring (Delbanco & Bell, 2007). Thus, more work is needed to understand how we can design interventions that encourage patients to change their existing behaviors and speak up about their concerns more readily—and to incorporate patient perspectives and values into the design of those interventions to make them more likely to work (Vikki A. Entwistle, Mello, & Brennan, 2005; David L.B. Schwappach, 2010).

6.2 METHODS

Although the methods for this study were described in the previous chapter, here I provide some additional detail about how I adapted IBM methods for this study and my reasons for doing so, as well as some additional detail about the interview protocol.

6.2.1 Adaptation of IBM Methods for HCI research

As described in the last chapter, the current study applies the Integrated Behavioral Model (IBM) (Montano & Kasprzyk, 2008) as a lens to understand speaking up behavior in patients, and through which to design interventions. This model has been applied to a variety of other health behaviors, including condom use (Kasprzyk, Montaño, & Fishbein, 1998), strength training (Patterson, Umstattd Meyer, & Beville, 2015), food purchases (Rahman & Noor, 2016), and high-risk drinking behaviors (Braun, Glassman, Sheu, Jordan, & Yingling, 2014).

The IBM is often applied first through elicitation interviews to identify the specific underlying beliefs that constitute people's experiential and instrumental attitudes (underlying behavioral beliefs), beliefs about descriptive and subjective norms (underlying normative beliefs), and beliefs about perceived control and self-efficacy (underlying efficacy beliefs). After identifying these underlying beliefs, researchers can devise measures for IBM constructs, administer questionnaires to evaluate the relative weight of the constructs for a specific population and behavior, and devise interventions targeting those constructs (Montano & Kasprzyk, 2008). As described in the last chapter, my methods differ somewhat from this procedure. Because my goal is to explore not just the influence of different mediators, but also how to design for those mediators, I adapted the elicitation interview into a hybrid elicitation and low-fidelity prototype study, using prototypes targeted at individual mediators to explore patient responses to different design strategies. In addition, although the IBM is often applied to very targeted behaviors (e.g., using a condom), I used a somewhat broader approach, targeting ‘speaking up’ in general (rather than something more specific like asking clinicians if they have washed their hands), although ‘speaking up’ can encompass a variety of behaviors including asking different kinds of questions, voicing concerns, pointing out problems, seeking a second opinion, and even insisting on particular changes to care in the face of clinician opposition. I used this approach because the variety of undesirable events patients risk experiencing in their care (Haldar et al., n.d.) means that patients are likely to need to perform any one of those behaviors, and it may be unfeasible to design targeted interventions for each specific type of behavior.

6.2.2 Interview protocol

As mentioned in the last chapter, I used a semi-structured interview protocol with patients. The protocol opened with Bell et al.’s questionnaire about patient and family comfort with speaking up in various situations (Bell et al., 2018). Although initially developed for the ICU, this questionnaire allowed me to get a baseline understanding of participants’ comfort speaking up in various situations. Following this, I asked participants about undesirable events they had experienced in the hospital, and whether they had spoken up to clinicians about the event. I asked participants questions about IBM constructs, for example whether anyone had supported or been against their speaking up, what had make speaking up easy or hard, etc. Following this, participants were presented with the prototype deck described in the previous chapter. Participants were recruited and data analyzed as described earlier.

6.3 FINDINGS

As described earlier, the goal of this study was twofold: to explore what kinds of mechanisms motivated people to speak up or prevented them from doing so, and to explore how patients might respond to different kinds of targeted interventions. In the findings below, I describe participant comments, either from their descriptions of their experience with UEs or their responses to prototypes, that illustrate how different mechanisms of change from the IBM could influence patients to be either more or less willing to speak up. I present these findings in terms of the general category of mechanism: perceived norms (descriptive and injunctive), attitudes (experiential and instrumental), and personal agency (perceived control and self-efficacy). For each category of mechanism, I additionally describe the underlying beliefs that participant comments reflected, and design considerations that participants raised concerning the intervention prototypes.

6.3.1 Perceived Norms (Descriptive and Injunctive)

The IBM describes two kinds of norms: descriptive, or people's beliefs about what other reference groups do, and injunctive, or beliefs about what other reference groups think *should* be done, and the individual's interest in complying. The IBM describes two kinds of norms: descriptive, or people's beliefs about what other reference groups do, and injunctive, or beliefs about what other reference groups think *should* be done, and the individual's interest in complying. My findings showed that both descriptive norms (in this context, the belief that other patients also speak up) and injunctive norms (the belief that other people think patients *should* speak up)—had the potential to be influential for some participants but not others. We also found that three distinct reference groups had the potential to influence participants. Participants varied on the relative value of information about descriptive and injunctive norms, and in how they responded to different design strategies for conveying information about descriptive and injunctive norms.

6.3.1.1 Varied responses to descriptive norms

Participants varied both in their beliefs about how frequently other patients spoke up about issues in their care, and in how much value they put on knowing that other patients did so. For instance, Y07 commented that although patients were *"supposed to"* speak up, *"I do think not many people actually do."* By contrast, Y09 thought it *"common"* for patients to speak up. Some participants also had no idea: A15 said he *"[didn't] have a good feeling about it,"* but speculated, *"Half on one and half on the other, but that's just totally making it up."* Some participants felt that knowing other people were speaking up would make them more likely to speak up themselves. For instance, Y02 felt that getting information about other patients speaking up would make her more likely to speak up herself by increasing her self-efficacy. As she put it: *"Knowing that other people could have speaked up there, maybe I could have too. Because I'm kind of a follower and not a leader. [sic]"* A01 similarly felt that information suggesting that it was normal for patients to speak up was motivational, saying, *"This is great to see the number of patients that do it. ... It's normal and it's a good thing to do and people are doing it."* This motivational value may have lain in the fact that participants did not always know if it was their role to say something. As Y10 wondered, *"...when something's off, I'm like is someone going to say something? Am I supposed to say something?"*

Some participants reflected that the motivational value of information about other patients speaking up depended greatly on how common the behavior actually was. For instance, looking at a prototype showing a graph of how often patients in the hospital spoke up, A04 said, *"If I was looking at this, I think it would inspire me seeing the higher numbers, knowing that other people* *spoke up. It might make me ... a little more bold, to say these people did it, let me do it and see what I can get out of it. ... [If I saw low numbers,] I'd have probably kept my mouth shut."*

Other participants flatly rejected the idea that knowing what other patients did would or should have any impact on their behavior at all, on the grounds that other patients' experiences were not relevant to them. As A06 put it, *"I don't see why it matters. ... I don't really care what other patients do. I need to speak up."* Similarly, Y06 commented, *"I don't think using what other patients do to affect my decision is a very good way to choose."* In some cases, this indifference towards other patients' actions stemmed from concerns over how similar to them other patients really were. A05 stated, *"I don't really care how other people feel because I don't know what they're going through, they don't know what I'm going through. They might be severely depressed and have heart disease and a brain tumor. Or they might just be medically slightly impaired, which would – it's a totally different situation."*

6.3.1.2 Different reference groups for injunctive norms

With regards to injunctive norms, I discussed three different populations with participants: other patients, clinicians, and family and friends. As with descriptive norms, participants varied in how they valued information about these populations' thoughts about what patients *should* do.

Participants had mixed reactions to the idea of other patients as a reference group for injunctive norms. A few participants felt it would potentially be valuable to know that other patients approved; as Y03 put it, it *"[j]ust kind of shows you're not alone.*" However, some participants simply did not care whether other patients would approve of their actions or not. A11, for instance, believed that other patients would approve of her speaking up—but did not care about it in the slightest. She said, *"I think most patients think that you should speak up and let the doctor know what's on your mind or if you have some questions or things like that. ... Do I think it's important* *what patients think of me for speaking up? No."* A09 was equally dismissive of the idea that other patients' opinions mattered, saying, "*I'm not trying to be rude or anything, but me as a patient, why would [it concern me] what other patients think they should do in regards to speaking up?"*

As has been noted by other researchers (R. Davis et al., 2015; V. A. Entwistle et al., 2010), clinician attitudes loomed quite large for participants. In large part, this feeling stemmed from concerns about the outcomes of speaking up, as will be discussed in the next section. However, clinician attitudes in and of themselves also seemed to be an important factor for many patients. Clinician signals that they were not interested in hearing patient concerns were discouraging for several participants. Y05, for instance, reported having a hard time speaking up to his first surgeon about concerns he had about the procedure, because *"[m]y first surgeon comes off like cocky, and it makes it sound like he doesn't care about what I'm saying. It makes me feel very uncomfortable."* A02 likewise struggled with a clinician who "*was kind of irritated by having to be there and talk to me. So she didn't feel ... invested in my dilemma. If we have a dilemma ... it's concerning, and it may be embarrassing, and it may have taken everything we could think of to bring it up with a total stranger. So you expect a certain amount of professionalism and kindness ... not just dismissive rudeness."* On the other hand, participants expressed gratitude for clinicians they had encountered who were more interested in hearing what they had to say, and generally supportive of the idea that *".. the doctors or whatever should make it very clear that you are to speak up if you have any concerns"* (A07). Participants frequently responded positively to prototypes demonstrating that clinicians wanted to speak up and would approve of their doing so. For instance, one prototype consisted of a hypothetical poll result showing that 95% of clinicians at the hospital thought patients should speak up about their care. Several participants responded positively to this prototype, like Y04, who explained that seeing that information would be important *"[j]ust* *because if like the doctors want you to speak up to them, then it's important to communicate with them everything. Especially when it comes from them, that you need to communicate with them, it is more important."* Indeed, some participants were inclined to view all the prototypes favorably simply because in the interview protocol, the prototypes were introduced as hypothetical tools provided by the hospital. Participants like A08 took this setup as *"...say[ing] that they're willing to listen, that there's a way to open the box of communication"* with hospital staff.

As with descriptive norms interventions, numbers mattered for some participants. Asked if the poll had shown that only 35% of clinicians felt that patients should speak up, A08 commented, *"I'd be scared. If the team that is helping me fight for my life isn't willing to listen to me when I know my own body, then there's a big problem."* Y06 speculated that her threshold was around 60/40: *"I would never give my opinion if it was ... [below] like 40 percent said they didn't."* However, clinician support for speaking up was not uniformly seen as important. A10, in the minority, commented, *"[W]hy would the patients care what the clinicians think about it? .... They might think whatever they want to think, but the patients are going to do what they're going to do."*

Participants also brought up family and friends as an important reference group whose support and approval mattered. For instance, A14 found the courage to speak up about needing additional pain medications in the face of clinician resistance by *"[j]ust continuing to talk to friends and they really encouraged me to do something about it."* Similarly, when Y02 struggled to speak up to clinicians who claimed her symptoms were caused by intoxication, she sought support and approval from her mother: "*when people are going through all these things and telling a whole bunch of different things, I don't have the guts to be like hey, no, you're wrong. That's why I had to call my mom and be like 'they think I'm drunk or on alcohol when this happened.'"*

6.3.1.3 Relative value of injunctive and descriptive norms

The relative value of injunctive and descriptive norms varied by person. For instance, Y06 was not at all interested in whether other patients spoke up or what they experienced, but did respond positively to a prototype showing that other patients thought it important to speak up. She explained her preferences by saying, *"I appreciate other people's opinions, I just don't think their experience is important."* Y02 also suggested that injunctive norms might be influential for her, but worried that information about injunctive norms might not reflect the reality of descriptive norms. She said, *"This is where it gets hard, because even though patients think patients should speak up, you see the amount of patients that do speak up versus who don't. Because they'll say that you should, but most people – you never know, they might not."* Y02 felt that only information showing very high levels of agreement that patients should speak up, from multiple reference groups, would really imply that patients frequently spoke up: *"Only if you see like doctors think you should and patients think you should, then you're like okay, everybody does."*

6.3.1.4 Underlying beliefs for descriptive and injunctive norms

Participant comments suggest that patients vary quite a bit in the degree to which they believe that other patients speak up, or think that it is important to speak up. While clinicians were generally a very important reference group for injunctive norms, participants varied in the degree to which they believed that clinicians actually wanted them to speak up; these beliefs were largely determined by patients' previous experience with clinicians, and tended to be specific to individual clinicians. Participants also generally considered family and/or friends to be an important reference group, and varied to the extent that they cared about the judgment of other patients, in particular because they did not always believe that other patients had anything in common with them.

6.3.1.5 Design considerations for descriptive and injunctive norms

As described in the last chapter, participants perceived information about norms even in prototypes that were not intended to show information about norms. However, participants' responses to a few prototypes in particular frequently reflected a change to beliefs about descriptive or injunctive norms. These prototypes were created with two major design strategies: graphs (a bar graph of how often patients speak up, a bar graph of how many errors patients have prevented, and pie charts showing poll results patient and clinician attitudes about speaking up) and stories (a prototype where patients could anonymously share their own stories of speaking up, and a prototype where patients could share their opinions about the importance of speaking up). Below we discuss the pros and cons of each design approach.

A few participants found the graphs simply easier to digest than more wordy stories. For instance, Y07 commented that he "*would prefer something quick, like a graph. I personally am not a fan of reading*". A15 similarly preferred the pie charts, which had accompanying interpretive statements (e.g., "95% of clinicians think patients should speak up about their concerns") to more complex prototypes because *"they just seem simpler and give me the information without me having to try and figure it out".* However, other participants preferred stories, even participants who at first said they were completely uninterested in information about other patients. For instance, A06, as quoted earlier, declared herself completely uninterested in other people's behavior. However, she responded positively to the prototype in which patients shared their experiences, saying, *"I don't respond well to graphs and data, I respond well to narratives."* Y06 similarly ranked the same prototype in her top 3 despite her lack of interest in what other people did, simply because she found the content engaging: *"I don't care about people's experiences, but I like reading about them. ... I like stories."*

Participants also liked stories because they offered more information than graphs. Although the stories-based prototypes offered no concrete numbers about how often patients actually spoke up, participants still interpreted them as suggesting that it was normal for patients to speak up, and could additionally glean other information from them that could shape their beliefs about potential outcomes and strategies. For instance, A08 felt the prototype in which patients could share their experiences was valuable *"[b]ecause it's not just a statement, it's showing people how somebody felt, what they did, and the fact that it came out okay."* However, this very depth posed a problem for Y08, who wanted to isolate herself from even superficial knowledge of other patients' situations and actions to help her maintain emotional distance from others in the hospital. She commented, *"... the way I came into cancer is when I get emotionally involved with other patients, I get sad so I kind of just stick to our situation and I realize everyone else has their path and this is our path right now, so ... I wouldn't really want to know about how other patients are going through."*

Although the stories design strategy ostensibly offered more detail than graphs, however, participants displayed a tendency to read more information into the graphs than was really there. For instance, A01, looking at a graph of how often other patients spoke up (descriptive norms), read into it implicit approval for her own speaking up (injunctive norms): "*All right. So that just occurred to me, it's like people have your back."* Looking at a pie chart showing what percentage of patients believed patients *should* speak up, Y07 took away ideas about how often patients do speak up and what kinds of outcomes they experienced, even though this information was not present: *"it shows you that others do it so it's okay for you to, and they also think you should, because it helped benefit them or something."* A14 likewise read information about outcomes into the graph showing how often patients spoke up, concluding that after looking at it patients would *“know if we should – if speaking up actually works and helps us in the long run, or if it doesn't.”*

6.3.2 Attitudes (Instrumental and Experiential)

Participant comments yielded insight into both experiential attitudes, or the affective component of people’s attitudes towards a behavior, and instrumental attitudes, or the cognitive component of people’s attitudes towards a behavior, including beliefs about outcomes.

6.3.2.1 Negative experiential attitudes

On the Bell questionnaire (Bell et al., 2018), participants generally rated themselves as relatively comfortable speaking up in various situations. Of all possible responses (every participant’s rating, 1-4, to every situation in the questionnaire), 61.5% were “4,” or “most comfortable”, and an additional 21% were “3”. However, when describing real-life events, participants almost uniformly described speaking up as some version of “*scary*” (A02), “*very hard*” (Y02), and even “*awkward*” (Y06). Even A06, who felt comfortable speaking up about her needs, viewed speaking up as an unpleasant necessity, saying, *“The fact that I have to speak up and question my care makes me angry… .”* Participants’ comments suggested that despite the ratings they gave on the questionnaire, in real life scenarios, they had negative experiential attitudes towards speaking up.

Although experts classified three prototypes as operating through experiential attitudes, participant comments generally suggested they had impacts that were more closely related to instrumental attitudes. I describe instrumental attitudes below.

6.3.2.2 Instrumental attitudes shaped by possible outcomes

Weighing in with participants’ negative affective assessment of speaking up were their instrumental attitudes towards speaking up, in particular their expectations of what would result from speaking up. Participants envisioned a number of possible outcomes, both negative and positive. Negative outcomes included the possibility of nothing happening, the possibility of being perceived negatively by their clinicians, and the possibility of emotionally hurting clinicians. Positive outcomes included the possibility of improved health outcomes and the possibility of improving the system for future patients. A few participants also commented on outcomes involving the emotional results of speaking up.

Some participants described concerns that speaking up would result in no action from clinicians, especially when clinicians did not appear to support patients when they were vocal. For instance, A08 described trying to get clinicians' attention to attend to her sick parent. After clinicians *"blew [her] off"* the first time, *"the next time that things started to change and I said it again and the same thing happened, I was afraid to say anything more. Because I had been completely disregarded ....".* Y05, describing his first surgeon's arrogant manner, said, *"[I]t basically makes me not want to say anything because I don't feel like I'm going to be heard."* Patients could be concerned about clinician non-response to their complaints even when they did not feel clinicians disapproved of their speaking up. For instance, A05 was not concerned that his clinicians would disapprove of his speaking up, but felt that nonetheless they would not act on his words, saying, *"I don't think anybody was against the speaking out, it's just who was going to listen?"*

Participants were also concerned about the effects speaking up might have on how clinicians perceived them. A14, for instance, was concerned that speaking up about her pain *"might look like I'm seeking drugs, and kind of asking for more".* A11 refused to voice her concerns about not getting attention from the nurses because, *"They wouldn't like me to say that. I just feel like they would feel like I didn't understand how many other patients that they have."*

A02 discussed how "*hard*" it would be to ask clinicians about suspected errors *"because you don't want to introduce doubt or mistrust, because you're going to continue the relationship unless it's catastrophic"*. Y02 was concerned that because he/she was a child, speaking up was even more likely to be futile, saying, *"there's always cons of they'll think I'm lying, they'll twist my words around, they won't listen to me, I'm just a kid."* Y10 and A07, by contrast, were concerned not about she herself would be perceived but about *"hurt[ing] her [doctor's] feelings"* (A07) or making clinicians *"feel like they're incompetent"* (Y10) by expressing doubts about the doctor's plan or actions.

Weighing against this negative affective assessment was the potential for speaking up to improve participants' health outcomes. A15 described how he had learned that speaking up was worth it through *"age. Just getting older and done it so many times. Hearing all the bad stories of things that could happen. I think there were medical errors made in people that I know."* The outcomes that motivated patients to speak up varied in extremity. Y03 described speaking up to unwilling clinicians to modify his diet plan so that he could eat in order to improve his comfort: *"I was hungry and did not like sitting here uncomfortable, and I made it very clear – they went over the technical aspects, why they couldn't, but I didn't want my stay here to be uncomfortable and I strongly urged them and pushed them to go for a more stronger approach, if they would nudge any. ... my persistence, I would say, paid off."* Other participants, like A04 and A05, felt their very lives were on the line. Indeed, concern about the risk to her life motivated A04 to overcome other obstacles to speaking up about her cancer diagnosis: *"I just had a gut feeling that it wasn't correct and that I was being kind of pushed aside, that my concerns were nothing. .... finally I had to step outside that box and just take it into my own hands, and sure enough, I saved my own life."*

Some participants also responded positively to prototypes that showed how speaking up could improve health outcomes in general. For example, A06 praised a prototype showing the number of errors patients had prevented by speaking up, because it would help her in *"[u]nderstanding that you're not just shouting into the wind, that your speaking up makes a difference*" (A06). Y02 similarly felt it would encourage patients to "*be like hey, you know, are you giving me the right dose? Because it says right here, like somebody messed up*" (Y02).

A few participants, like A01 and A02, spoke of the possibility that if they were willing to take on the burden of speaking up, it could help other, future patients. A02 described this viewpoint almost as a way of life, saying, *"I was raised to have conversation, listen effectively and give and get feedback on both sides, so you can learn and move forward and solve the problem for other persons."* Y09 similarly spoke to the need to speak up and report problems regardless of how clinicians responded, for the sake of future patients, likening speaking up to knocking at the door: *"Because sometime, even the door's not open, we can knock. Someday maybe nobody passing by at this time, they keep knocking. Maybe sometime people walking by – oh, somebody knocked the door. They're going to listen and open the door. [sic]"*

In addition to the health-, care-, and clinician-patient relationship- related outcomes described above, participants sometimes spoke about affective outcomes—the emotional consequences of speaking up. Comments about affective outcomes generally arose in response to a prototype tracking how patients felt before and after speaking up, which showed more negative emotions before speaking up and more positive emotions after speaking up. As with other prototypes, responses to this prototype were mixed, with participants feeling that the emotional states depicted in the prototype were realistic to varying degrees. A01, for instance, called it "*too optimistic"* and *"Pollyanna-ish"*. However, several participants commented its motivational value. For instance, A08 praised it for offering “a possible light at the end of the tunnel,” while Y07 called it *“motivational …. because it shows that after they spoke up, all these people felt these good feelings and that probably motivates you to feel the same way.”* These comments suggest that attitudes about affective outcomes, while not foremost in people’s minds, may still hold some motivational value for encouraging patients to speak up.

6.3.2.3 Underlying beliefs for experiential and instrumental attitudes

With regards to beliefs about attitudes, participants almost uniformly found speaking up to be a difficult task, and their beliefs about whether it was worth the effort depended greatly on projected outcomes. Participants worried about being perceived as confrontational or unsympathetic to clinicians, but concerns about potential negative health outcomes drove several participants to speak up anyway. Participants were also interested in considering the emotional benefits of speaking up about issues in their care, although they varied as to whether they felt speaking up would necessarily provide emotional relief or not.

6.3.2.4 Design considerations for attitudes

Three major themes emerged regarding different design strategies for attitudes, particularly for instrumental attitudes. The first was the appeal of showing affective outcomes, the second was considerations about the depiction of negative outcomes, and the third was whether digital interventions were appropriate at all for conveying information about the clinician-patient relationship.

As mentioned above, participants were offered a prototype showing a progression in affective state from negative emotions (e.g., anxious, worried, concerned) to more positive emotions (e.g., relieved, calmer) as a result of speaking up. One interesting aspect of participant responses to this prototype was how strongly several participants identified with the negative emotions depicted. A03, for instance, immediately exclaimed, *“Yeah, this is actually kind of how I felt on my stay here,”* while Y02 commented, *“All those first words you see, that's stuff like me.”* A05-C speculated that this very identification might help patients realize that speaking up was an option. She said that such an intervention *“might have encouraged us”* to speak up in the past, explaining, *“Because if you are worried and helpless or stressed or whatever, you might not recognize that a relief to that is speaking up. People who are depressed, they don't know how to get out of being depressed until somebody shows them that there can be [action items that can help].”* These comments suggest that interventions to encourage patients to speak up may gain impact simply by surfacing affective states that patients may be feeling and unable to voice. Another consideration is the depiction of negative outcomes. Some participants preferred to not dwell on the risks of speaking up. For instance, Y01 felt *“bad”* (Y01) *and “overwhelm[ed]”* (Y01-C) at a prototype showing the possible impacts of speaking up on the clinician-patient relationship. Although the prototype painted the impact of speaking up in a positive light, showing improved trust and communication resulting more frequently than conflict, the very possibility of conflict was enough to discourage her from voicing her opinions. As her mother (Y01-C) put it: *“So there's certain people who try to avoid confrontation at all cost, and she is definitely one of them.”* Similarly, looking at a graph of errors prevented by patients speaking up, A05 commented that such information *“would scare the hell out of me”.*

Another design consideration that arose in interviews concerned specifically prototypes that centered on the clinician-patient relationship. Some participants commented that they felt information about the clinician-patient relationship could only reasonably be determined by in-person interactions with the clinician themselves, rather than by generic information about other clinicians in the hospital. For instance, Y02 said she would not just rely on a graph, but also *“go* *off the vibe I get from my doctor*," while A05-C commented, *"I wouldn't have to look at a survey to have an opinion about the relationship between my care and the staff. You just know it. You feel it, you see it."* This finding points to the limits of technology in affecting patient beliefs about the outcomes of speaking up on the patient-clinician relationship.

6.3.3 Personal Agency (Self-Efficacy and Perceived Control)

The last two constructs we examined in the IBM both relate to personal agency—namely, perceived control (an individual's belief that the behavior is under their control to perform) and self-efficacy (an individual's belief in their own ability to perform the behavior). Participants cited some obstacles that impeded that control, namely the lack of opportunity to speak up, and their own physical condition, and generally responded favorably to prototypes that facilitated the creation of opportunities to speak up. Participants also described how various factors impacted their confidence in their ability to speak up, including how particular prototypes could help build self-efficacy. Participant comments highlighted two themes in designing for personal agency: the social acceptability of interventions and the compatibility of interventions with situational impairments.

6.3.3.1 Impediments to perceived control

Participants felt that speaking up was not under their control under two circumstances: when they simply lacked opportunity to speak up and when they felt too ill to do so. For example, some participants felt that clinicians were often too rushed to allow them time to voice their concerns. For this reason, participants frequently responded positively to a prototype representing a stop button, that would allow the patient 30 seconds of uninterrupted talk time. For instance, Y04 felt the stop button could have helped her communicate to her clinicians when she felt they were mistaken about the source of her pain: *"I think that could be useful, just because sometimes it's* *hard to fit what you want to say into the conversation that's going, so if you had that, you'd be able to communicate more just what needs to be communicated."* Similarly, Y10 responded positively to the idea, *"because sometimes they're all just busy doing their own stuff and only one person in the room is listening to me. And I had the courage to speak to everyone, but they're not really paying attention."* Y01-C was likewise enthusiastic about the prototype because she felt it would give her daughter, who habitually needed time to think before speaking, a better opportunity to speak up about concerns: "*I think something like that would be fantastic. Give a patient a chance, who maybe does have a delay in communication, to give her a chance to say hey, I've got something to say."* Participants described how access to different kinds of hospital staff was at times invaluable in helping them speak up, because it gave them the opportunities they needed. For instance, Y08 described how she could call on the social worker when she felt like she could not reach clinicians.

Y01-C brought up the risk of patients not even realizing that they could speak up about concerns, thereby missing opportunities to do so. This risk was also evidenced by occasional participant responses indicating that they did not know they could speak up about specific things, such as asking for a meeting with the medical team to review their health status (A04). Y01-C described how an intervention that showed that other patients were speaking up (descriptive norms) could help such patients realize that speaking up was something they had control over. In response to a prototype graphing how many errors patients had prevented, she said, *"I think having something like that, if that was ... shown to kids that you have the opportunity to speak up, that a person of their age group does stand up and speak up for themselves, ... this is their health, this is their life, ... that yeah, you can say something. It's not just about your parents saying something."* Y09 similarly felt that the 'stop' button could actually help patients by simply making them aware that they could speak up at all, saying, *"Visually it's immediately going to give the patient more caution."* Y09 likened the process to the 'stop' button on an airplane assembly line, emphasizing the importance of encouraging everyone in the chain to highlight problems: *"For example ... testing aircraft. ... You do the hot button – oh, this is something I have to check, I should be careful. ... When you do something, there's all these related together, so if you miss one thing, it's going to break everything. It's more than critical in chain. ... [O]ne person missing the circuit breaker ends up killing everybody."*

Several participants were concerned that their physical state in the hospital would frequently limit their ability to even consider speaking up. A06, for instance, vividly described how both physical illness and medication got in the way of her ability to speak up: *"...it's harder to be articulate when you're pumped full of morphine, and because I'm allergic to morphine, I had to take Benadryl, so morphine and Benadryl makes me very foggy, and trying to be articulate when you're full of that crap is very hard. It's easy to be malleable in that state where they say 'you need to do this,' you're like okay."*

6.3.3.2 Factors influencing self-efficacy

Although we did not explicitly measure self-efficacy, participants described how various factors contributed to their confidence in their ability to speak up, including the amount of experience they had with medicine or healthcare, and the absence or presence of social support. Participants also commented on the potential of interventions to increase their self-efficacy.

Participants who had a lot of experience with the hospital often described how they had developed confidence in their ability to speak up over time. For instance, A01 described how she had *"been through a lot with the cancers, two surgeries, two radiations, chemo and now another one coming. I think I've learned a lot, so I just think it's personal growth, and age, wisdom."*

Similarly, A15 said, *"You just learn to talk up for yourself, or it doesn't get done."* While experience with healthcare contributed to self-efficacy, lack of knowledge of medicine could detract from it. Participants described how lack of knowledge about medicine made them less confident in their ability to detect a problem and speak up about it. As Y10 put it, *"I don't know what could be wrong, and if something's not going that right, I'm not sure if that's just because I don't know what's going on or if it actually is something wrong."*

Both isolation and implicit support from other patients could help participants develop self-efficacy. The feeling of having no other option also drove A02 to develop the confidence to speak up for herself, even though it was still difficult. As she put it, *"...there's nobody waiting in the wings to help me do stuff so I have to be very clear on what I want to gain. But it's still scary."* By contrast, Y01-C described how a prototype in which patients could share with each other stories about speaking up could *"give somebody else the courage to stand up and speak up or give you the courage .... to speak up and make sure that you say, 'Hey, I'm not so sure I like what you're [doing]'"*. A14 likewise described how support from friends and professionals helped her develop confidence, saying, *"I talked to social workers and my family about it, and they helped me build that confidence and stand up and say something."*

Some participants, in particular those who struggled with confrontation, responded positively to an intervention designed to build self-efficacy by helping patients think through how they might have difficult conversations with clinicians. For instance, Y07 liked the idea of a conversation starter aid, saying, *"It's just harder for me, I have to really think in order to start a conversation, how I'm going to say it to make it sound right to other people."* A01 likewise was enthusiastic about the prototype because it was so *"self-reflective, which is great. Understanding that we all have experiences that make it really difficult and it's good to review those and then you* *can kind of step back … And then kind of running a little course of what you would say, what you think might happen and what you could then do in response.”* A few participants, however, felt that they did not need help, because the prototype only suggested what they did in their heads anyway. As Y03 said, *“I feel like you can do that in your head. You don't need an app to do that.”*

6.3.3.3 Underlying beliefs about perceived control and self-efficacy

Participant comments reveal that participants were often concerned that illness or lack of opportunity would prevent them from speaking up. Participants varied in the degree to which they felt they had the skills and language with which to broach their concerns to clinicians, and the degree to which they felt they would benefit from additional training in how to do so.

6.3.3.4 Design considerations for personal agency

Participant comments highlighted two major themes for designing interventions to build personal agency: social acceptability and situational impairments. I discuss both below.

One of the prototypes we presented to participants was a ‘stop’ button which, when pressed, would allow patients 30 seconds of talk time that clinicians could not interrupt. This prototype frequently aroused extreme reactions in participants, ranging from outright laughter to longing. Participant comments revealed that these very different reactions arose from divergent ideas over whether such tools for giving patients more control of the conversation were socially appropriate, and whether they could result in positive or negative outcomes. In one camp were participants like A04, who said, *“Oh my gosh, I would love that button. Because they all just giving their opinion and nobody's listening to you. And you're the patient.”* Similarly, Y06 commented, *“I like it. I have trouble speaking up just in general, so having a way that would not interrupt them but still give me control of the situation would be nice.”* Other participants, however, felt the button would be socially inappropriate. A01 was concerned that *“pressing the* *button just feels kind of abrupt and rude,"* while A09 protested that the button should not be necessary because *"… we're all adults."* Y03 likewise felt that *"it's almost too like, 'all right, focus on me' type thing,"* while Y07 was concerned that patients might, wittingly or no, abuse the privilege: *"I don't know, what if you hit it many times? Stop, stop, just shuts them up and then you never get anything done. … Too much control to the patients could take away time from other patients."*

Another design issue that arose with participant comments about personal agency was that of situational impairments. As mentioned earlier, multiple participants were concerned that while hospitalized they would not be able to make use of any prototypes, because they would be too cognitively demanding. A05, responding to one prototype, said candidly, *"I'd rather read National Geographic …. When I'm in the condition that I've been in these last few weeks, I'm not interested in data like that. I just want to get well. I want to breathe. I want to focus on what I do next, not statistical surveys or whatever."* A06, looking at a prototype designed to raise self-efficacy by helping people plan out the conversation in advance, immediately said, *"Wow, you are assuming a higher level of cognitive ability than is absolutely going to be happening in a hospital."* Both A05's wife A05-C and A06 felt that caregivers should have access to such interventions to compensate for patients' situational impairments. As A05-C said, *"I think that the patient might not have that capacity but the family might."*

6.4 DISCUSSION

My findings yield several implications for the design of interventions to support speaking up. In addition, my findings yield insights into possible connections between mediators in the context of speaking up, and the connection between mediators and design. I discuss these topics below.

6.4.1 Designing interventions to support speaking up

My findings suggest that all mediators are influential when it comes to speaking up, and also that individuals vary quite a bit from each other. My findings also suggest that, as has been noted by other researchers in HCI (Klasnja et al., 2011), the design of interventions is extremely important for whether they will be successful. In particular, my findings illustrate different design tensions that arose with regard to the design of interventions for particular mediators. In what follows, I discuss what the findings suggest about the need to design for multiple mediators, as well as ways to approach designing for negative or discouraging information, and ways to explore designing for social appropriateness.

6.4.1.1 Designing for multiple mediators

Participant comments suggested that for different individuals, any of the mechanisms described in the IBM have the potential to contribute to behavior change and encourage people to speak up about their concerns. In addition, I found significant variation between individuals. These findings add to existing literature about the factors that influence patients' willingness to speak up by demonstrating that all mediators—not just perceived control and self-efficacy, as noted in the related work, but also attitudes and normative beliefs—can influence patients' willingness to speak up, and by highlighting that patients are not a monolithic entity, but rather eight billion individual points with differing beliefs and values.

What this finding suggests is that any one type of intervention to promote speaking up is likely to work only for selected individuals. Instead, researchers must pursue a wide variety of interventions, to support an equally wide variety of patient values, needs, and beliefs. This recommendation is in line with suggestions from other researchers to explore different approaches to engaging patients in their safety (Agapie et al., 2019), and even to account for differing preferences in the role technology plays in care (K. O'Leary et al., 2015).

6.4.1.2 Designing for negatives

One issue that arose across multiple mediators was that of designing for negatives. As described in the findings, numbers mattered for some participants in terms of their reactions to graphical prototypes about descriptive and injunctive norms. Participants also worried about negative outcomes of speaking up that could equally be depicted on a graph, such as negative impacts on the clinician-patient relationship or decreases in patient satisfaction. Just as experiencing negative outcomes from speaking up could discourage patients from speaking up again in the future (V. A. Entwistle et al., 2010), one concern with designing interventions designed to influence instrumental attitudes via outcome expectations is that depicting negative outcomes could discourage people from speaking up. And as pointed out by researchers in behavioral science, scare tactics are not always the best approach for encouraging behavior change (Kok et al., 2004).

We suggest two strategies to approach this problem. One is to use the stories design strategy rather than the graph design strategy. While stories can still depict negative outcomes, users may be able to glean more information from stories about the reasons behind positive or negative outcomes, and to adapt their behavior accordingly. Thus, stories may give users a greater sense of control in the face of potential negative outcomes to speaking up. Stories could also be effective in normalizing speaking up even if a minority of patients actually speak up, because they can offer detailed accounts of the experience without revealing actual numbers. It is important to note that employing the stories design strategy could be ethically questionable, because stories have the potential to suggest that speaking up is common even if that is not actually the case—in other words, such a design strategy could be used to mislead users about how common the behavior actually is. Deceitful design must at all times be approached with extreme caution. However, if the goal is to encourage patients to speak up in order to make speaking up a more common behavior, then stories may be a valuable strategy for encouraging patients to speak up in an effort to change norms for the better.

The second strategy we suggest is to increase the transparency of hospital responses to negative statistics. In response to prototypes showing the impact of speaking up on people's satisfaction with their care and relationship with their clinicians, several participants commented that if the outcomes were generally negative, then the hospital and clinicians ought to make some kind of organized response to amend the matter. Making visible to patients any hospital initiatives to remedy poor outcomes could go some way towards alleviating the impact of data about negative outcomes, and demonstrate to patients that the hospital and its staff care about their needs and want them to speak up about their concerns.

6.4.1.3 Designing for social appropriateness

The issue of social appropriateness came up mainly in regards to the stop button prototype, which bought patients 30 seconds of talk time. As discussed in the findings, some participants were concerned that to use such a tool would be to overstep their role as patients. This finding parallels findings in the literature that patients can be reluctant to speak up if it will make them seem confrontational or endanger their relationship with clinicians (V. A. Entwistle et al., 2010; Rainey et al., 2015). Another possible concern with the 'stop button' approach is the possible negative response of clinicians to interventions designed to give patients more control. Although we did not include clinicians in our sample in this study, outside literature suggests that clinicians may be concerned about loss of control. Even without obtrusive interventions, clinicians are sometimes suspicious of patient motives in speaking up and may afterwards engage in counterproductive behaviors like avoiding the patient (Hrisos & Thomson, 2013). Similarly, one vignette study featuring fictional scenarios about safety problems found that less than half of surveyed health care providers thought that family member intervention would have a positive impact on their relationship with their clinician (Rachel Davis, Savvopoulou, Shergill, Shergill, & Schwappach, 2014). Research on the relatively unobtrusive tool OpenNotes, which allows clinicians to share their notes with patients, found that prior to implementation, many clinicians were concerned about the consequences of the loss of control of their notes, including concerns about increased workload (Delbanco, Walker, Darer, Elmore, & Feldman, 2010). A stop button granting patients talk time in order to give them greater control of the conversation could in theory pose similar threats: for instance, clinicians may fear having their workflow disrupted and time eaten up by talkative patients. As described in the findings, however, many participants in our study relished the prospect of having a way to voice their concerns, assert control of the conversation, and in Sigall Bell's words, "stop the line" (Bell & Martinez, 2019).

One way to resolve this tension is of course to try out something like a stop button and collect empirical findings on the deployment. The OpenNotes deployment found that clinician concerns often did not transpire (Delbanco et al., 2010); concerns about a stop button could go the same way, as people who do not feel comfortable using it could simply avoid using it, and possible abuse or increased workload for clinicians could be measured. Another option is to explore whether patients can be given more control in a way structured by clinicians, for instance by giving clinicians a mandatory 30 second waiting period when they visit patient rooms, to allow for patient questions and comments.

Researchers seeking to give patients additional opportunities for speaking up about concerns while walking the line of socially appropriate control can also explore other means. The stop button was simply one possible prototype. Researchers should also explore techniques like allowing patients to schedule a time to talk to clinicians, not just to avoid missed connections (as discussed in an earlier chapter), but also see if such a design technique, by implicitly placing patients and clinicians on a more equal footing, helps patients see and take advantage of the opportunity to speak up about their concerns. Researchers should also explore the possibility of tools to help patients reach specific clinicians while in the hospital, as has been suggested in an earlier chapter and discussed in outside literature (Grossman et al., 2017). A couple of participants (Y08, Y10) described how hospital staff members like therapists and social workers created opportunities for them to voice concerns by agreeing to act as messengers to the care team, while another participant spoke of the benefits of being able to reach a specific nurse to voice concerns. The benefits of this direct outreach to alternative hospital staff for some participants suggest that interventions that help patients connect with the hospital staff members of their choice may create socially appropriate opportunities for patients to speak up and voice their concerns about their care.

As always with patient engagement technologies, it is also important to remember that while opportunities should be created for patients to speak up, patients who are sick should not be obligated to act as sole watchdog for their care. Empowering patients who are capable of participating in their care neither necessitates their participation if they are unwell, nor obviates the responsibility of clinicians to ensure safe and high-quality care for all patients.

6.4.2 Mediators and Intervention Designs

In addition to implications for the design of patient-facing interventions to promote speaking up, my findings yield insights into possible connections between mediators. My findings also show surprising interactions between the design of interventions and participants' implied responses to specific mediators. I discuss these topics below.

6.4.2.1 Connections Between Mediators

Although my goal was not to examine the relative weight or connections between mediators in this study, participant comments suggested some possible causal pathways. In particular, as described earlier, some participant comments suggested that beliefs about injunctive norms, with reference to both patients and clinicians, could influence instrumental attitudes; and that descriptive norms could influence self-efficacy. More work would be needed to verify that these causal pathways exist. However, doing this work is important because these pathways could guide the design of patient-facing interventions to support speaking up. For instance, if perceived clinician attitudes (injunctive norms) influence outcome expectations (instrumental attitudes), it becomes important to develop interventions that can preserve positive outcome expectations for speaking up even if clinician attitudes are not what they should be. Even the most well-meaning clinician can have an off day and inadvertently signal that they are not interested in hearing what the patient has to say. When clinician responses suggest negative attitudes to patients speaking up, a system where patients could lodge concerns and then transparently see clinician actions taken as a result of their speaking up could compensate for that failure. In addition, understanding how mediators relate to each other in different contexts adds to our scientific understanding of behavioral models—what some authors have referred to as the goal of science (Eric B. Hekler et al., 2016).

6.4.2.2 Interactions of Design and Responses to Mediators

The design of an intervention can impact its efficacy. For example, one study found that patients were more likely to thank clinicians for washing their hands than to follow a script to remind them to do so (R. Davis et al., 2015; Lent et al., 2009). My findings also highlighted how the design of interventions can interact with patients' motivations. In other words, people do not necessarily exist in a state where a certain mediator has the potential to be impactful or not impactful—instead, individuals may be influenced by interventions designed one way versus another way, even if those interventions appeal to the same mediator.

This phenomenon emerged in our findings in two ways. First, as discussed in the findings about norms, the stories-based prototypes at times grabbed the attention and interest of participants even if they had otherwise expressed lack of interest in knowing what others were doing. While to some extent this was because the stories offered more information than the graphs, participant comments suggested that it was also because they offered *different* information—more subjective information (e.g., information about someone's feelings and their individual opinions), and different objective information (more information about the details of an individual case, which allows people to tell if the writer is a 'patient like them' or not; and less information about the behavior of patients in general). Second, the feelings tracker which showed participants the emotional outcomes of speaking up made emotions more salient for participants as a potential outcome. Although participants did not typically speak of feeling relieved or calmer as a result of speaking up on their own, the prototype strongly resonated with some participants and made positive emotions a relevant outcome that could help motivate speaking up. These findings show an interaction between conscious valuations of different beliefs and the form in which information affecting those beliefs takes.

6.5 LIMITATIONS AND FUTURE WORK

There are a number of limitations on this work. First, as discussed earlier, my goal was not to create and deploy instruments to measure the relative influence of different mediators in speaking up behavior. That work remains to be done to further guide the design of interventions. In addition, my method explored ‘speaking up’ in a broad sense, to account for patients’ differing experiences. However, not all speaking up is the same (Bell & Martinez, 2019; O’Hara & Lawton, 2016). Future work should involve exploring the differences in patient motivations for speaking up in different contexts. Similarly, future work should explore differences in patient populations. This study recruited a broad sample of patients with different conditions and at different hospitals to get a holistic view of patient experience. Future work must explore differences in specific patient populations.

In addition, I focused on patients’ own descriptions of their experiences and of their responses to different intervention prototypes. Researchers in the field have raised concerns that patients may overestimate their own behavior when it comes to their willingness to speak up (Abbate, Di Giuseppe, Marinelli, & Angelillo, 2008; David L.B. Schwappach, 2010; Waterman et al., 2006a). This concern may extend to patient responses to the prototypes we discussed—in other words, just because a participant responded positively to a prototype does not mean the intervention would necessarily work as intended. Future work should include development and deployment of a variety of interventions, both to account for the fact that multiple mediators appear to influence patients’ speaking up and to further explore the design and efficacy of interventions.

6.6 CONTRIBUTION

In this study, I explored the design of technologies to support patient engagement (**RQ3**), specifically in terms of speaking up about concerns in the hospital. I identified some of the underlying beliefs that influence patients to speak up or not speak up about issues in their care. I further explored design tensions that arose when designing for different mediators, and the implications for designing interventions to encourage patients to speak up. These findings advance our understanding of how we can design interventions to encourage patients to speak up.

Chapter 7. CONCLUSION

In this chapter, I review my research questions and summarize how my findings answer these questions. I summarize my contributions and discuss opportunities for future directions.

7.1 REVIEW OF RESEARCH QUESTIONS

In this dissertation, I explored the following research questions:

RQ1: What does engagement in the hospital look like from patients' and caregivers' perspectives? I worked with colleagues to conduct semi-structured interviews with hospitalized patients and their caregivers to understand how they currently engage in their care, as well as how they would prefer to be involved in their care (Chapter 2). I found that patients and caregivers envision themselves assuming a variety of functions on the care team, working collaboratively with clinicians to monitor and improve the patient's health. Patient and caregiver participants described themselves as playing one of five roles: bedside monitor, apprentice, historian, decision maker, and team manager. Individuals varied in the degree to which they took on each role for a variety of reasons, including their attitudes towards partnership in their care and their relationship with clinicians. Understanding the ways in which patients and caregivers envision engaging with their care in the hospital yielded insights into the design of technologies to support hospitalized patients and their caregivers in engaging with care in this environment.

RQ2: How does the clinician-patient relationship impact patients' and caregivers' willingness to engage in safety behaviors in the hospital? To explore in more depth the impact of the clinician-patient relationship on patients' and caregivers' willingness to engage in their care, I, together with colleagues, conducted two studies with hospitalized patients and caregivers (Chapter 3). In Study 1, we conducted a low-fidelity prototype study with patients and caregivers, which included prototypes designed to support or impact different aspects of clinician-patient communication. In Study 2, we conducted a longitudinal interview study with patients during and after their hospital stay, in which we investigated patients' needs for keeping track of information about their stay for the purpose of error prevention. After analyzing the data, I found that some aspects of the clinician-patient relationship, including trust in clinicians, a desire to keep the peace, and a desire to protect clinicians' feelings inhibited patients from engaging in safety behaviors. By contrast, a feeling of personal connection with clinicians and a desire to ease clinicians' burden encouraged patients to engage in safety behaviors. These findings yielded insights into how to frame engagement in the design of interfaces to encourage patients and caregivers to engage with their safety in the hospital.

RQ3: How we can design technologies to help patients and caregivers in the hospital engage with their care and safety? I explored RQ3 in two different case studies. In the first (Chapter 4), I analyzed findings from a low-fidelity prototype study that included prototypes designed to support self-tracking in the hospital—an engagement-related task that could potentially support patients and caregivers in performing every role identified in RQ1. I found that patients and caregivers desire tools that will help them collaboratively track their health and care with clinicians. I described how patients and caregivers hoped to collaborate with clinicians through each stage of the stage-based model of personal informatics. Based on these findings, I outline both implications for the design of technologies to support people in collaborative tracking in the hospital, and implications for the stage-based model when applied to collaborative contexts. In the second case study (Chapters 5 and 6), I conducted a low-fidelity prototype study with prototypes based on theoretical constructs that have the potential to influence behavior change. I used these prototypes to understand what kinds of mechanisms might encourage patients and caregivers to speak up about concerns they have about their care—a potentially confrontational rather than collaborative act. Two major sets of findings resulted from this study. First, I uncovered several methodological considerations for conducting this type of theoretically-driven research (Chapter 5). I found that it is difficult, if not impossible, to cleanly map an intervention onto a single mechanism, as both experts and patients interpret interventions differently. Second, I found that all mechanisms named in the Integrated Behavioral Model have the potential to influence patients and caregivers to speak up, but that there is a great deal of individual variation in how influential those mechanisms may be. I uncovered several insights for the design of technologies to promote speaking up behavior in patients and caregivers.

7.2 CONTRIBUTIONS

In this dissertation, I made the following empirical, design, and theoretical and methodological contributions:

7.2.1 Empirical contributions

1) A rich understanding of how patients and caregivers themselves envision their role in their care (Chapter 2), and how they envision themselves collaborating with clinicians to track their health and care (Chapter 4);

2) An analysis of different aspects of the clinician-patient relationship and insight into how they encourage or discourage patient and caregiver engagement in safety behaviors (Chapter 3);
3) A portrait of how different mechanisms of change have the potential to influence patients and caregivers to speak up in the hospital, and the different underlying beliefs that drive that influence, as well as a view into the great individual variation that exists in how people value those mechanisms (Chapter 6);

7.2.2 Design contributions

1) Design guidelines for designing technologies to support patients and caregivers in engaging with their care (Chapter 2) and safety (Chapter 3);
2) Recommendations for designing collaborative tracking technologies to support patient/caregiver-clinician collaboration over tracking data in the hospital (Chapter 4);
3) Insight into the design tensions that arise in designing IBM-based interventions to encourage patients and caregivers to speak up about concerns in the hospital (Chapter 6);

7.2.3 Theoretical and methodological contributions

1) Considerations for how the Stage-Based Model of Personal Informatics must be adapted to account for collaborative settings (Chapter 4);
2) Insights into the nature of the challenges inherent in translating theoretical constructs into behavioral interventions (Chapter 5); and
3) Suggestions for how to carry out HCI research with theoretically-based behavior change interventions in light of those challenges (Chapter 5).

7.3 LIMITATIONS

There are many limitations to the work presented in this dissertation. Some of these limitations have been articulated at the conclusion of each chapter. However, there are also some limitations that apply across all studies. All the findings presented here, except for the expert interviews in Chapter 5, come from the same two hospital sites: Virginia Mason Hospital and Seattle Children's Hospital in Seattle. While both of these hospitals draw patients from much larger geographic area, there may still be regional cultural biases inherent in the data. In addition, patients who agreed to participate in these studies did so only because they felt well enough to participate. Given how much physical and psychological condition can vary for patients in the hospital, it is unclear how well my findings apply to people who are very sick, although my participants often did reflect on times when they were more situationally impaired. The findings presented in these studies may also be skewed towards patients and caregivers who are more interested in engaging with their care—in other words, there may be some self-selection bias in the samples. In addition, my recruitment strategy was broad-based, cutting across conditions and services. While this gave me a holistic view of patient experience in the hospital, it also means that I cannot attest to differences between particular patient populations. However, despite these limitations, the findings and contributions presented in this dissertation contain valuable insights for how to support patients and caregivers in engaging with care in the hospital in order to improve care quality and prevent errors.

7.4 FUTURE DIRECTIONS

The work presented in this dissertation points to a number of new directions for future work. Direct continuation of much of the work presented here would involve studying the generalizability of this work to different patient populations and form factors, and exploring the impact of live deployments of the prototypes used in the current studies. However, this work also suggests that further exploration of how systems should be designed around the patient-clinician relationship is warranted. Finally, although the work presented here centers on promoting patient engagement, it is also important to consider the possible negative impacts of patient engagement. I discuss each of these topics below.

7.4.1 Direct Continuations of the Current Work

The work presented in this dissertation could be directly continued in three ways. As suggested by the limitations section, one possible direction is to explore how visions of engagement and the potential impact of different mechanisms of change vary between patient populations. Another option is to more fully explore the design of prototypes to encourage engagement and speaking up behaviors in any patient population. My studies in this dissertation ended with low-fidelity prototypes. Future work should push interventions to support engagement further along into the design process, to deploy prototypes in order to examine real effects and responses rather than projected ones. A third option is to explore how different form factors might affect the functioning of different interventions. I discuss the second two options in more detail below.

I particularly suggest two directions for the development and deployment of functional prototypes. The first is in collaborative tracking, building on the findings presented in Chapter 4. In addition to granting the ability to examine more detailed questions of user needs and design, functional support for collaborative tracking would allow researchers to examine clinician perspectives on collaborative tracking technologies, and how best to use these technologies to facilitate clinician-patient communication. Ongoing work on OpenNotes continues to examine the evolution of patient-clinician interactions over these interfaces (Bell et al., 2017). However, as discussed in Chapter 4, collaborative tracking technologies have the potential to extend far beyond sharing clinician notes and supporting patient annotations. Instead, the whole medical record could become one collaborative project document in which clinicians, caregivers, and patients participate. Future work should examine how more fully-featured collaborative tracking technologies can strengthen the patient-clinician partnership in the hospital, as well as investigate whether such technologies can play a role in improving patient self-management and follow-up clinician-patient communication after discharge and/or in succeeding hospitalizations.

My second suggestion is further work in the area of interventions to encourage patients and caregivers to speak up about problems that come up in their care. I used the lens of a single behavioral model to understand what factors influence patients' and caregivers' willingness to speak up. As discussed in Chapter 6, I did not investigate what factors are statistically associated with the act of speaking up. This work remains to be done. In addition, future research should include the exploration of additional design strategies to support patients in speaking up. While some researchers have begun, for example, investigating the use of patient peer portals in the hospital,[5] some design strategies require clinician participation. For instance, one possible strategy to help patients gain opportunities to speak up might involve allowing patients to dictate when they are ready and available to converse with clinicians. However, this strategy would require also supporting clinicians' complex and often unpredictable schedules in the hospital. In addition to

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[5] Haldar, Shefali, Mishra, Sonali R., Kim, Yoojung, Hartzler, Andrea, Pollack, Ari H, and Pratt, Wanda. *Use and impact of an online community for hospital patients.* Under review.

exploring additional design strategies, future research should include developing and deploying new technologies in order to measure the impact they have both on patient speaking up behavior and on the patient-clinician relationship, as encouraging patients and caregivers to speak up and take a more active role in their care may alter the patient-clinician dynamic in significant ways.

A third avenue to explore is the degree to which form factor matters in interventions to encourage patient engagement. Although a shared checklist was recommended in Chapter 3, all of the low-fidelity prototypes explored in this dissertation were presented as patient-facing systems on an ipad. It is possible that other form factors, for instance an ambient display visible to both clinicians and patients, could change the effect of certain interventions. For instance, a live graph that tracks when patients speak up to clinicians that is displayed in a way visible to both patients and clinicians (say, projected on the wall of the patient room) could operate differently from the same graph visible only to patients, as the former could act as a cue for clinicians to encourage patients to speak up, while the latter could patients feel a stronger bond to other patients but a more oppositional relationship to their clinicians. More work is needed to understand how different form factors can be exploited to encourage patient engagement.

7.4.2 Designing Systems Around the Patient-Clinician Relationship

Through all the studies presented in this dissertation, one continuous theme was the importance of the clinician-patient relationship in patient engagement. As described in Chapter 2, patients and caregivers in the hospital envision engagement in the hospital as a highly collaborative act. As described in Chapter 3, aspects of the clinician-patient relationship that reflect partnership (like a sense of helping out clinicians in their jobs) can encourage engagement while aspects that emphasize the negative impacts of engagement on the clinician-patient relationship (like concern about conflict) can discourage engagement. Similarly, in Chapter 4 I demonstrated that patients and caregivers seek tracking tools that help them collaboratively track their health and care in conjunction with clinicians, while in Chapter 6 I illustrated how perceived clinician attitudes towards patients speaking up and concerns about the consequences of speaking up on the clinician-patient relationship can weigh heavily with some individuals.

These findings highlight the need for designing tools that place patients on an equal footing with clinicians to promote patient engagement in the hospital, as well as for providing training for clinicians in how to help patients feel empowered in the administration of care. One way of achieving the first is to not just explore the types of interventions prototyped in this dissertation, but also to design existing systems in a way that implicitly emphasizes the importance of meeting patient needs. For instance, Haldar et al. (Haldar, Mishra, Khelifi, Pollack, & Pratt, 2019) describe several ways that inpatient portals could be improved to better meet patient needs. Designing hospital systems around patient needs could send the message that hospitals value patient input, subtly placing patients on a more equal footing with clinicians in the hospital and thereby encouraging patient engagement. In addition, clinician outreach efforts should be instituted to encourage patients to feel like partners in their care in order to promote engagement, as has been suggested by other researchers in the field (V. A. Entwistle et al., 2010; Waterman et al., 2006b). Joseph-Williams et al. argue that sending materials to patients encouraging them to see themselves as partners *before* the clinical encounter, so that patients have time to reflect on this new role, may be critical in promoting patient engagement in activities like shared decision-making (Joseph-Williams, Edwards, & Elwyn, 2014). My findings in Chapter 6 also suggest that intervention before the clinical encounter (admission, in this case) means that patients have more information on which to select a provider who will encourage them to engage actively with their care. Thus to find new ways to support patient engagement in the hospital, researchers should explore ways to support patients in forming attitudes and selecting providers before admission actually occurs as well as ways to help patients engage in care during the hospital stay.

7.4.3 Potential Negative Impacts of Patient Engagement

The goal of this work has been to explore ways to support and thereby to increase patient engagement with hospital care. I have justified this goal on the grounds of moral imperative from both Kantian and consequentialist perspectives (Chapter 1). However, it is important to consider also whether increased patient engagement could ever impose any negative consequences. There are two ways in which patient engagement could result in negative outcomes: 1) by contributing to clinician burden and 2) by creating negative health consequences for patients. I discuss each in turn.

First, one concern is whether increasing the level of patient engagement could ever contribute to clinician burden. This could come in the form of increased conflict with clinicians—one of the deterrants to engagement described in Chapter 3—or in the form of increased demand on clinicians' time, as more engaged patients might in theory demand more time from clinicians, for instance to discuss different treatment options rather than simply following clinician guidance. With regard to the latter, while this outcome is certainly possible, the results of existing interventions suggest it is unlikely. For instance, increased clinician workload as a result of increased engagement was a concern with the launch of OpenNotes (Delbanco et al., 2010). However, once the system was deployed, increased time burden for clinicians was very rarely reported (Bell et al., 2017; Delbanco, Walker, Bell, Darer, Elmore, et al., 2012). With regard to the former, or conflicts between patients and clinicians, further study is needed to evaluate whether additional conflict results from increased patient engagement, or whether conflict in fact decreases. One study on sources of conflict in the ICU found that some conflicts arise as the result of poor communication and misaligned expectations between patients and clinicians (Meth, Lawless, & Hawryluck, 2009). This finding suggests that at least some potential conflicts between patients and clinicians could be eliminated by better patient engagement, which would by definition include increased sharing of knowledge and communication of values and priorities between patients and clinicians. Other kinds of conflict, for instance disagreements about whether the patient is ready to be discharged (Meth et al., 2009), could in theory become more frequent with patients and their caregivers more willing to advocate for themselves. However, the proper resolution to such conflict is not the steamrolling of patients' and caregivers' desires, but rather the opening of communication channels and the facilitation of discussion about patients' and caregivers' concerns—in other words, increased patient engagement. Thus while further study is still needed to evaluate the effects of patient engagement on the clinician-patient relationship, evidence thus far suggests that increased patient engagement would likely reduce rather than increase conflict. To deal with cases when conflict arises, clinicians should be trained in conflict resolution techniques such as those described by Lask (Lask, 2003) and Moore and Kordick (Moore & Kordick, 2006) to help maintain a positive clinician-patient relationship and promote ongoing patient engagement.

Another potential concern is whether increased patient engagement could ever result in poorer health outcomes. As described earlier in this dissertation, most work on patient engagement and health outcomes has found the opposite effect, linking increased patient engagement to better health outcomes. However, some evidence exists that increased emphasis on patient values in care may occasionally lead to worse health outcomes. Meth et al.'s work studying sources of conflict in the ICU (Meth et al., 2009) points out that conflict can arise when patients and clinicians disagree about what is in the patient's best interest, for instance if patients' and caregivers' values dictate a course of action that clinicians feel would lead to worse health outcomes. One pilot study of patients' decisions to refuse cancer treatment suggests that such disagreements between patients and clinicians may arise because clinicians focus on treatment outcomes, whereas patients' decisions are made in the context of other values that form part of their world view (Huijer & van Leeuwen, 2000). Another reason patients asserting their values may result in lower health outcomes is that prescriptive health goals may not align with individuals' group identity or self-definition—for instance, the association of health promotion behaviors like exercise with white identity could discourage members of minority groups from engaging in those activities (Oyserman, Fryberg, & Yoder, 2007).

In all of the above cases, when worse health outcomes arise, it is because of patients making decisions about their care in accordance with their values. When considering such cases, it is important to remember that health outcomes may not always be the most important outcomes—for instance, patients may also value quality of life or religious beliefs that affect their decisions about care, and that are no less important to them than clinically measured health outcomes. Thus even if increased patient engagement occasionally yields worse health outcomes, a holistic consideration of the consequences reveals that supporting patient engagement is still important, as it supports patient autonomy and enables patients to act in accordance with their own values.

7.5 CONCLUSION

Most of us reading this dissertation have a good chance of ending up in a hospital at some point or other in our lives. The goal of the work I have presented in this thesis is to improve that (almost) inevitable hospital experience, and hopefully to ensure that we all achieve improved health outcomes. In this dissertation, I have illustrated that patients and caregivers want to be involved with their care in the hospital, and discussed factors that impact the degree to which people want to engage in their care and safety, including the patient-clinician relationship. I have described how we might design technologies to support patients and their caregivers in engaging with care, specifically by supporting collaborative tracking and by encouraging patients to speak up about issues in their care. These contributions are valuable, but much work remains ahead of us to translate these hypothetical technologies into real change. Being in the hospital will likely always be some degree of terrible—it is fundamentally a place that people go when they are very sick. But we can and must make it *less* terrible, and more importantly, make it a place where patients are less vulnerable to terrible accidents. We can do better than Hippocrates's dictum to "do no harm."[6] As researchers and designers of health systems, we have the power to improve the patient experience in the hospital, and we must exercise it.

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[6] "μὴ βλάπτειν". From Hippocrates's *Epidemics 1* (Hippocrates of Cos, 1923).

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APPENDIX A: INTERVIEW GUIDE FOR ENGAGEMENT INTERVIEWS (CHAPTER 2)

Please note that this interview protocol was in large part created by another member of the Patients as Safeguards research team, Logan Kendall.

Semi-structured Interview Questions

Opening Script: As part of this research study, we are interested in understanding what type of information is most useful and desirable from your perspective over the course of your hospital stay. Everything that you say in this interview will remain confidential. The research team is not affiliated with your care team and anything that you say during this interview will have no impact on the care that you receive.
{Provide brief statement about interviewer for rapport: name, background, icebreakers}

Opening

1. To get us started, it will be really helpful to know a bit about your hospital experience so far. Why are you in the hospital? What has happened so far?
2. Have you been to this hospital before as a patient? Any hospital before?
    a. If yes: what about your last hospital visit helped you prepare for or manage this stay?
    b. If no: what have you had questions about since you've been here?

Access to information

3. How do you normally get updates on what is happening with your care? How do you find out information when you have a question?
4. What kinds of questions do you have right now about your care? Have you talked with anyone about these questions?
5. How have your doctors and nurses shared information with you? When do you typically talk with them?
6. How easy has it been to understand and keep track of what you have been told (or given) so far? *(Prompt for example)*

    Now I'd like your help with a short exercise to help me understand which information is most important for you to get updates about in the hospital.

    Q-SORT EXERCISE (refer to separate instruction sheet)

Tools and Resources

I'd like to learn a little more about the types of devices or other tools that you may use.

7. How do you keep track of information you get from your doctors? *(probe on printed vs. verbal)*
    a. Do you use any tool to write down or capture information that you receive? Can you show me?

8. (If applicable) Do you make use of the whiteboard in your room? How is it useful to you? What kind of information would be most helpful to have there? Are there times when it is not helpful?
9. Have you asked for any printed information about your care? Tell me more.
10. Have you used an online patient portal that has information about your health (such as test results, prescriptions, etc.)? To do what? How accessible is information about the current stay?
11. Have you gone to look up information on a mobile phone, tablet, or PC? What did you look up? *Probe on how phone, tablet, etc. are used during the hospitalization.*

Expectations for what's next

12. How easy or hard is it to find out what will be happening next (e.g. upcoming test or doctor's visit)?
13. Do you know when you expect to leave the hospital? How did you find out?
14. Do you know when you expect to see a doctor or nurse next?
    Probe: how do you know? Main doctor vs consult. Other services. Shift changes.

Challenges/Barriers/Positive Experiences

Sometimes during a hospital stay it can be difficult to get timely access to information…

15. Have you run into any challenges with getting information about your care during your hospital stay? Can you explain more?
16. What other things make it difficult to know what's happening with your care?
17. What have been positive experiences so far with how you have received information?
18. Have you experienced any issues with your care? If so, what happened? How did you know?
    Example issues to prompt a response: sudden change in health status, availability of care team, things you think should have happened but didn't, or things you think should not have happened.

Sharing

19. How do you keep friends and family updated about what's going on? *(Probe on different strategies)*
20. What kinds of things are useful to share?
21. Would you like to share more information than you currently do?
22. Are there other people you would want to share information with? *Probe.*

Closing

23. Are there still questions that you have related to you care? If so, can you please explain?
24. Is there anything that the hospital or your care team could do differently to improve the way they give you information?

Additional areas to probe on

1. Do you know what needs to happen before you can leave the hospital? Probe.
2. Is there anything that would be useful to see a history of? (e.g. tests, vitals, labs, recent care activity)

3. Are there things that are important to know right at the beginning of a hospital stay vs now?
4. Is there a particular time or context when you would like to receive information? (morning, rounding, right before something happens, all these times, …)
5. Is there information you would like to know more about for what happens after the hospital stay?
6. What kind of information about you do you think is important to share with your care team?

<u>Condition of Instruction (to explain to the participant)</u>:
For this activity, we would like you to read through some statements that have to do with how you like to get information in the hospital. Read through all the statements now and think about them in terms of how much you agree or disagree with each one. Please ask us questions about anything you don't understand and feel free to talk out loud about how the statements relate to your experience of being in a hospital.

1. To begin, sort the statements into three piles. One pile should be the statements that you agree with or feel positive about, another pile should be the statements that disagree with or feel negative about. Put any statements you are not sure about in a third pile. Do not worry if the piles are not the same size.

2. Now, from the pile of statements with which you agree, pick out the two (only two) statements that you agree with the most. Place them in the column at the extreme right hand side of the sorting grid. It doesn't matter what order they are placed in the column.

    a. *If they are having trouble picking 2, have them start sorting the Agree pile using the arrow on the right-hand side - ones they feel more positive about towards the top, and less positive about towards the bottom.*

3. From the same pile of statements, pick out the next 3 statements that you agree with the most. Place these statements in another column (+3) just to the left of the two you already selected. (*Point to the column*)

4. Repeat this process for the next two columns (+1 and +2) until you run out of statements from the Agree pile.

5. Now work with the second pile of statements – those you disagree with. Selecting the two items you disagree with the most out of the disagree pile. Place them in a column on the far left side of the grid.

6. Continue for each column from the left until all of the disagree statements have been placed on the grid.

7. Finally, take another look at the statements in the third pile. Are there any you feel like you agree with or disagree with more than the others? Place any you agree with in the open spots in the column on the right side, and any you disagree with in the column on the left side. Put the rest of the statements in the middle.

8. Finally, take one last look at all of the statements. You can rearrange the statements if you want to.

After the q-sort is complete

Now that you have arranged the cards, I'm going to ask you some questions about them.
Begin with the extremes of the sorting arrangement, and then move on to other items in the distribution that seem interesting, unusual or where the participant maybe didn't understand an item.

- Let's begin with the ones you agreed with the most. What does this card mean to you? Why do you feel so strongly about it?
- How about these cards that you disagreed with? Why do you feel so strongly about them?
- Were there any cards that didn't make sense to you or that you had trouble understanding? Please explain.
- Was there anything missing from these cards? Is there something else that you would include in this group?
- For the statement, is that information that you already know about your current hospital stay? Or is that reflective of your current stay?
    - *If time, ask participants to mark each card with whether someone gave them that information or they feel like the comment reflects their current care.*

Q patient statements:

- It is important to know the names and responsibilities of my doctors, nurses, and other health care providers
- It is important to know what will happen with my care today
- It is important to know why each medication is given to me
- It is important to know when I can leave the hospital
- It's important to know the cost of being in the hospital
- It is important to speak up to doctors and nurses when I have a question
- It is important to know about different options for how to treat my illness
- It is important to know how to get help if I am worried or need information
- It is important that I know what I will need to do for my health after leaving the hospital
- It's important to know when I will see my doctor next
- It's important to get information in a way that I can understand
- It's important that I am not a bother to my doctors and nurses
- It's important to know what to ask my doctors or nurses
- It's important to feel like my doctors have time to answer my questions
- It's important to know how serious my illness is
- It's important that I get information about how my health condition is changing over time
- It's important that I be an active participant in my healthcare
- It is important that I keep track of things by writing them down so that I remember them
- It's important that someone else helps me keep track of things
- I like to keep track of things by just paying attention and remembering

- It's important that my doctors and nurses listen to me
- It's important to know how my doctors and nurses are communicating with each other when there are shift changes
- It's important that I know right away when there is a change of plan for my care
- It's important to get information in a way that's easy to share with others
- It's important to know what kinds of safety errors can happen with patients in my situation
- It's important that my doctors and nurses agree with my decisions for my care
- It's important that I have a positive relationship with my doctors and nurses
- It's important that the hospital respects my need for privacy
- It's important to know what activities are okay based on my current condition
- I prefer to leave decisions about my medical care up to my doctor
- I only want to know what my doctors think is important
- It's important to get information at a time when I can focus
- It's important that I understand my doctors' reasoning when they give a recommendation
- It's important that my doctors and nurses understand what is most important to me

Q caregiver statements:

- It is important to know the names and responsibilities of our doctors, nurses, and other health care providers
- It is important to know what will happen with the patient's care today
- It is important to know why each medication is given to the patient
- It is important to know when the patient can leave the hospital
- It's important to know the cost of being in the hospital
- It is important to speak up to doctors and nurses when I have a question
- It is important to know about different options for how to treat the patient's illness
- It is important to know how to get help if I am worried or need information
- It is important that I know what we will need to do for the patient's health after leaving the hospital
- It's important to know when we will see my doctor next
- It's important to get information in a way that I can understand
- It's important that I am not a bother to the doctors and nurses
- It's important to know what to ask the doctors or nurses
- It's important to feel like our doctors have time to answer my questions
- It's important to know how serious the patient's illness is
- It's important that I get information about how the patient's health condition is changing over time
- It's important that I be an active participant in the patient's healthcare
- It is important that I keep track of things by writing them down so that I remember them
- It's important that someone else helps me keep track of things
- I like to keep track of things by just paying attention and remembering
- It's important that the doctors and nurses listen to me
- It's important to know how the doctors and nurses are communicating with each other when there are shift changes

- It's important that I know right away when there is a change of plan for the patient's care
- It's important to get information in a way that's easy to share with others
- It's important to know what kinds of safety errors can happen with patients in our situation
- It's important that the doctors and nurses agree with my decisions for the patient's care
- It's important that I have a positive relationship with the doctors and nurses
- It's important that the hospital respects my need for privacy
- It's important to know what activities are okay based on the patient's current condition
- I prefer to leave decisions about the patient's medical care up to the doctor
- I only want to know what the doctors think is important
- It's important to get information at a time when I can focus
- It's important that I understand the doctors' reasoning when they give a recommendation
- It's important that the doctors and nurses understand what is most important to me

APPENDIX B: INTERVIEW GUIDE AND CARDS FOR LOW-FIDELITY PROTOTYPE STUDY (CHAP 3, 4)

This is the protocol and cards used for the Low-Fidelity prototype study which is described as Study 1 in Chapter 3, and which is the only study used for Chapter 4. Please note that the interview protocol and low-fidelity prototypes for this study were a collaborative effort from PAS team members, including me, Shefali Haldar, and Maher Khelifi.

The images used in the low-fidelity prototypes fall under fair use as described by Crews (Crews, 2013). The purpose and character of the use are scholarly, as the images were used as part of research instruments to elicit responses from users. In addition, the use of these images was transformative: Crews states that "cutting, adjusting, and altering the work to place it in the context of a scholarly study can be transformative" (Crews, 2013). Many of these images were clipped and all were placed in the context of a scholarly study. The effect of the use of these images on the potential market for or value of the original is also likely to be negligible.

Interview Guide

Introduction:

- Why are you in the hospital? Tell us about what's been going on.
  Possible prompts:
  - *How have things been going?*
  - *How are you feeling?*

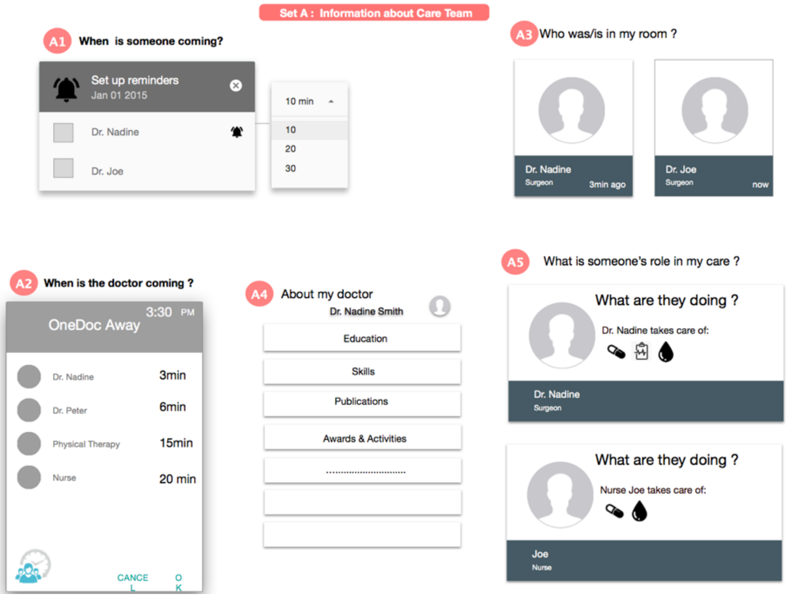
Introduce the activity:

- We're working on building an ipad app that will help give patients like you more information about their care in the hospital. We'll give you this board and these cards, and we're going to ask you to think about different things you've experienced while in the hospital and pick out the cards that you think would help you in a situation like that. Some of the cards represent pieces of information like names of medications. Some of them represent other things that could be in the ipad app, like the ability to record a conversation, take notes, or express your feelings. There are even some to represent the layout. And some of the cards are blank – you can write or draw whatever you want to on those cards. You can arrange the cards on the board however you like – this way, you get to tell us what's most important to you.
- Do you have any questions before we begin?

Example follow up questions for the cards:

- What makes this card useful or not useful for you?
- Is this information on this card something you already have access to? What additional information would make this more useful?
- How would having this card impact your hospital experience?

Cards used during the interview



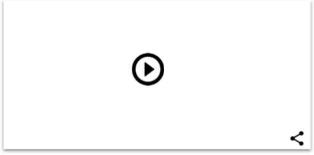
Set B : Take notes/recording/ reminders

B1 Take Notes

Type your notes here

B2 Record audio

B3 Record video



B4 Remind me later

Things I need to remember:

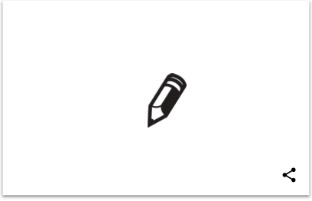
☐ Ask doctor when am I going home?

☐ Find out why am I taking medicines

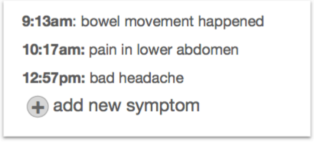
☐ ……………………………………

B5 Take a photo

B6 Draw a picture



B7 Keep track of my symptoms



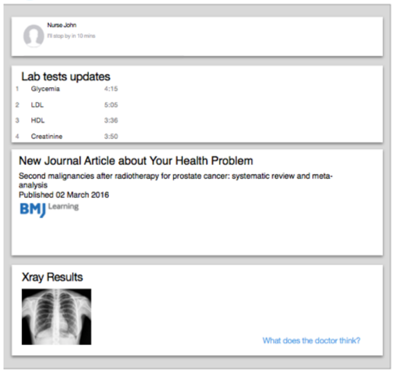
9:13am: bowel movement happened

10:17am: pain in lower abdomen

12:57pm: bad headache

Set C : News feed

C1 **News feed**



Nurse John

I'll stop by in 10 mins

Lab tests updates

1	Glycemia	4:15
2	LDL	5:05
3	HDL	3:36
4	Creatinine	3:50

New Journal Article about Your Health Problem

Second malignancies after radiotherapy for prostate cancer: systematic review and meta-analysis

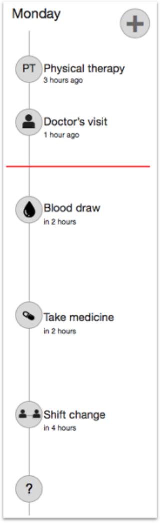
Published 02 March 2016

BMJ Learning

Xray Results

What does the doctor think?

C2 **Calendar**



Monday

PT Physical therapy
3 hours ago

Doctor's visit
1 hour ago

Blood draw
in 2 hours

Take medicine
in 2 hours

Shift change
in 4 hours

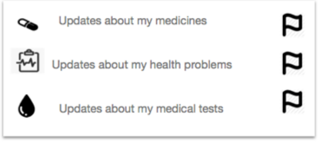
C3 **Last lab results**

Sodium 80

Potassium 120

CO2 5

C4 **Get updates about:**



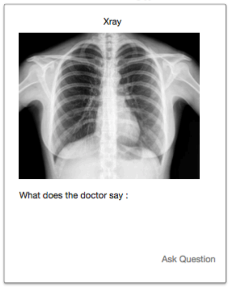
Updates about my medicines

Updates about my health problems

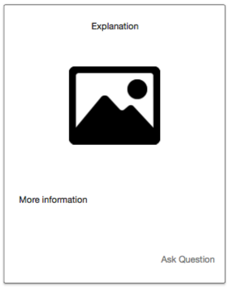
Updates about my medical tests

Set D : Learning more about my health

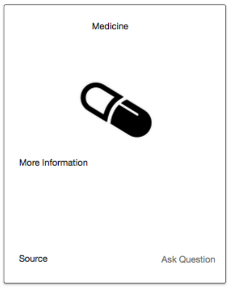
D1 **What does my result mean?**



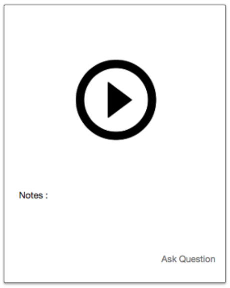
D2 **Doctor's drawing**



D3 **Why am I taking this medicine?**

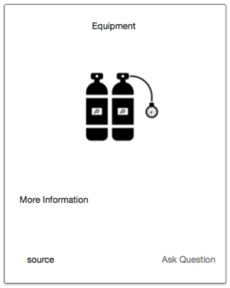


D4 **Educational video**



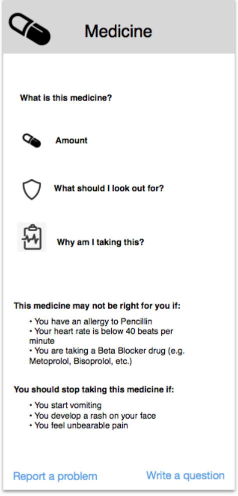
D5 **What does my doctor say ?**

D6 **How does my equipment work ?**



Set E: More info and safety

E1 **Learn more about my medicine**



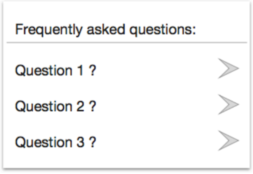
This medicine may not be right for you if:

- You have an allergy to Pencillin
- Your heart rate is below 40 beats per minute
- You are taking a Beta Blocker drug (e.g. Metoprolol, Bisoprolol, etc.)

You should stop taking this medicine if:

- You start vomiting
- You develop a rash on your face
- You feel unbearable pain

E2 **FAQ by patients like me**

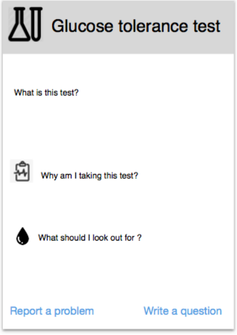

Frequently asked questions:

Question 1 ?

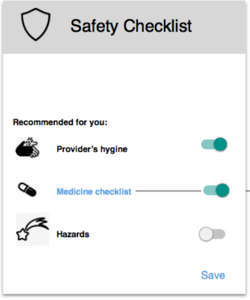
Question 2 ?

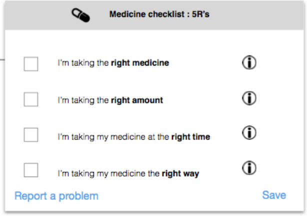
Question 3 ?

E3 **Learn more about my medical tests**



E4 **Personalize my safety checklist**





☐ I'm taking the **right medicine**

☐ I'm taking the **right amount**

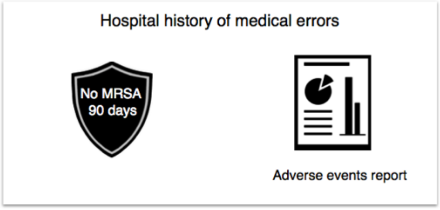
☐ I'm taking my medicine at the **right time**

☐ I'm taking my medicine the **right way**

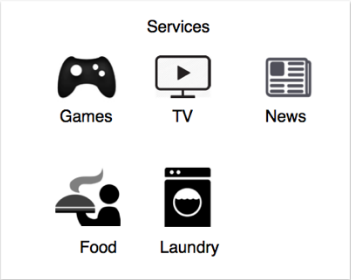
Set F : Hospital

F1 Support

F3 Hospital news

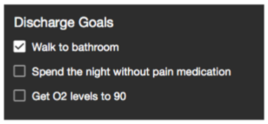


F2 Services



Set G : Health status

G1 **My progress towards discharge goals**



Discharge Goals

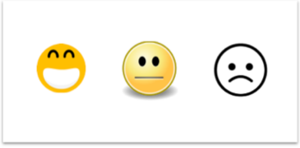
☑ Walk to bathroom

☐ Spend the night without pain medication

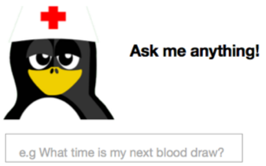
☐ Get O2 levels to 90

G4 **My health problems**

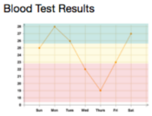
G2 **Doctor's feelings about my health**



G5 **Ask Jesse Penguin**



G3 **Lab results over time**



G5 **Search for anything**

Set H1: Doctor-Patient Communication

H1 Get a second opinion


Request a second opinion

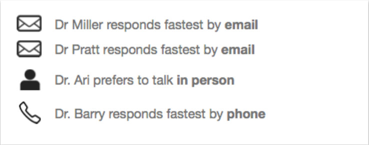
Who do you want to ask?

○ Whoever is appropriate (automatically determined)

○ A specific doctor: ______________________

○ A friend or family member: ________________

H2 Get a hold of your doctors or nurses

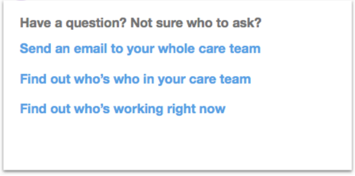

✉ Dr Miller responds fastest by **email**

✉ Dr Pratt responds fastest by **email**

Dr. Ari prefers to talk **in person**

☎ Dr. Barry responds fastest by **phone**

H3 Who should I ask?

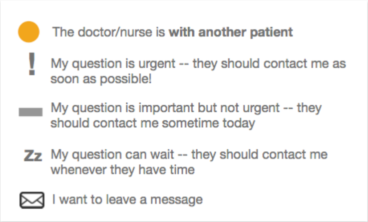

Have a question? Not sure who to ask?

Send an email to your whole care team

Find out who's who in your care team

Find out who's working right now

H4 Tell your doctor/nurse if your question is urgent


● The doctor/nurse is **with another patient**

! My question is urgent -- they should contact me as soon as possible!

My question is important but not urgent -- they should contact me sometime today

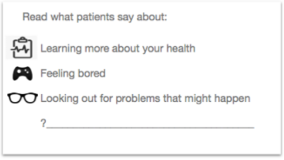
Zz My question can wait -- they should contact me whenever they have time

✉ I want to leave a message

H5 Feeling Meter: Show the doctor how you feel

Set I : Connecting with other patients

I1 Advice about being in the hospital


Read what patients say about:

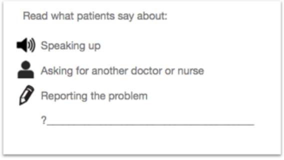
Learning more about your health

Feeling bored

Looking out for problems that might happen

?______________________________

I2 What to do when you notice a problem


Read what patients say about:

Speaking up

Asking for another doctor or nurse

Reporting the problem

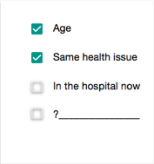
?______________________________

I3 Share your advice with others

I4 Chat with another patient

I5 Read other patient's stories

I6 Filter Patients By:


☑ Age

☑ Same health issue

☐ In the hospital now

☐ ?____________

APPENDIX C: INTERVIEW GUIDE FOR TRACKING INTERVIEWS (CHAPTER 3)

This is the protocol used for the Tracking interview study which is described as Study 2 in Chapter 3. Please note that the interview protocol was a collaborative effort from PAS team members, especially Jordan Eschler.

Interview 1

[Give the participant materials for activity]

This interview starts with an activity. Here's a board that's laid out like a comic strip, where we're going to work together to make a story. After I explain the beginning of the story, I will ask you to show me how the story ends, using the magnets and the board and the markers. Do you have any questions?

OK, here is the beginning of the story. Let's look at Box 1 and Box 2 while I read:

Earlier this morning, Dr. A came by during rounds and told you that they would be increasing your medication dose. Just now, Dr. B came in and said they would be lowering your medication dose. What happens next?

[Allow the participant time to construct the next parts of the story]

Now, I'm going to add to the story. This is what happens next:

Nurse C just came to hook up a new IV bag with your medicine, but the color looks different than the IV bags you have been receiving. What happens next?

[Allow the participant time to respond to this event in constructing the story]

OK, we are almost done with this activity. Before we put this stuff away, can you walk me through the story you have built, from start to finish, for the audio recording?

[Put away materials if necessary for interview]

Now, I'm going to ask you some questions about your stay here in the hospital. Do you have any questions before we move on?

Follow-up questions:

How do your care team members currently coordinate to make sure they are all on the same page about what should happen?

In a situation like this activity, how should decisions get made by doctors and nurses?

How would you be sure that your care team had resolved the situation in this activity? Who would you follow up with?

If you encountered a situation like this medication confusion in the activity, what would you change about how you communicate with your care team? How should they change their communication with you?

What things are particularly important for your care team to communicate with each other?

Who here in the hospital helps you to have a “voice” with your care team?

Interview Script

What kinds of information are you trying to remember while in the hospital?

How do you remember these things?

Follow-up questions:

How do the things you track relate to your goals while you are in the hospital?

What are some of your goals in the hospital?

How would you describe the routine here in the hospital?

What is your role in this routine?

Has the routine changed over the course of your stay?

When you track [blood pressure/temperature/pain—follow up on each thing], how does the routine around tracking pain help manage your [blood pressure/temperature/pain]?

What things would you like your doctors and nurses to ask you more often? What things would you like your doctors and nurses to ask you less often?

Do your doctors or nurses ever ask you questions that you can’t answer?

What aspects of the hospital stay worry you the most?

What would help you to feel better about your worries? E.g. What kinds of information would help?

How would you want to keep track of that information to reduce your worries?

Who on your team of nurses and doctors makes you feel safest? [Also ask about therapists, etc.] Why do you think that is?

Follow-up questions

If you feel relatively safe here in the hospital, why do you think that is?

What things are the nurses and doctors doing the right way to help you feel safe?

What are some things you see doctors or nurses doing here in the hospital that make you safer?

Think of a nurse or doctor or other care team member you feel you particularly trust. What about working with that person helps you to trust them?

Did you get any advice about coming into the hospital? Where did that advice come from?

What did you think about before deciding to follow the advice from another person?

Are there more questions you would want to ask a person giving you the advice about a hospital stay?

What are some things you want to know about what will happen to you here at the hospital?

What are some things you want to know about how you will feel here at the hospital?

What are some things you want to know about medications or routines here in the hospital?

What are some things you want to know about the hospital?

When would it be useful or helpful to know these things about being in the hospital?

Interview 2

Notes from the last interview:

Review this information prior to engaging with participant.

Last time we talked, we spoke about the things you were seeing in the hospital, and how you were keeping track of things that were important to you. I am going to ask you some more questions like that in this interview. Do you have any questions before we begin?

Interview Script

What kinds of information are you keeping track of while in the hospital?

What kinds of information are your doctors and nurses tracking while you are in the hospital?

What is the most important information to keep track of during your hospital stay?

Follow-up questions:

How do the things you track relate to your goals while you are in the hospital?

What are some of your goals in the hospital?

How would you describe the routine here in the hospital?

What is your role in this routine?

Has the routine changed over the course of your stay?

When you track [blood pressure/temperature/pain—follow up on each thing], how does the routine around tracking pain help manage your [blood pressure/temperature/pain]?

What things would you like your doctors and nurses to ask you more often? What things would you like your doctors and nurses to ask you less often?

Who is responsible for keeping track of information about your hospital stay?

Who would you like to be responsible for keeping track of information about your hospital stay?

Has there ever been a time you felt your doctors or nurses forgot to do something that was important to you? Tell me more about that.

Have you ever seen something happen here in the hospital, during this stay, that caused a problem or an issue for you? Tell me more about that.

Follow-up questions

If you feel relatively safe here in the hospital, why do you think that is?

What things are the nurses and doctors doing the right way to help you feel safe?

What are some things you see doctors or nurses doing here in the hospital that make you safer?

Think of a nurse or doctor or other care team member you feel you particularly trust. What about working with that person helps you to trust them?

Who here helps you to feel like you have a “voice” in your care?

What things about your hospital stay do you think could be better for you?

Has there been a time you needed or wanted to speak up with a nurse or doctor about something happening to you that you didn’t want? Tell me more about that.

What kinds of information do you share with others about your health? Tell me more about that.

What are your thoughts on sharing information about your hospital stay with other patients and families?

Would you be interested in reading information that other patients and families have to share with you?

Is there anything important about your stay so far that you would want other families to know?

Which people here in the hospital make you feel safest? Why do you think that is?

Which people here in the hospital are best able to help you? Why do you feel that way?

Which people here in the hospital are the best at answering your questions? Why do you feel that way?

What are some things you want to know about being in the hospital? [Probe: procedures, medications and routines, how the patient will feel, services]

Interview 3

Notes from the last interview:

Review this information prior to engaging with participant.

Last time we talked, we spoke about your stay in the hospital. I am going to ask you some more questions like that in this interview. Do you have any questions before we begin?

Interview script

Was there ever a time you felt your doctors or nurses forgot to do something that was important to you? Can you think of any way this could have been prevented?

Was there ever a time when you thought something happened that shouldn't have? Tell me more about that.

What kinds of information were you keeping track of while in the hospital?

What kinds of information were your doctors and nurses tracking while you are in the hospital?

What kinds of things did your doctors and nurses know that you wish you had known too?

Was there information you tracked at the hospital that seemed more important to you than your doctors and nurses?

What do you wish your doctors and nurses had explained to you about tracking important information before you left the hospital?

What have you learned about keeping track of information during and after your hospital stay?

How have your ideas about keeping track of information changed since the beginning of your hospital stay?

Since you've left the hospital, how do you keep track of important information now, at home?

What are your thoughts on sharing information with patients who are going into the hospital now?

What kinds of information would you like to share? Why would you want to share it? How would you want to share this information?

Can you think of some things you would only want to talk about with your doctor, and things you would only want to talk about with another patient? Why?

How would you have used information from other patients while at the hospital? Would it have changed your stay at all?

APPENDIX D: EXPERT VALIDATION SURVEYS (CHAPTERS 5-6)

Since the two rounds of survey were identical except for the interventions presented, I have combined them into a single survey here.

The images used in the prototypes fall under fair use as described by Crews (Crews, 2013). The purpose and character of the use are scholarly, as the images were used as part of research instruments to elicit responses from users. In addition, the use of these images was transformative: Crews states that "cutting, adjusting, and altering the work to place it in the context of a scholarly study can be transformative" (Crews, 2013). Many of these images were clipped or altered, and all were placed in the context of a scholarly study. The effect of the use of these images on the potential market for or value of the original is also likely to be negligible.

W UNIVERSITY *of* WASHINGTON

Info and consent

ID: 3

About the study

We are researchers at the University of Washington. This study is part of a series of studies to understand how technology can improve the quality and safety of care for hospitalized patients and their caregivers. We want to understand how we can help patients and caregivers communicate successfully with their clinicians.

In this study, we are trying to understand how to design technological interventions that target different mediators of behavior.

What are we asking you to do?

Below we depict several different features that could be used to help patients and caregivers communicate with their clinicians. For each feature, we would like you to tell us the mechanism (the behavioral mediator) by which the feature operates. We are basing this study around the Integrated Behavioral Model, which builds on the Theory of Planned Behavior and the Theory of Reasoned Action. We will provide more information about this model in the survey.

How long will this take?

We expect this will take you 15-30 minutes.

Do I get anything for participating in the study?

We will send you a $25 giftcard as a thank you for your participation.

Do I have to participate?

NO!! Participation is completely voluntary. If you decide to participate and change your mind later, that's also fine.

Who can participate?

We are looking for people who hold a graduate degree in behavioral science, psychology, or a related field. If you are not sure if you can participate, contact us at patientsassafeguards@gmail.com.

What are the potential harms and risks?

Worry, discomfort, or fatigue: We may ask you questions that bring up unpleasant or uncomfortable feelings or memories. You do not have to share any information that you do not want to share. You can skip any questions you do not want to answer, or withdraw from the study at any time.

Privacy and confidentiality: We will not share your identity outside of the research team. We will make every effort to keep your responses confidential.

There are some reasons that we may need to share the information you give us with others:

- If it’s required by law.
- If we think you or someone else could be harmed.
- Sponsors, government agencies or research staff sometimes look at forms like this and other study records. They do this to make sure the research is done safely and legally.

Anyone who reviews study records would keep your information confidential. Agencies or sponsors that may look at study records include:

- Hospital auditors and Institutional Review Boards
- The study sponsor: Agency for Health Research and Quality

What are the potential benefits if I join this study?

We do not expect that you will benefit directly from joining this study. However, your participation can help us improve patient-facing technologies in hospitals to improve the quality and safety of hospital care.

Who can I contact if I have questions about the study?

For general questions about the study, you can contact the research team at patientsassafeguards@gmail.com. For research-related questions or complains, you can contact Dr. Wanda Pratt at 206-543-6653. For information about your rights as a research participant, you can contact the the IRB Administrator at the University of Washington at:

UW Human Subjects Division
UW Tower 17th Floor
4333 Brooklyn Ave NE
Box 359470
Seattle, WA 98195-9470
Tel: 206-543-0098
Email: hsdinfo@uw.edu

ID: 4

1) By checking this box, I agree that I have been informed about this study and I agree to participate.*

I consent to participate in this research.

Integrated Behavioral Model

Page exit logic: Skip / Disqualify Logic**IF:** #2 Question "How familiar are you with the Integrated Behavioral Model?" is one of the following answers ("Very familiar: I can draw out the model, define each construct, and/or have used it in my work") **THEN:** Jump to page 6 - Features/Interventions

Page exit logic: Skip / Disqualify Logic**IF:** #2 Question "How familiar are you with the Integrated Behavioral Model?" is one of the following answers ("Not at all familiar: I have never heard of it before","Somewhat unfamiliar: I have heard of it but don't know much about it","Somewhat familiar: I know something about it but I couldn't tell you all the details") **THEN:** Jump to page 3 - Integrated Behavioral Model review

ID: 55

2) How familiar are you with the Integrated Behavioral Model?

Not at all familiar: I have never heard of it before

Somewhat unfamiliar: I have heard of it but don't know much about it

Somewhat familiar: I know something about it but I couldn't tell you all the details

Very familiar: I can draw out the model, define each construct, and/or have used it in my work

---

Integrated Behavioral Model review

ID: 21

Review of the Integrated Behavioral Model

We are going to ask you to look at hypothetical features/interventions in an app to motivate hospitalized patients to speak up about their concerns, and map them to the appropriate constructs in the Integrated Behavioral Model (see Fig. 1 for Integrated Behavioral Model illustration). Accordingly, we would like to help you become more familiar with the model. This model builds on the Theory of Reasoned Action and the Theory of Planned Behavior. Below we define the essential constructs of the model. We will ask you to correctly match definitions to constructs before classifying the features/interventions.

The Integrated Behavioral Model names six mediators of behavioral intention:
Experiential attitude: the affective component of someone's attitude towards a behavior, i.e. their overall feelings about a behavior, like whether the individual perceives a behavior as pleasant or unpleasant.
Instrumental attitude: the cognitive component of someone's attitude towards a behavior, based on evaluations of things like the outcomes of the behavior, i.e. whether someone judges a behavior good or bad, or wise or foolish.
Injunctive norms: people's beliefs about whether other people approve or disapprove of the behavior.
Descriptive norms: people's beliefs about whether other people perform the behavior.
Perceived behavioral control: people's perceived power over things that make it easy or hard to do the behavior.
Self-efficacy: people's confidence in their ability to do the behavior, especially in the face of obstacles.
In addition to these six mediators, four other factors affect whether behavioral intention translates into behavior:
Knowledge and skills to perform the behavior: people's technical ability to do the behavior.
Salience: the behavior's relevance and availability in the situation.
Environmental constraints: the fact that the person must not face outside circumstances that prevent the performance of the behavior, and
Habit: whether the person has an established history or routine of performing the behavior.

ID: 56

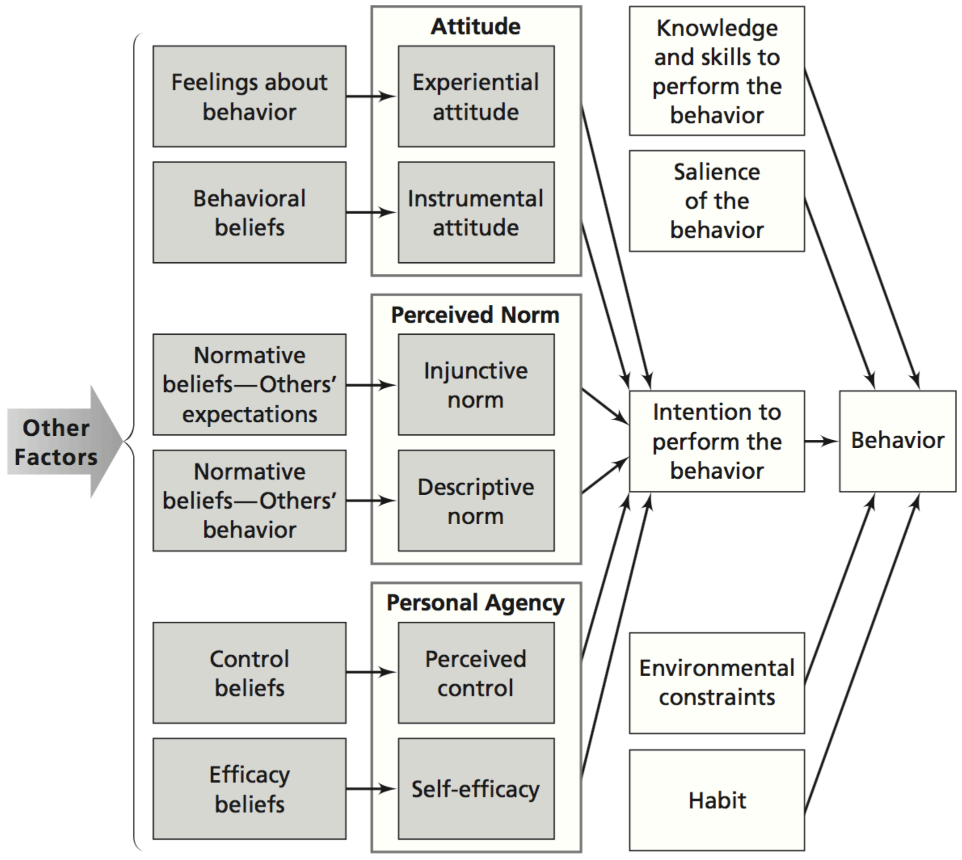


FIGURE 4.2. Integrated Behavior Model.

The Integrated Behavioral Model, from Montano and Kasprzyk 2008.

Integrated Behavioral Model quiz

ID: 65

3) This construct refers to people's confidence in their ability to do the behavior, especially in the face of obstacles.

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

Environmental constraints

Habit

Not sure

ID: 59

4) This construct refers to the cognitive component of someone's attitude towards a behavior, based on evaluations of things like the outcomes of the behavior, i.e. whether someone judges a behavior good or bad, or wise or foolish.

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

Environmental constraints

Habit

Not sure

ID: 62

5) This construct refers to people's beliefs about whether other people perform the behavior.

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy
Knowledge and skills to perform the behavior
Salience of the behavior
Environmental constraints
Habit
Not sure

ID: 58
6) This construct refers to the affective component of someone's attitude towards a behavior, i.e. their overall feelings about a behavior, like whether the individual perceives a behavior as pleasant or unpleasant.
Experiential attitude
Instrumental attitude
Injunctive norm
Descriptive norm
Perceived control
Self-efficacy
Knowledge and skills to perform the behavior
Salience of the behavior
Environmental constraints
Habit
Not sure

ID: 72
7) This construct refers to outside circumstances that can prevent the performance of the behavior.
Experiential attitude
Instrumental attitude
Injunctive norm
Descriptive norm
Perceived control
Self-efficacy

Knowledge and skills to perform the behavior
Salience of the behavior
Environmental constraints
Habit
Not sure

ID: 61

8) This construct refers to people's beliefs about whether other people approve or disapprove of the behavior.

Experiential attitude
Instrumental attitude
Injunctive norm
Descriptive norm
Perceived control
Self-efficacy
Knowledge and skills to perform the behavior
Salience of the behavior
Environmental constraints
Habit
Not sure

ID: 64

9) This construct refers to people's perceived power over things that make it easy or hard to do the behavior.

Experiential attitude
Instrumental attitude
Injunctive norm
Descriptive norm
Perceived control
Self-efficacy

Knowledge and skills to perform the behavior
Salience of the behavior
Environmental constraints
Habit
Not sure

ID: 73

10) This construct refers to whether the person has an established history or routine of performing the behavior.

Experiential attitude
Instrumental attitude
Injunctive norm
Descriptive norm
Perceived control
Self-efficacy
Knowledge and skills to perform the behavior
Salience of the behavior
Environmental constraints
Habit
Not sure

ID: 70

11) This construct refers to people's technical ability to do the behavior.

Experiential attitude
Instrumental attitude
Injunctive norm
Descriptive norm
Perceived control
Self-efficacy
Knowledge and skills to perform the behavior
Salience of the behavior

Environmental constraints

Habit

Not sure

ID: 71

12) This construct refers to the behavior's relevance and availability in the situation.

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

Environmental constraints

Habit

Not sure

Integrated Behavioral Model Quiz Feedback

Quiz score action: Integrated Behavioral Model Quiz Feedback

Quiz Type: Pass/Fail (A score of 100% passes)

Pass Message: Congrats! You got all the questions right. Feel free to proceed on to the next part of the survey.
Fail Message: Oh no! You got [quiz("questionswrong")] questions wrong. Here are the correct responses:

Features/Interventions

ID: 35

Classify Features/Interventions

Below we describe several hypothetical features/interventions that could appear in an ipad app for hospitalized patients and their caregivers. The goal of this app would be to motivate patients to speak up to clinicians about their concerns in order to help prevent medical errors.

For each intervention, you will be given both a description of the intervention and an illustration containing example content that we have created that shows how the intervention might be used. When classifying each intervention, consider the intervention as a whole, as well as how it might be used. For example, in the Patient Stories intervention, consider both the nature of the intervention (patients sharing stories with each other) and the types of content that are likely to be shared (like the fictional story we provide in the illustration). Then, for each intervention, select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.

ID: 37

13) Patient Stories Intervention: This intervention allows hospitalized patients to share with each other their own personal stories of speaking up to clinicians about their concerns. *Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.*

“I spoke up”: Stories from patients

“I spoke up because I needed time to think.”

I was asleep when a bunch of doctors I didn’t know came to my room. They said I needed a risky procedure, but no one had ever mentioned my needing it before. They tried to rush me along, but I wouldn’t let them take me anywhere until I found out more about what this risky procedure entails. I also demanded to speak to my normal doctors. Ultimately I got the procedure, but I made my own decision — it’s MY body!

Posted **yesterday** by **azer1593**

azer1593

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

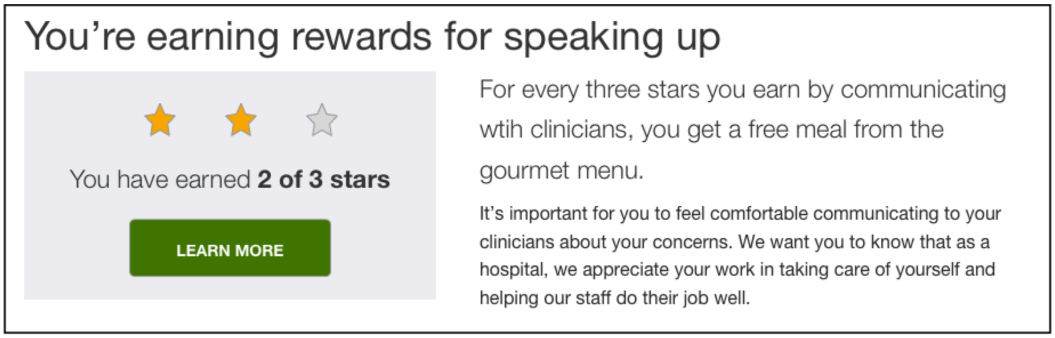
Environmental constraints

Habit

Not sure - Write In:

ID: 47

14) Rewards Intervention: This intervention allows hospitalized patients to earn rewards from the hospital for speaking up to clinicians about their concerns. *Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.*



You're earning rewards for speaking up

You have earned **2 of 3 stars**

For every three stars you earn by communicating wtih clinicians, you get a free meal from the gourmet menu.

It's important for you to feel comfortable communicating to your clinicians about your concerns. We want you to know that as a hospital, we appreciate your work in taking care of yourself and helping our staff do their job well.

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

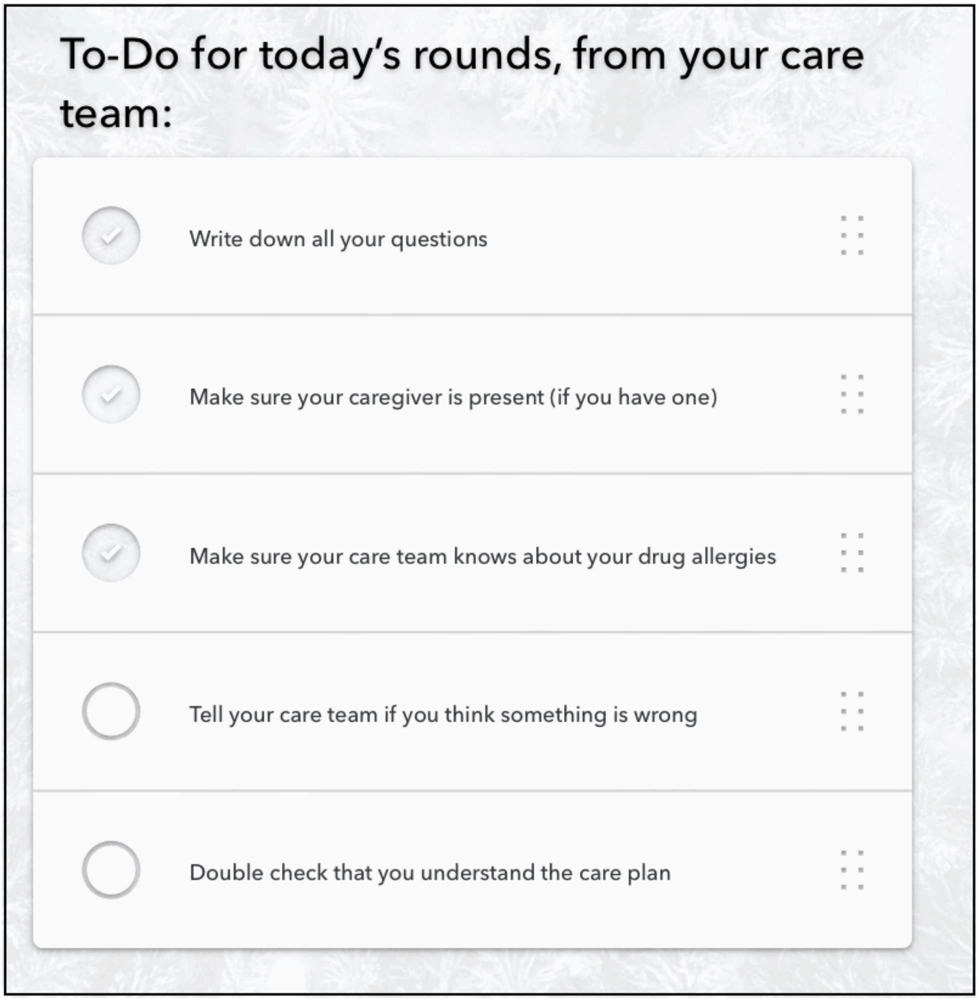
Environmental constraints

Habit

Not sure - Write In:

ID: 40

15) To-Do List Intervention: This intervention gives patients a daily to-do list, created by their clinical team, that instructs them to perform particular safety behaviors like voicing concerns and double-checking that the care team knows about their drug allergies. *Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.*



To-Do for today's rounds, from your care team:

- ☑ Write down all your questions
- ☑ Make sure your caregiver is present (if you have one)
- ☑ Make sure your care team knows about your drug allergies
- ○ Tell your care team if you think something is wrong
- ○ Double check that you understand the care plan

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

Environmental constraints

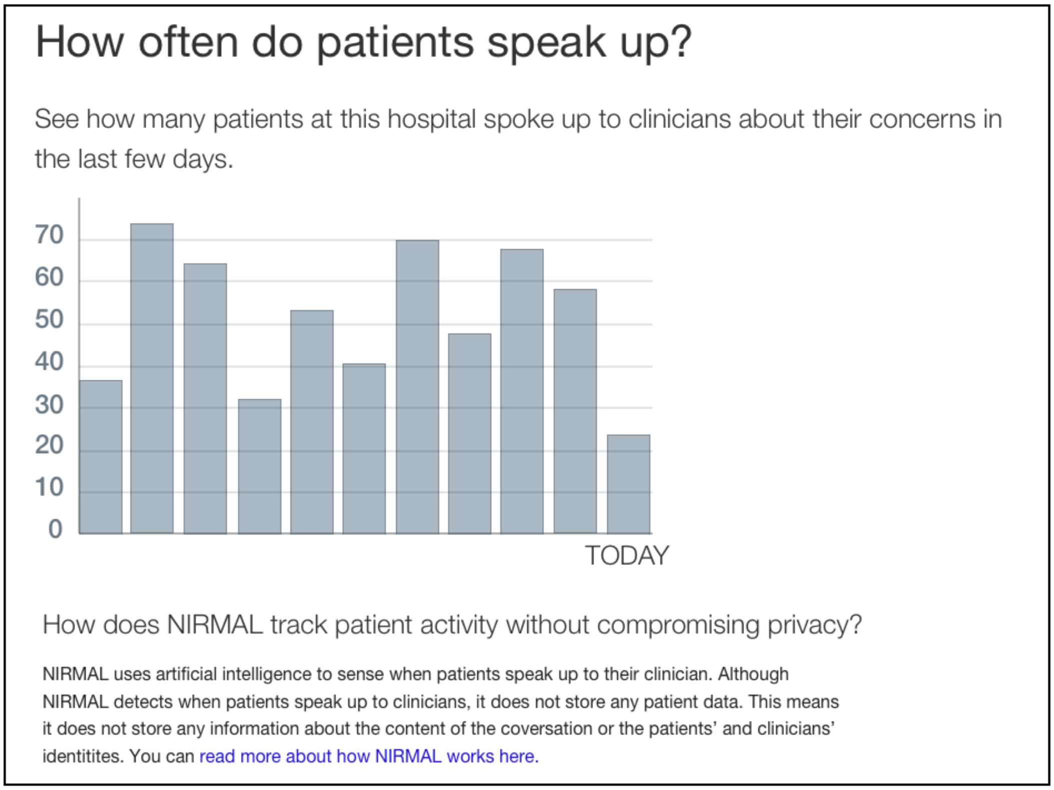
Habit

Not sure - Write In:

ID: 43

16) Speak-Up Tracking Intervention: This intervention automagically tracks how often patients speak up about their concerns to clinicians, and displays aggregate information while preserving patient privacy.

Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.



How often do patients speak up?

See how many patients at this hospital spoke up to clinicians about their concerns in the last few days.

How does NIRMAL track patient activity without compromising privacy?

NIRMAL uses artificial intelligence to sense when patients speak up to their clinician. Although NIRMAL detects when patients speak up to clinicians, it does not store any patient data. This means it does not store any information about the content of the coversation or the patients' and clinicians' identitites. You can read more about how NIRMAL works here.

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

Environmental constraints

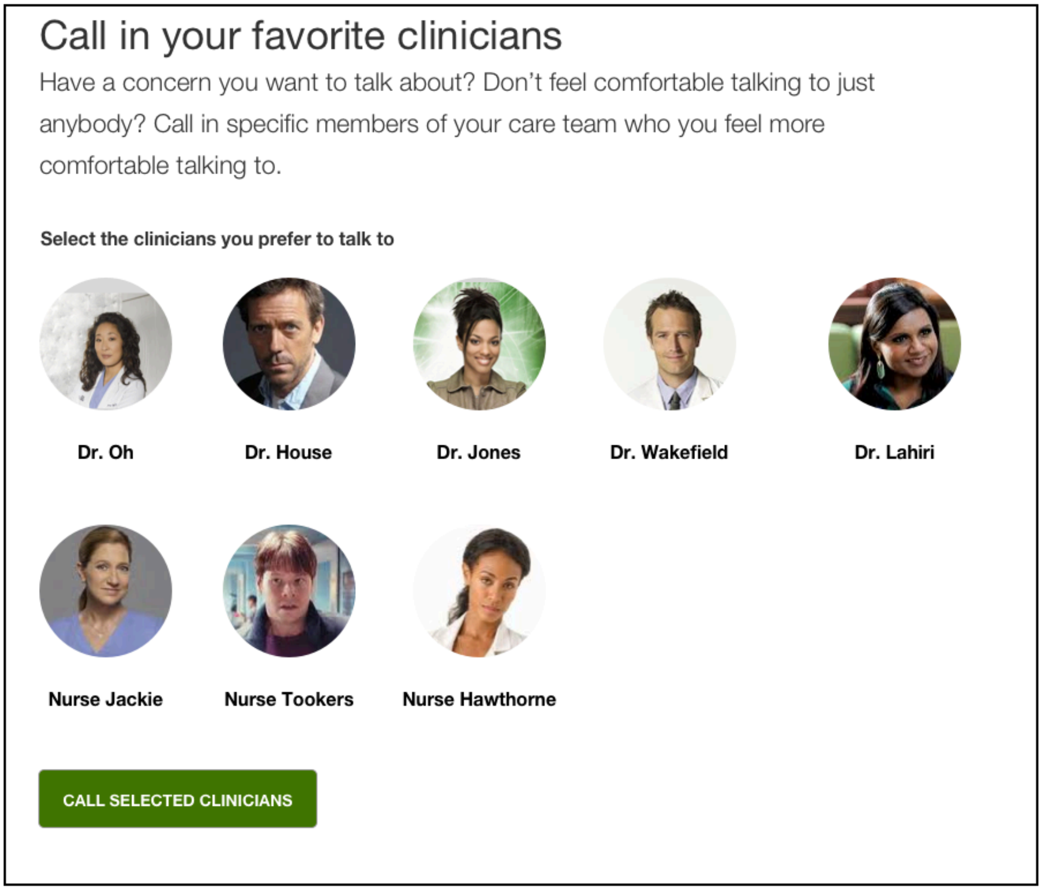
Habit

Not sure - Write In:

ID: 41

17) Calling Favorite Clinicians Intervention: This intervention allows hospitalized patients to call their preferred clinicians when they have a concern, rather than limiting their communication to whoever is currently in their room.

Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.



Call in your favorite clinicians

Have a concern you want to talk about? Don't feel comfortable talking to just anybody? Call in specific members of your care team who you feel more comfortable talking to.

Select the clinicians you prefer to talk to

Experiential attitude
Instrumental attitude
Injunctive norm
Descriptive norm
Perceived control
Self-efficacy
Knowledge and skills to perform the behavior

Salience of the behavior

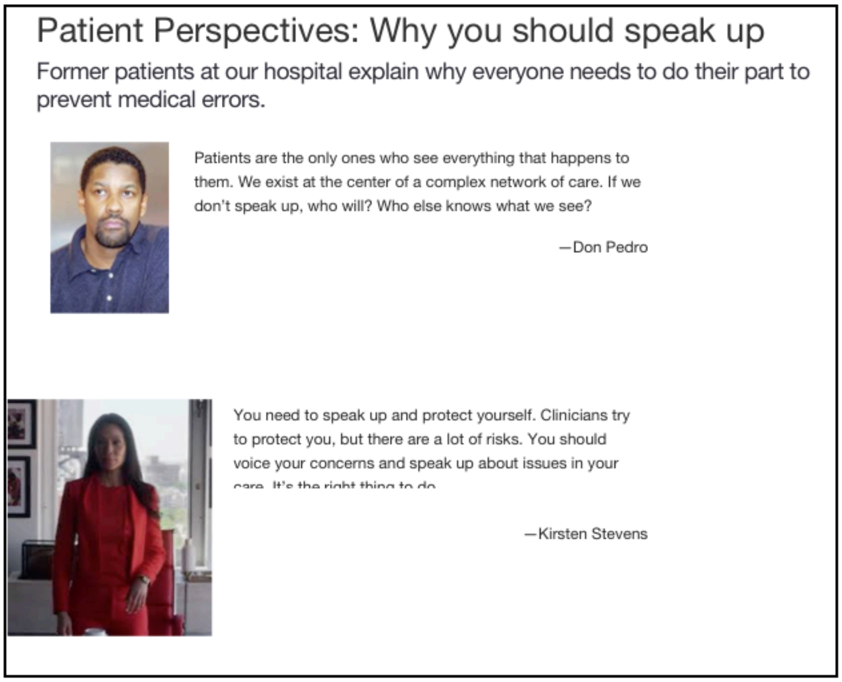
Environmental constraints

Habit

Not sure - Write In:

ID: 75

18) Patient Voices Intervention: This intervention contains messages from previous patients, encouraging current patients to speak up about their concerns. *Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.*



Patient Perspectives: Why you should speak up

Former patients at our hospital explain why everyone needs to do their part to prevent medical errors.

Patients are the only ones who see everything that happens to them. We exist at the center of a complex network of care. If we don't speak up, who will? Who else knows what we see?

—Don Pedro

You need to speak up and protect yourself. Clinicians try to protect you, but there are a lot of risks. You should voice your concerns and speak up about issues in your care. It's the right thing to do

—Kirsten Stevens

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

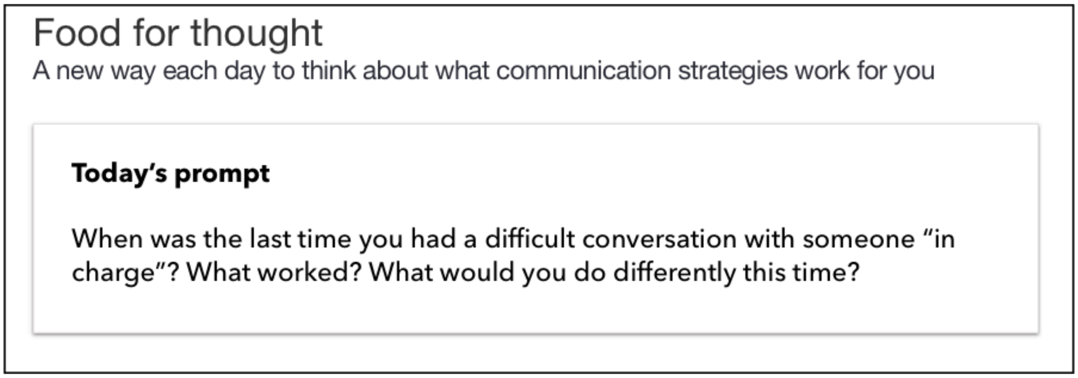
Environmental constraints

Habit

Not sure - Write In:

ID: 45

19) Food for Thought Intervention: This intervention prompts hospitalized patients to reflect on their own experience to gain insights into successful communication strategies. *Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.*



Food for thought

A new way each day to think about what communication strategies work for you

Today's prompt

When was the last time you had a difficult conversation with someone "in charge"? What worked? What would you do differently this time?

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

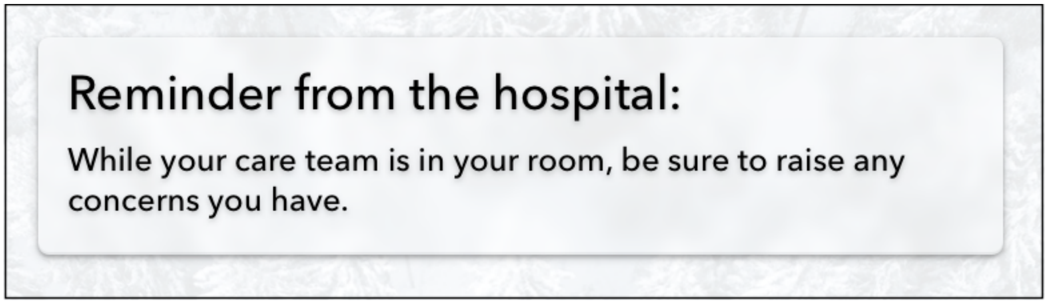
Environmental constraints

Habit

Not sure - Write In:

ID: 42

20) Hospital Reminder Intervention: This intervention allows the hospital to send patients reminders prompting them to speak up about their concerns.
Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.



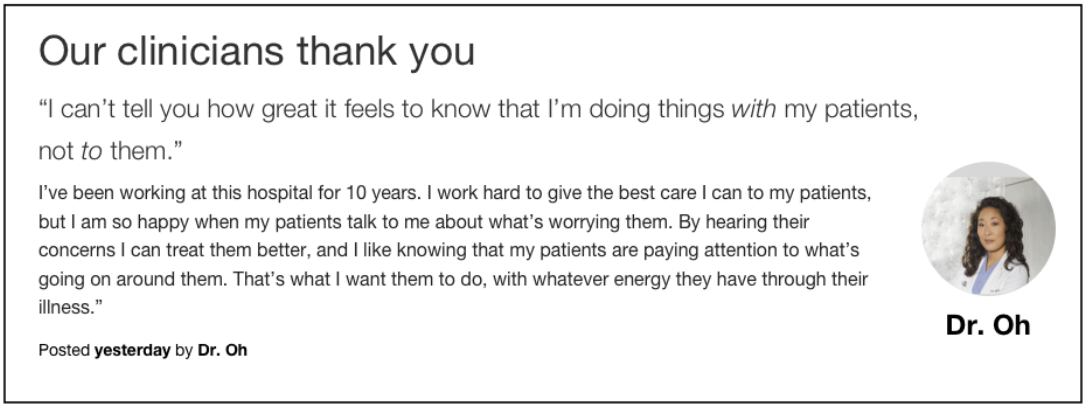
Reminder from the hospital:

While your care team is in your room, be sure to raise any concerns you have.

Experiential attitude
Instrumental attitude
Injunctive norm
Descriptive norm
Perceived control
Self-efficacy
Knowledge and skills to perform the behavior
Salience of the behavior
Environmental constraints
Habit
Not sure - Write In:

ID: 39

21) Clinician Thank-You Intervention: This intervention allows hospitalized patients to see messages of gratitude, written by clinicians in the hospital, thanking patients for speaking up about their concerns.
Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.



Our clinicians thank you

"I can't tell you how great it feels to know that I'm doing things *with* my patients, not *to* them."

I've been working at this hospital for 10 years. I work hard to give the best care I can to my patients, but I am so happy when my patients talk to me about what's worrying them. By hearing their concerns I can treat them better, and I like knowing that my patients are paying attention to what's going on around them. That's what I want them to do, with whatever energy they have through their illness."

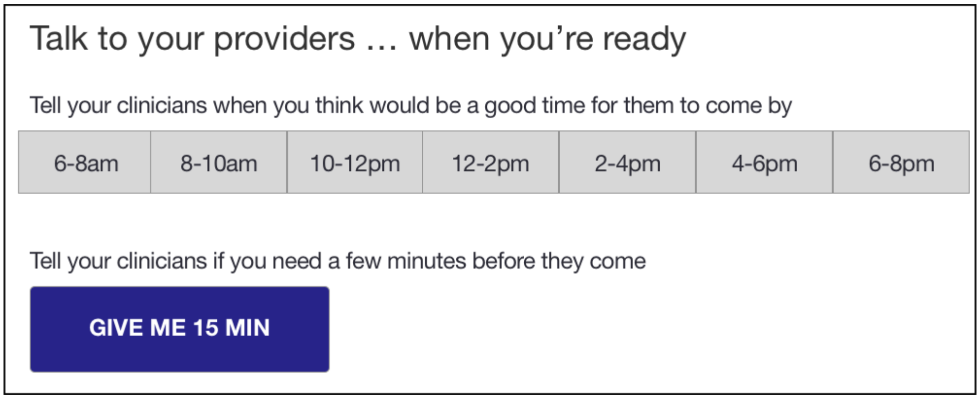
Posted **yesterday** by **Dr. Oh**

Dr. Oh

Experiential attitude
Instrumental attitude
Injunctive norm
Descriptive norm
Perceived control
Self-efficacy
Knowledge and skills to perform the behavior
Salience of the behavior
Environmental constraints
Habit
Not sure - Write In:

ID: 48

22) Schedule Availability Intervention: This intervention allows hospitalized patients to choose blocks of time for clinicians to come talk to them, so that they can plan to be awake and in their rooms when their clinicians come by. *Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.*



Talk to your providers … when you're ready

Tell your clinicians when you think would be a good time for them to come by

Tell your clinicians if you need a few minutes before they come

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

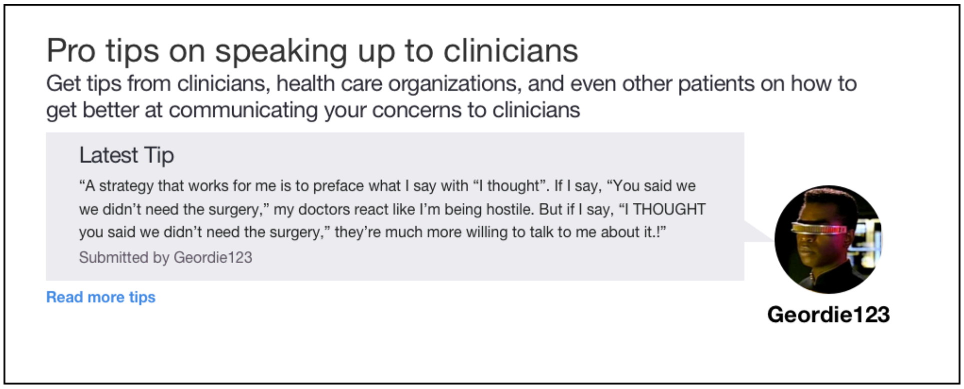
Environmental constraints

Habit

Not sure - Write In:

ID: 50

23) Pro Tips Intervention: This intervention allows patients to read tips on how to speak up to clinicians about their concerns. Tips can come from a mix of sources including clinicians, organizations like the Joint Commission or the Agency for Healthcare Research and Quality, and other hospitalized patients. *Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.*



Pro tips on speaking up to clinicians

Get tips from clinicians, health care organizations, and even other patients on how to get better at communicating your concerns to clinicians

Latest Tip

"A strategy that works for me is to preface what I say with "I thought". If I say, "You said we we didn't need the surgery," my doctors react like I'm being hostile. But if I say, "I THOUGHT you said we didn't need the surgery," they're much more willing to talk to me about it.!"

Submitted by Geordie123

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

Environmental constraints

Habit

Not sure - Write In:

ID: 76

7.5.1.1 24) Clinicians Survey Intervention: This intervention shows patients data about the attitudes of clinicians in the hospital about patients speaking up about their concerns. *Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.*

How many clinicians here at the hospital think patients can help prevent medical errors?

We surveyed our clinicians to find out what percentage of them think patients have a role to play in speaking up to prevent medical errors.

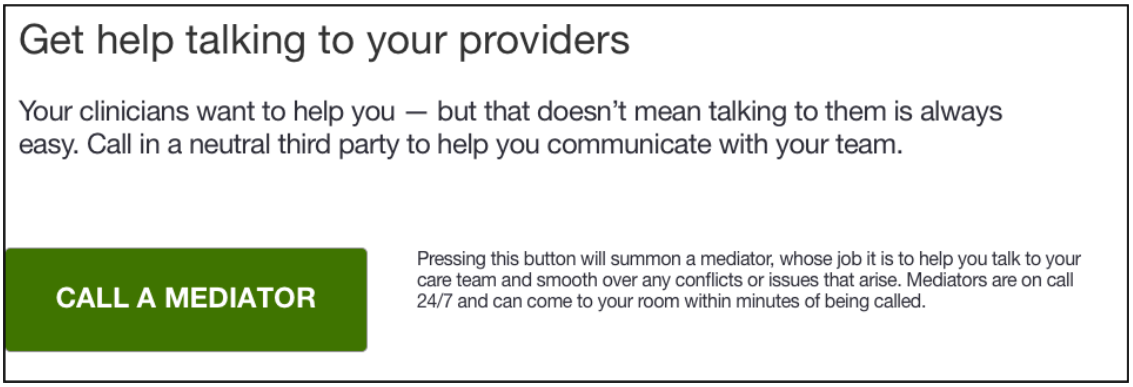
99% of our clinicians like it when patients speak up to prevent medical errors.

Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.

Experiential attitude
Instrumental attitude
Injunctive norm
Descriptive norm
Perceived control
Self-efficacy
Knowledge and skills to perform the behavior
Salience of the behavior
Environmental constraints
Habit
Not sure - Write In:

ID: 38

25) Calling a Conflict Mediator Intervention: This intervention allows hospitalized patients to call in a neutral third-party conflict mediator to help them speak up to clinicians about their concerns. *Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.*



Get help talking to your providers

Your clinicians want to help you — but that doesn't mean talking to them is always easy. Call in a neutral third party to help you communicate with your team.

Pressing this button will summon a mediator, whose job it is to help you talk to your care team and smooth over any conflicts or issues that arise. Mediators are on call 24/7 and can come to your room within minutes of being called.

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

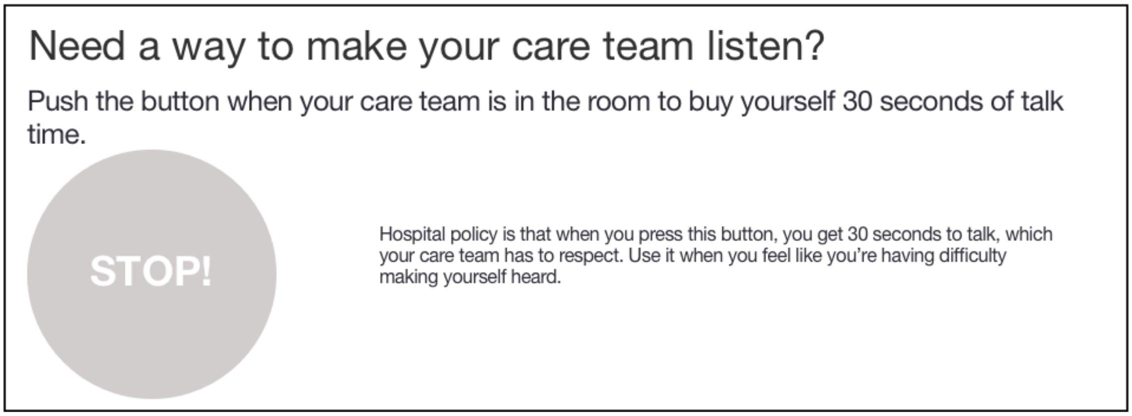
Environmental constraints

Habit

Not sure - Write In:

ID: 46

26) Stop Button Intervention: This intervention gives hospitalized patients a 'stop' button which will buy them 30 seconds of silence from their clinicians. Hospital clinicians will be trained to always stop and listen for 30 seconds when patients or caregivers use this button. *Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.*



Need a way to make your care team listen?

Push the button when your care team is in the room to buy yourself 30 seconds of talk time.

Hospital policy is that when you press this button, you get 30 seconds to talk, which your care team has to respect. Use it when you feel like you're having difficulty making yourself heard.

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

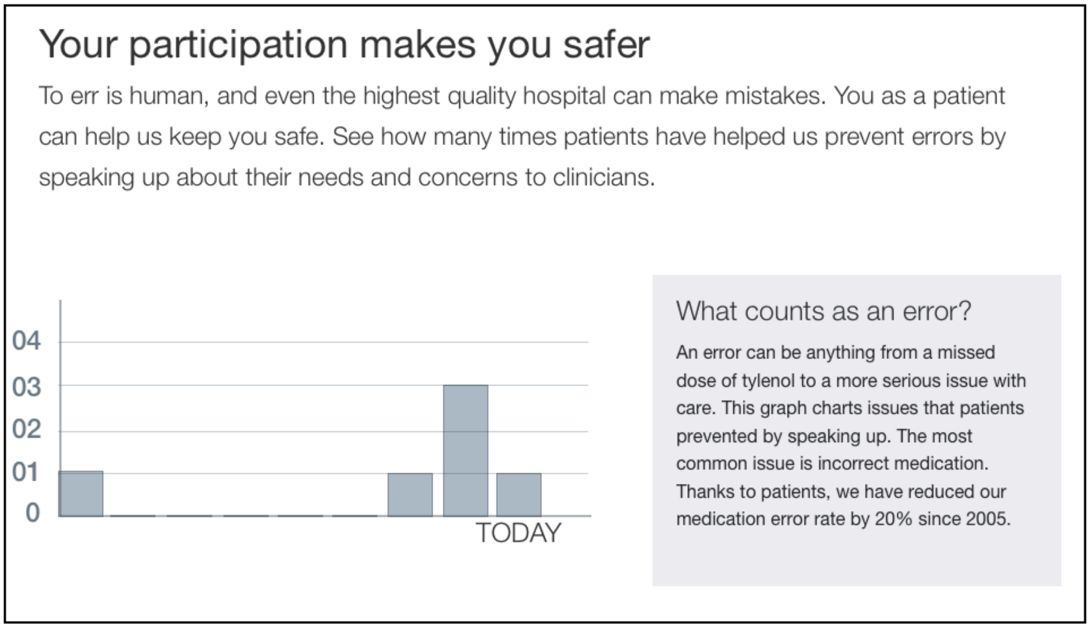
Environmental constraints

Habit

Not sure - Write In:

ID: 49

27) Prevented Error Tracker Intervention: This intervention automagically tracks the number of medical errors that patients at the hospital have prevented by speaking up, and presents aggregate data to preserve patient privacy. *Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.*



Your participation makes you safer

To err is human, and even the highest quality hospital can make mistakes. You as a patient can help us keep you safe. See how many times patients have helped us prevent errors by speaking up about their needs and concerns to clinicians.

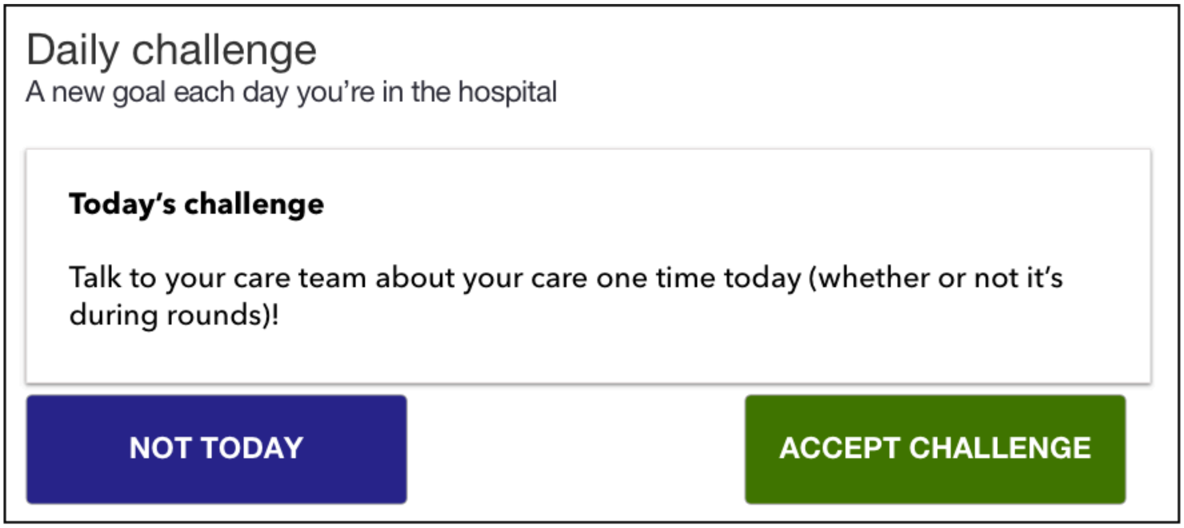
What counts as an error?

An error can be anything from a missed dose of tylenol to a more serious issue with care. This graph charts issues that patients prevented by speaking up. The most common issue is incorrect medication. Thanks to patients, we have reduced our medication error rate by 20% since 2005.

Experiential attitude
Instrumental attitude
Injunctive norm
Descriptive norm
Perceived control
Self-efficacy
Knowledge and skills to perform the behavior
Salience of the behavior
Environmental constraints
Habit
Not sure - Write In:

ID: 44

28) Daily Challenge Intervention: This intervention gives hospitalized patients a challenge which they can choose whether or not to take. The challenge changes every day but always gives patients a goal related to communicating with clinicians. *Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.*



Daily challenge

A new goal each day you're in the hospital

Today's challenge

Talk to your care team about your care one time today (whether or not it's during rounds)!

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

Environmental constraints

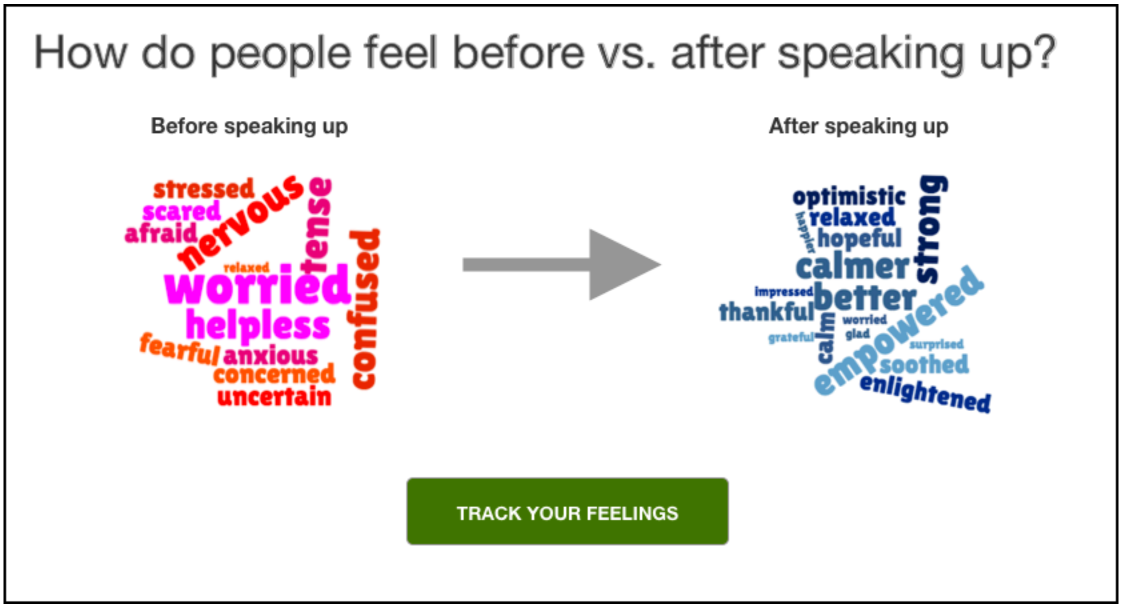
Habit

Not sure - Write In:

ID: 74

29) Affect Tracker Intervention: This intervention shows aggregate data about how speaking up about their concerns makes people feel, and allows patients to track their own feelings about speaking up.

Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.



How do people feel before vs. after speaking up?

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

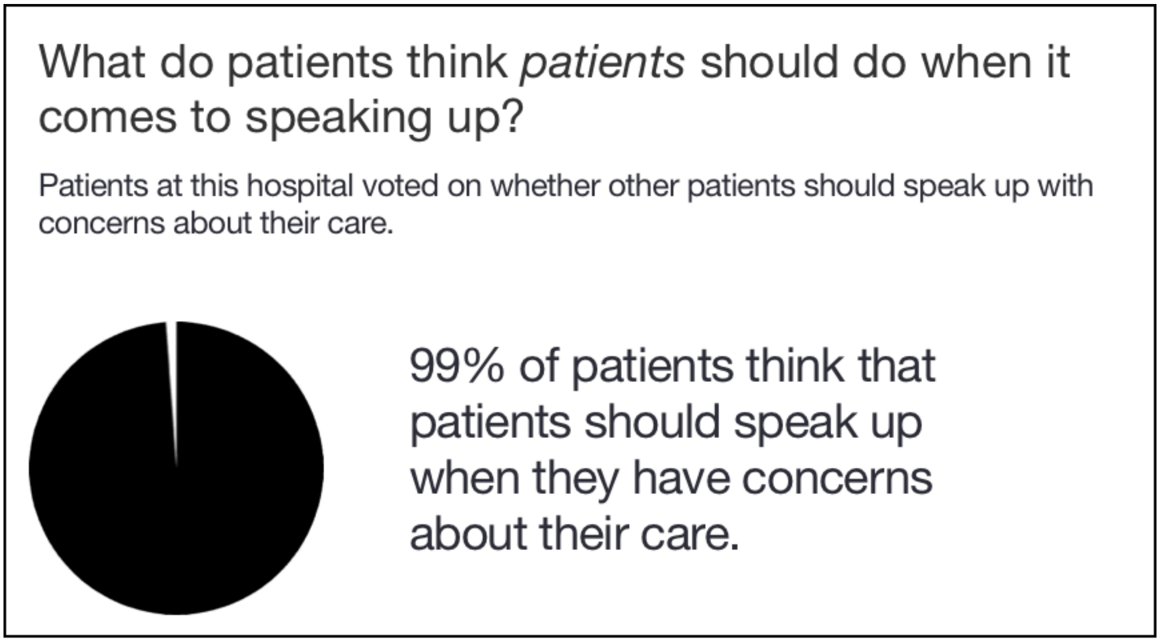
Environmental constraints

Habit

Not sure - Write In:

{Remaining interventions inserted from second iteration of this survey:}

13) What Do Patients Think Intervention: This intervention shows data about other patients' beliefs about whether patients should speak up about their care. The graph shows that most patients think patients should speak up.
Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.



What do patients think *patients* should do when it comes to speaking up?

Patients at this hospital voted on whether other patients should speak up with concerns about their care.

99% of patients think that patients should speak up when they have concerns about their care.

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

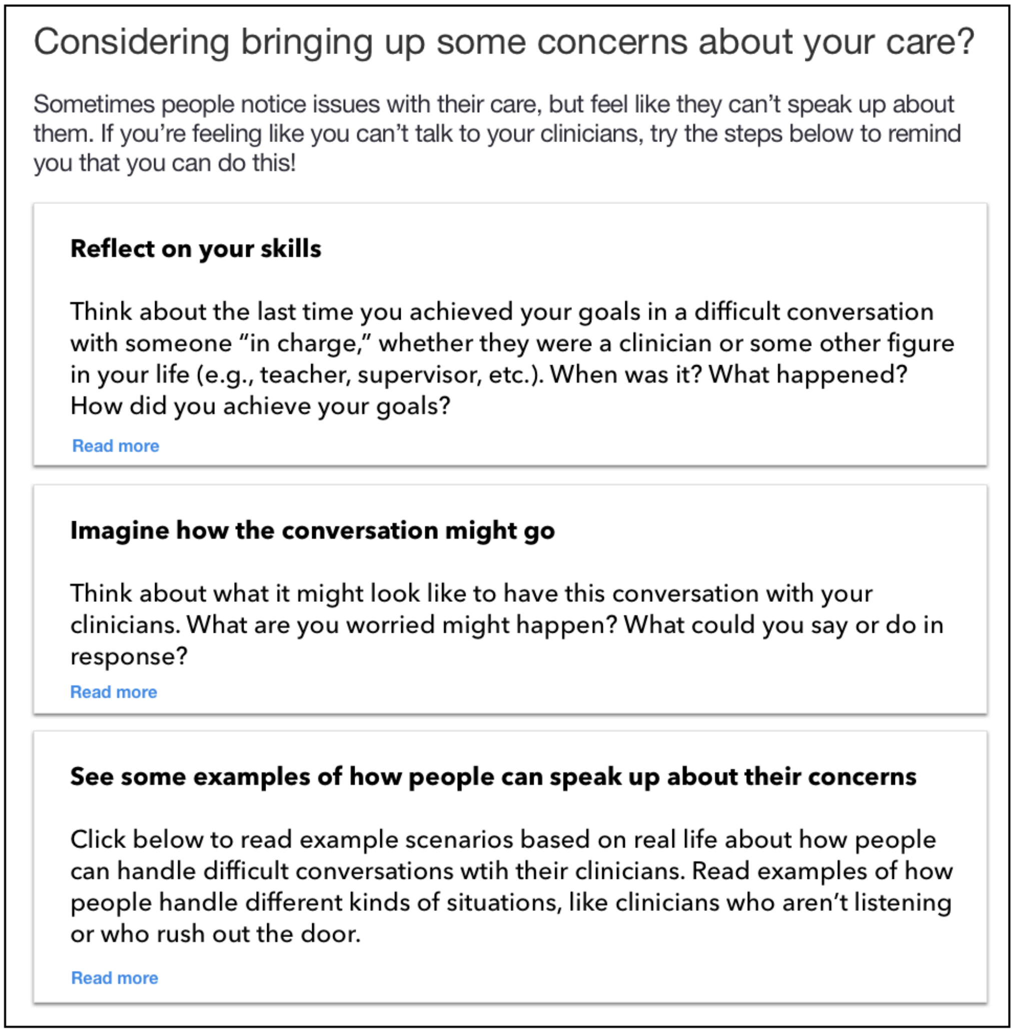
Environmental constraints

Habit

Not sure - Write In:

ID: 47

14) Build Your Skills Intervention: This intervention suggests different ways for patients to build skills and confidence in speaking up about their concerns. *Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.*



Considering bringing up some concerns about your care?

Sometimes people notice issues with their care, but feel like they can't speak up about them. If you're feeling like you can't talk to your clinicians, try the steps below to remind you that you can do this!

Reflect on your skills

Think about the last time you achieved your goals in a difficult conversation with someone "in charge," whether they were a clinician or some other figure in your life (e.g., teacher, supervisor, etc.). When was it? What happened? How did you achieve your goals?

Imagine how the conversation might go

Think about what it might look like to have this conversation with your clinicians. What are you worried might happen? What could you say or do in response?

See some examples of how people can speak up about their concerns

Click below to read example scenarios based on real life about how people can handle difficult conversations wtih their clinicians. Read examples of how people handle different kinds of situations, like clinicians who aren't listening or who rush out the door.

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

Environmental constraints

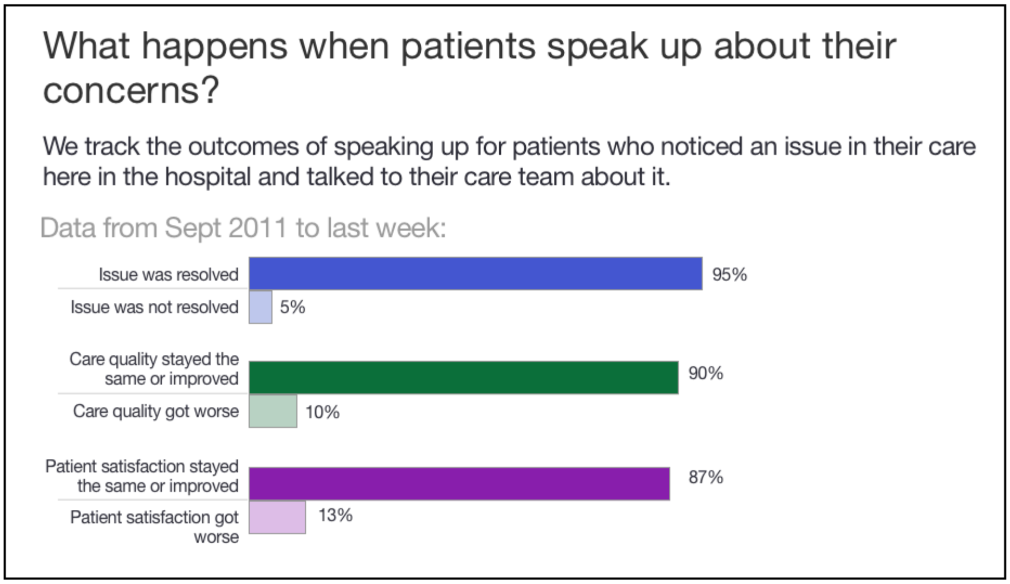
Habit

Not sure - Write In:

ID: 40

15) Care Impact Tracker Intervention: This intervention shows data collected by the hospital about what impact speaking up has had on patients' care at the hospital, and whether the issue was resolved.

Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.



What happens when patients speak up about their concerns?

We track the outcomes of speaking up for patients who noticed an issue in their care here in the hospital and talked to their care team about it.

Data from Sept 2011 to last week:

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

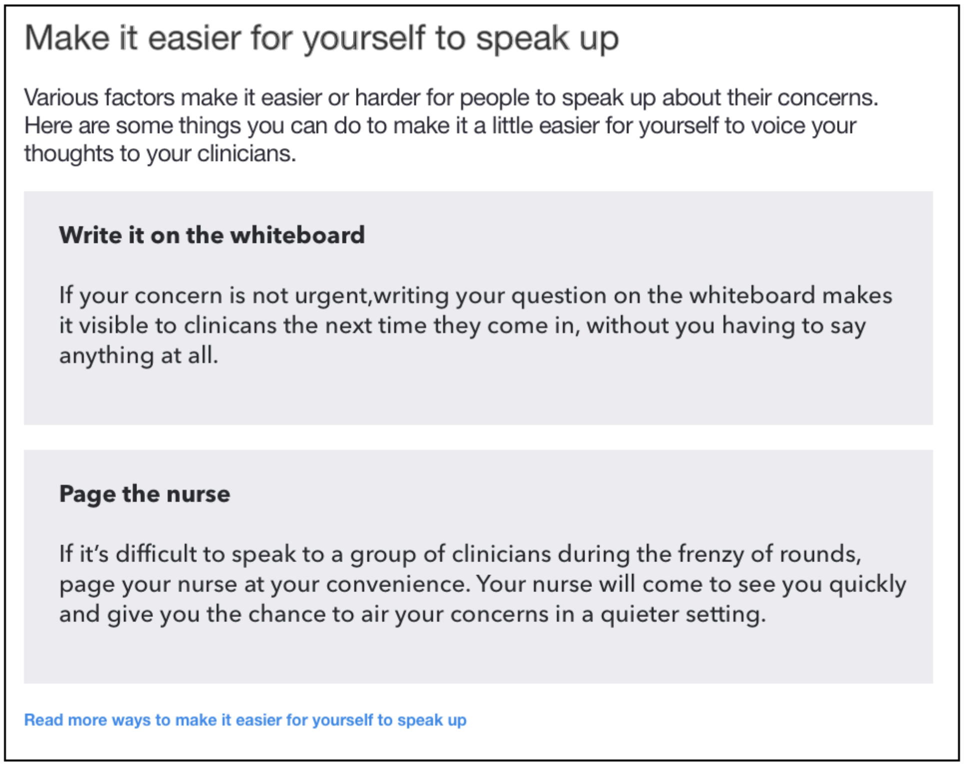
Environmental constraints

Habit

Not sure - Write In:

ID: 43

16) Make it Easier Intervention: This intervention suggests strategies that patients can use to make it easier for themselves to speak up to clinicians about their concerns. *Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.*



Make it easier for yourself to speak up

Various factors make it easier or harder for people to speak up about their concerns. Here are some things you can do to make it a little easier for yourself to voice your thoughts to your clinicians.

Write it on the whiteboard

If your concern is not urgent,writing your question on the whiteboard makes it visible to clinicans the next time they come in, without you having to say anything at all.

Page the nurse

If it's difficult to speak to a group of clinicians during the frenzy of rounds, page your nurse at your convenience. Your nurse will come to see you quickly and give you the chance to air your concerns in a quieter setting.

Read more ways to make it easier for yourself to speak up

Experiential attitude
Instrumental attitude
Injunctive norm
Descriptive norm
Perceived control
Self-efficacy
Knowledge and skills to perform the behavior
Salience of the behavior
Environmental constraints
Habit
Not sure - Write In:

ID: 41

17) What Do Clinicians Think Intervention: This intervention provides data about the attitudes of clinicians at the hospital towards patients speaking up about their care. The graph shows that most clinicians think that patients should speak up about their concerns. *Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.*

What do clinicians think patients *should* do when it comes to speaking up?

Clinicians at this hospital voted on whether other patients should speak up with concerns about their care.

95% of clinicians think that patients should speak up when they have concerns about their care.

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

Environmental constraints

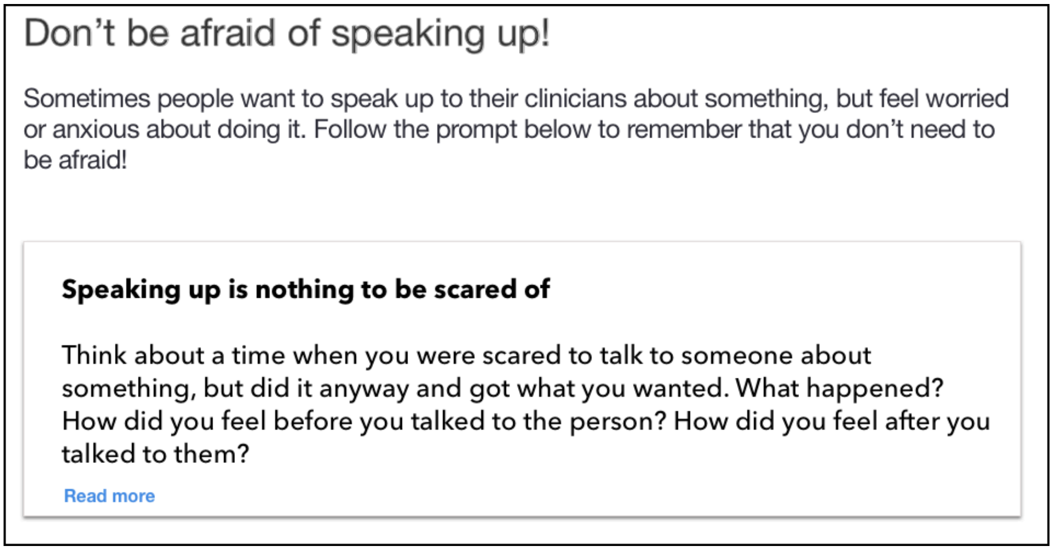
Habit

Not sure - Write In:

ID: 75

18) Fear Not Intervention: This intervention offers suggestions to patients on how to work through their fears about speaking up to their care team.

Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.



Don’t be afraid of speaking up!

Sometimes people want to speak up to their clinicians about something, but feel worried or anxious about doing it. Follow the prompt below to remember that you don’t need to be afraid!

Speaking up is nothing to be scared of

Think about a time when you were scared to talk to someone about something, but did it anyway and got what you wanted. What happened? How did you feel before you talked to the person? How did you feel after you talked to them?

Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

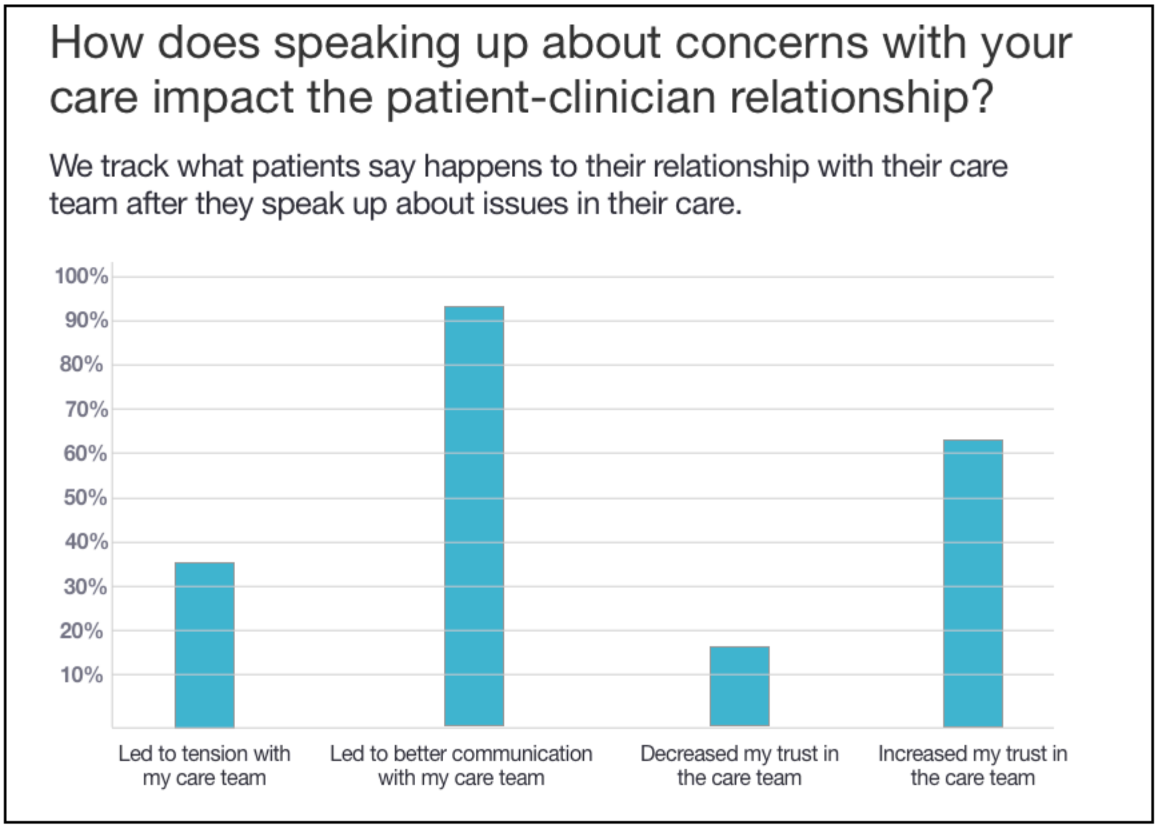
Environmental constraints

Habit

Not sure - Write In:

ID: 45

19) Relationship Impact Tracker Intervention: This intervention offers data about how speaking up has impacted the clinician-patient relationship for other patients in the hospital. *Instructions: Select the construct(s) from the Integrated Behavioral Model through which you think the intervention operates. Check all construct(s) that apply.*



Experiential attitude

Instrumental attitude

Injunctive norm

Descriptive norm

Perceived control

Self-efficacy

Knowledge and skills to perform the behavior

Salience of the behavior

Environmental constraints

Habit

Not sure - Write In:

ID: 8

30) Questions, comments, thoughts?

ID: 14

31) What is your age?

18 to 24

25 to 34

35 to 44

45 to 54

55 to 64

65 to 74

75 or older

ID: 15

32) What is your gender?

Male

Female

Another gender::

Prefer not to answer

ID: 16

33) What is your race/ethnicity? Select all that apply.

Asian

Native Hawaiian or Other Pacific Islander

Black/African-American

White

Hispanic/Latino

American Indian/Alaska Native

Other - Write In:

Prefer not to answer

ID: 17

34) What is the highest degree that you hold?

Less than high school

Graduated high school

Trade/technical school

Some college, no degree

Associate degree

Bachelor's degree

Master's degree

Doctoral degree

Other terminal degree (e.g. MD, MD/PhD, JD)

Other - Write In:

ID: 18

35) What field is your degree in?

ID: 51

36) What field are you in now?

ID: 53

37) What is your current position?

Student

Post-Doc

Faculty

Researcher or practitioner outside of academia

Other - Write In (Required): *

ID: 54

38) How long have you been in your current position?

Validation: %s format expected

ID: 9

39) Tell us what we email address we should send your Amazon gift card to! If you don't want the gift card, you can leave this blank.

Thank You!

ID: 1

Thank you so much for your help!

APPENDIX E: INTERVIEW GUIDE AND PROTOTYPES FOR LOW FIDELITY PROTOTYPE STUDY ABOUT SPEAKING UP (CHAPTERS 5-6)

This protocol was used together with 12 prototypes in the patient and caregiver interviews in the study described in Chapters 5 and 6.

Interview Protocol

Experience and Attitudes (Assuming UE inclusion criteria)

1) On a scale of 1-4, 4 being most comfortable: If you were hospitalized again, how comfortable would you be asking a member of your medical team:
    a. To review with you the name, dose, or reason for medications when they are administered (to be sure they are correct)? (1-4)
    b. Whether they have cleaned their hands? (1-4)
    c. For a meeting with the medical team to review your health status? (1-4)
    d. About concerns you may have regarding your medical care? (1-4)
    e. To discuss a disagreement where you want less aggressive medical care than the team is proposing? (1-4)
    f. To discuss a disagreement where you want more aggressive medical care than the team is proposing? (1-4)
    g. About a possible mistake in your medical care? (1-4)
    h. To clarify if they give you confusing information? (1-4)
2) Did any of the above situations come up during your stay in the hospital? (Or any other kind of UE? = situation where something happened or didn't happen in a way that you think could have been better/prevented)
    a. Tell me about it.
        i. What happened?
        ii. Did you talk to your medical team about the issue? (before the UE, during, after?)
        iii. Why/why not?
        iv. How did you feel about speaking up? What did you like/dislike about it?
            1. To extent did you feel speaking up would make you feel confrontational / like a bad patient?
            2. To what extent did you feel speaking up would make your clinical team respond negatively?
            3. To what extent did you feel like speaking up would make you look worried about nothing?
            4. To what extent did you feel like speaking up would make the clinicians take patients more seriously / help other patients?
            5. To what extent do you feel like patients are supposed to speak up about their concerns vs. trust in their clinicians and be patient?
            6. How common do you think it is for patients to speak up to clinicians about their concerns?

        v. What were the benefits of speaking up? What were the drawbacks?
        vi. Who supported your speaking up? Who was against it?
        vii. What made it easy to speak up? What made it difficult?
            1. Did you feel like you had the option of speaking up? / that speaking up was under your control?
        viii. If something like this happened again, how certain are you that you could speak up?

NOTE: MAKE SURE TO GET BOTH POSITIVE AND NEGATIVE RESPONSES TO EACH QUESTION

        ix. Has this experience changed anything about how you interact with your care team/how likely you think you would be to speak up in the future?

Interventions

We're trying to understand how new technologies might affect the patient experience here in the hospital, especially when it comes to times when you might want to speak up or question the medical team. I've got some mockups here to show you. These designs are futuristic and some of them incorporate technologies that aren't real yet. We call those "automagical". But since they could exist in the future, we'd like to get your thoughts about them.

{Introduce mockups in random order}

For each feature:

3) What are your thoughts about this feature?

BY MEDIATOR:

1. {mediator specific questions, e.g. how would injunctive norm feature change attitudes about approval/disapproval .ALSO, make a feature for injunctive norm from caregiver/other patients}
    a. What do you think about this feature?
    b. How does this feature impact your feelings/attitudes?
    c. How do you see it fitting into your situation?
    d. DESC/INJ NORMS: How is this information valuable or not valuable to you? Why?
    e. SELF-EFF: How does this feature influence your level of confidence in your ability to speak up? / Does this make you feel more or less confident in your ability to speak up? / Do you think this would make you feel more or less able to speak up?
    f. PERC CONTROL: How does this feature influence your ideas about whether speaking up would be effective?
        i. TECHNIQUES TO EXPLORE:
            1. Talk to diff doctors/instantly transfer to a new team/second opinion
            2. Broadcast affective state/feelings without voicing them (to change how doctors talk to you)
            3. Take control of the conversation (e.g. stop button)
            4. Get a neutral moderator (person or system)
    g. EXPER ATT: How does this feature impact how you feel about speaking up?
    h. INSTR ATT: How does this feature impact what you think would happen as a result of speaking up?

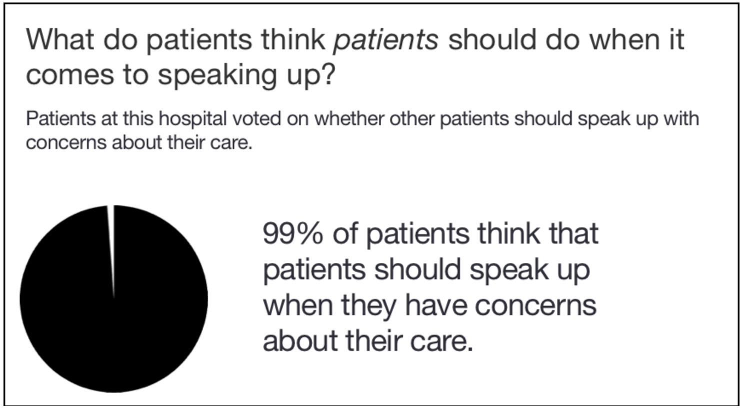
        i. OTHER FOLLOWUPS:
            i. Relationship vs. clinical outcomes

4) What would you change about this feature?

After all mockups

5) What are your top 3 features of all the ones we talked about?
6) Are there any other features that would be useful to you that are not on any of the mockups?

Prototypes



What do patients think *patients* should do when it comes to speaking up?

Patients at this hospital voted on whether other patients should speak up with concerns about their care.

99% of patients think that patients should speak up when they have concerns about their care.

What do clinicians think patients *should* do when it comes to speaking up?

Clinicians at this hospital voted on whether other patients should speak up with concerns about their care.

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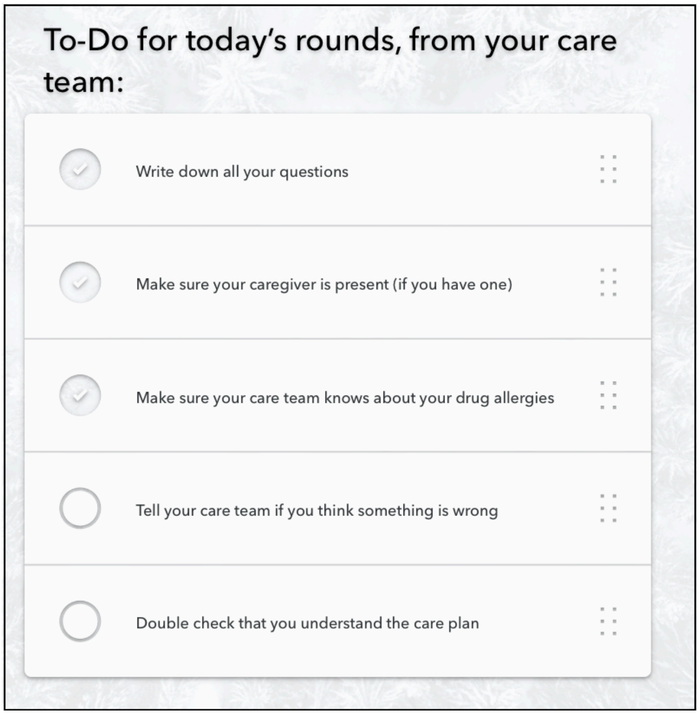
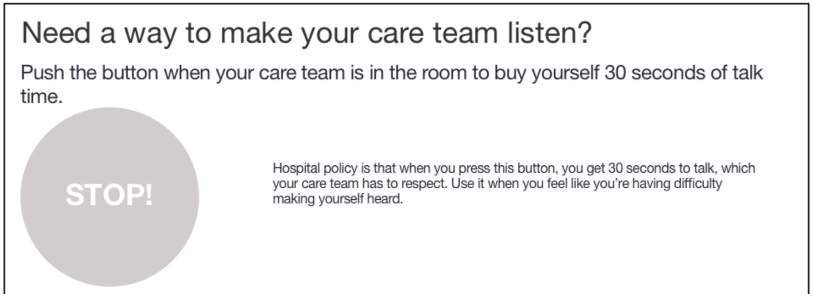


To-Do for today's rounds, from your care team:

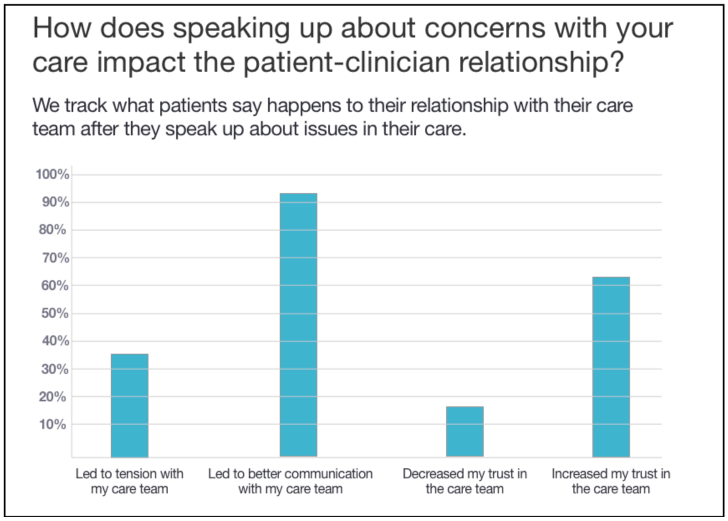
- ✓ Write down all your questions
- ✓ Make sure your caregiver is present (if you have one)
- ✓ Make sure your care team knows about your drug allergies
- ○ Tell your care team if you think something is wrong
- ○ Double check that you understand the care plan



Need a way to make your care team listen?

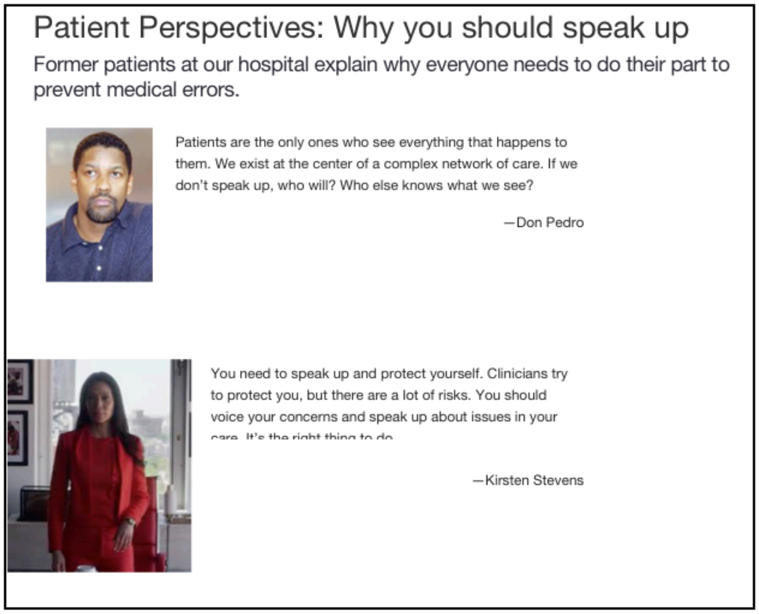
Push the button when your care team is in the room to buy yourself 30 seconds of talk time.

Hospital policy is that when you press this button, you get 30 seconds to talk, which your care team has to respect. Use it when you feel like you're having difficulty making yourself heard.



How does speaking up about concerns with your care impact the patient-clinician relationship?

We track what patients say happens to their relationship with their care team after they speak up about issues in their care.



Patient Perspectives: Why you should speak up

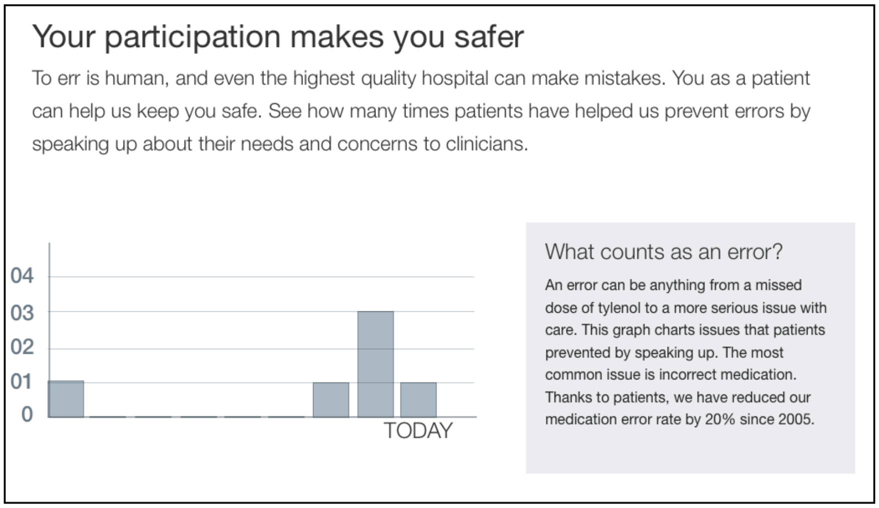
Former patients at our hospital explain why everyone needs to do their part to prevent medical errors.

Patients are the only ones who see everything that happens to them. We exist at the center of a complex network of care. If we don't speak up, who will? Who else knows what we see?

—Don Pedro

You need to speak up and protect yourself. Clinicians try to protect you, but there are a lot of risks. You should voice your concerns and speak up about issues in your care. It's the right thing to do.

—Kirsten Stevens



Your participation makes you safer

To err is human, and even the highest quality hospital can make mistakes. You as a patient can help us keep you safe. See how many times patients have helped us prevent errors by speaking up about their needs and concerns to clinicians.

What counts as an error?

An error can be anything from a missed dose of tylenol to a more serious issue with care. This graph charts issues that patients prevented by speaking up. The most common issue is incorrect medication. Thanks to patients, we have reduced our medication error rate by 20% since 2005.

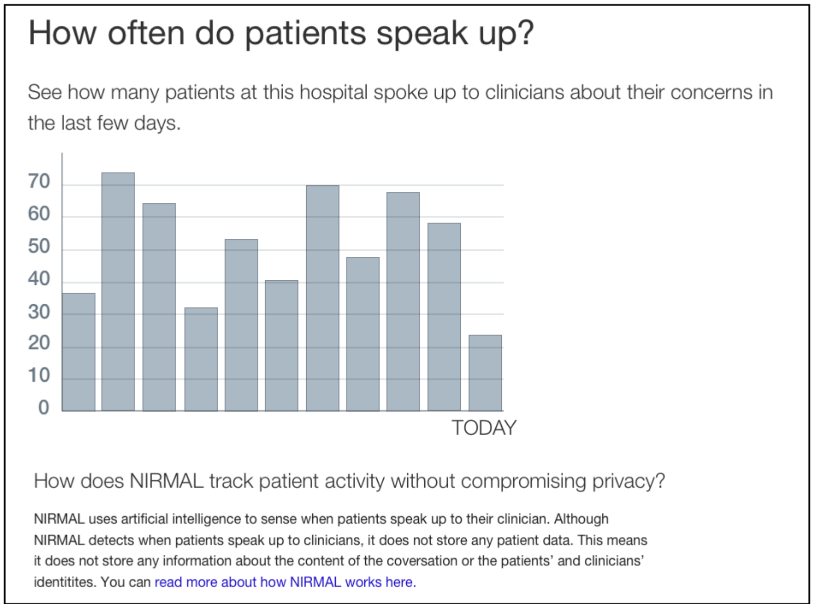
"I spoke up": Stories from patients

"I spoke up because I needed time to think."

I was asleep when a bunch of doctors I didn't know came to my room. They said I needed a risky procedure, but no one had ever mentioned my needing it before. They tried to rush me along, but I wouldn't let them take me anywhere until I found out more about what this risky procedure entails. I also demanded to speak to my normal doctors. Ultimately I got the procedure, but I made my own decision — it's MY body!

Posted **yesterday** by **azer1593**

azer1593

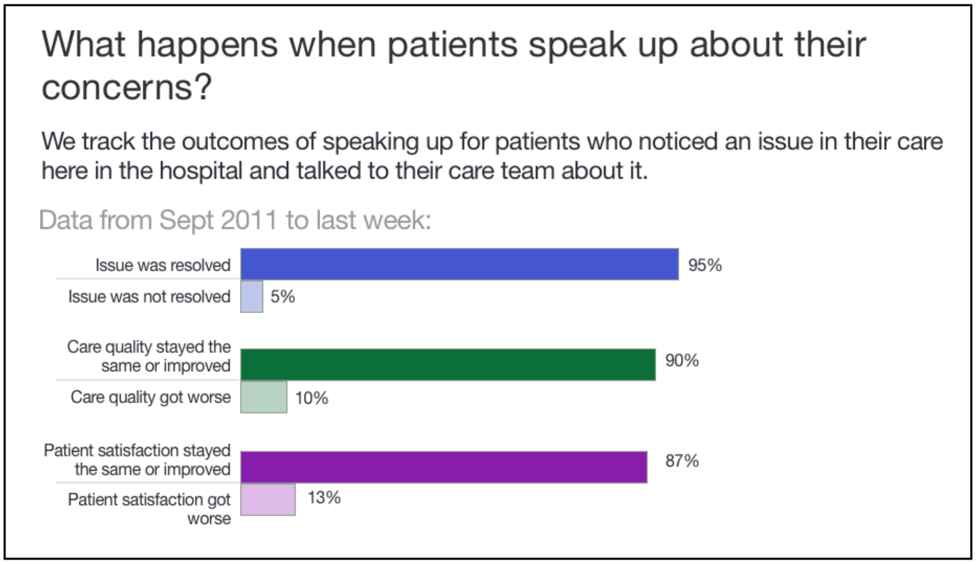


How often do patients speak up?

See how many patients at this hospital spoke up to clinicians about their concerns in the last few days.

How does NIRMAL track patient activity without compromising privacy?

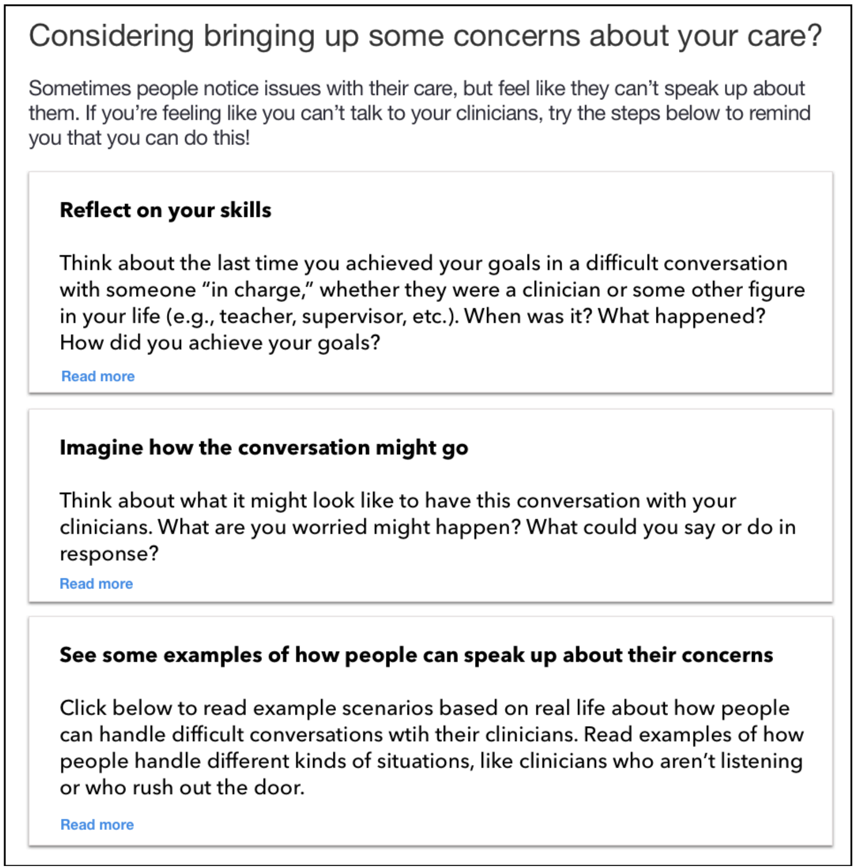
NIRMAL uses artificial intelligence to sense when patients speak up to their clinician. Although NIRMAL detects when patients speak up to clinicians, it does not store any patient data. This means it does not store any information about the content of the coversation or the patients' and clinicians' identitites. You can read more about how NIRMAL works here.



What happens when patients speak up about their concerns?

We track the outcomes of speaking up for patients who noticed an issue in their care here in the hospital and talked to their care team about it.

Data from Sept 2011 to last week:



Considering bringing up some concerns about your care?

Sometimes people notice issues with their care, but feel like they can't speak up about them. If you're feeling like you can't talk to your clinicians, try the steps below to remind you that you can do this!

Reflect on your skills

Think about the last time you achieved your goals in a difficult conversation with someone "in charge," whether they were a clinician or some other figure in your life (e.g., teacher, supervisor, etc.). When was it? What happened? How did you achieve your goals?

Read more

Imagine how the conversation might go

Think about what it might look like to have this conversation with your clinicians. What are you worried might happen? What could you say or do in response?

Read more

See some examples of how people can speak up about their concerns

Click below to read example scenarios based on real life about how people can handle difficult conversations wtih their clinicians. Read examples of how people handle different kinds of situations, like clinicians who aren't listening or who rush out the door.

Read more

How do people feel before vs. after speaking up?

VITA

Sonali R. Mishra earned her BA at the University of Pennsylvania in 2006, graduating summa cum laude with a major in linguistics and a minor in French. After polishing her Greek and Latin and then working for a short while and learning that HCI existed, she decided to do UX for libraries and earned her master's degree at the University of Michigan School of Information in 2011. She worked as a UX designer at the University of Michigan Libraries before coming to the University of Washington for her doctorate.