Supporting Hospitalized Patients through AI Technologies

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Abstract

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Involving hospitalized patients in their care has been shown to be valuable in terms of achieving

better health outcomes for them. Therefore, hospitalized patients are encouraged to actively

engage in their own care, manage their safety, make medical decisions, and monitor their

treatments' quality. However, engaged hospitalized patients face a dilemma. The complexity of

their care makes their engagement more important, yet harder to achieve. During their

hospitalization, engagement quality requires awareness and education about illness and

treatments. However, achieving comprehension can be challenging for complex healthcare

situations, especially when patients may not have a complete understanding of their health data.

Furthermore, with complex health problems, patients are cognitively and physically impaired

because of pain, stress, and medications. Simultaneously, they face a steep learning curve in

utilizing and absorbing the abundant information related to their health situation. Thus,

hospitalized patients face an engagement gap that grows deeper with the complexity of their

health problems. Artificial intelligence (AI) agents, technologies that automate information processing and its communication, could be a promising solution to providing patients with understanding and insights about their illness and its treatment, yet research into how AI agents could support patients in hospital settings has been limited. In this dissertation, I attempt to address this research gap by first defining technological opportunities, particularly via AI applications, that can support patient and information needs in hospital settings. To do so, I first introduce a user-centered research methodology called "Muse cards." This method aims to inspire patients and their family caregivers to envision hospital technologies that could provide them with enhanced support and to create new tools that can accommodate their evolving situation and roles in hospital settings. Second, I focus on the patient-clinician conversation, a core source of information in hospital settings, and describe the factors that influence the importance of verbally communicated information from the patients' perspective and from the clinicians' perspective. Third, I report the results found by testing NURI, an AI agent that I constructed to help hospitalized patients understand medical conversations with their clinicians, and the patients', caregivers', and clinicians' acceptance of NURI and perceptions of its usefulness. This work contributes to human-computer interaction research by giving patients a toolkit designed to help them to reimagine existing technologies and to contribute to our understanding of the role and value of automated agents for helping patients and their families in hospital settings. Furthermore, this work contributes to Personal Health Informatics research by providing an annotation framework to turn patient-clinician conversations into patient-facing notes. Lastly, this work contributes more broadly to evolving research and understanding about uses of AI agents in hospital settings by serving as a source of design and implementation guidelines.

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I always cherished the thought that in this grad school journey, I am a time traveler. In that thought, I perceive that every part of the world is living in their own time era that is defined by their societal and technological characteristics. For instance, if you land today in the middle of Daintree rainforest, you could experience the beauty of the earth millions of years ago: raw and untouched. Academically, my time travel consisted of traveling from a Tunisian to a US healthcare informatics system. What has been archived in the literature as attempts to develop informatics systems in US hospitals in the 80s, is happening right now in Tunisia. As beautiful as this jump in time is, it was also challenging for me as a forthcoming researcher. To succeed academically in this new land and era, I went through five stages of progress: understanding the new technological and societal rules, communicating within these new concepts, feeling that I finally belong, co-creating with my peers, and finally, innovating.

Most importantly, this progress would have not been possible without being surrounded by the right people, who can empathize with your struggles and believe that one day you will be able to succeed. Thus, today I thank everyone who supported me in this academic journey.

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DEDICATION

To my mom Habiba and my dad Nouri,

To my brothers Mohamed and Aymen,

For all of the moments you saw me leave to the other side of the world,

while always being supporting and encouraging.

I love you!

Chapter 1. AI AGENTS TO SUPPORT HOSPITALIZED PATIENTS:AN INTRODUCTION

Recent research has increasingly concluded that patient involvement in healthcare is a key element in improved health outcomes and healthcare experiences (Dentzer, 2013). Research studies have confirmed that providing patients with access to their health information leads to increased engagement in decision making, which can be a valuable component of overall healthcare quality and safety improvement(Prey et al., 2014).

Consequently, the Institute of Medicine (IOM) stated that patients should have access to their providers' electronic health records (EHRs) so they can retrieve their visit summaries, prescriptions, diagnoses, and laboratory test results and have a free flow of information (Tang & Lansky, 2005). The IOM also stated that patients should be equipped with the necessary information in order to be a significant stakeholder in their own healthcare decision making. As a result of the IOM's recommendation, different healthcare institutions have started endorsing a free flow of information.

Similarly, the agency for healthcare research and quality (AHRQ) has supported several efforts to facilitate patient engagement, including this research. The agency provides guidelines and tools to support patients in actively managing their care, such as "My Questions for This Visit," a list of questions to ask during medical visits (Rozenblum & Bates, 2017).

With these measures in place, patients and their family caregivers can claim more advanced access to their medical information during a hospital stay. In a recent systematic review of the literature, Prey et al. reported that patients in hospital settings have become more engaged and want new ways to actively manage their healthcare progress (Prey et al., 2014). Collecting information regarding their vital signs, laboratory test results, prescriptions, and billing information enables them to preserve their autonomy. Yet, for patients and their family caregivers, the hospital environment remains an unfamiliar, isolated place filled with apprehension and unanswered questions (Prey et al., 2014).

1.1 HOSPITALS: A CHALLENGING ENVIRONMENT

More than 36 million hospital admissions occurred in 2019 (AHA,2020). During these stays, patients commonly experience disorientation as they battle for their lives. In fact, in a recent study, Cumber et al. found that while 94% of patients reported that they wanted to review their hospital medication list for accuracy and 81% reported that access to this information would improve their satisfaction with their hospital care, only 28% reported seeing their medication lists (Cumbler, Wald, & Kutner, 2010). In addition, O'Leary et al. reported that only 32% of patients could correctly name at least one of their hospital physicians (O'Leary et al., 2010).

Furthermore, patients in hospital settings face cognitive challenges in perceiving, understanding, and utilizing their health data. When admitted to a hospital, patients are usually cognitively and physically impaired and have been drained by pain, the diagnostic process, medication, and stress (Morris & Karlson, 2011). The struggle is even greater for patients with stressful and complicated diseases, such as cancer.

Stress and emotional events can also cause attentional narrowing (Wessel, Van der Kooy, & Merckelbach, 2000). As Ley explains, "when a doctor says, you have X disease, and this will affect everyday activities for the rest of your life, this central message can become the primary focus, limiting attentional resources for peripheral information". In such situations, the peripheral information, which could include critical details about the risks and benefits of the treatment plan, will not be processed and stored into the patient's memory. Thus, the patients will not be able to recall it (Ley, 1979).

Studies investigating the impact of stress on patients' recall of medical information have confirmed this phenomenon. Shapiro, Boggs, Melamed, and Graham-Pole (1992) found that when a physician showed concern, the level of distress in the patient increased and women at risk for breast cancer, in particular, recalled less information (Shapiro, Boggs, Melamed, & Graham-Pole, 1992). In addition, patients may encounter different stressors that cause them to feel disoriented, including sights, smells, sounds, and recurrent health worker rotations, resulting in highly dynamic challenges (Morris & Karlson, 2011). For that reason, Morris and Karlson argue that a "hospital patient should be treated as a situationally-impaired user" (Morris & Karlson, 2011).

In addition, Kessels (2003) suggests that unfamiliar and stressful environments, such as clinics and hospitals, might contribute to patients' struggles to remember their medical information (Kessels, 2003).

Research has identified additional factors that could affect a patient's recall of medical information, such as the age of the patient and their outdated beliefs relative to the medical situation. Ley reports that older patients are less likely to recall their medical information. Moreover, Rice & Okun found that older readers recall medical information less accurately if it contradicts their beliefs about the medical situation (Rice & Okun, 1994).

All of these factors lead to low recall, as patients immediately forget 40–80% of the information communicated by clinicians (Kessels, 2003). Furthermore, half of the information that patients can recall is incorrect (Anderson, Dodman, Kopelman, & Fleming, 1979).

The information flow models in hospital settings amplify this struggle. Until recently, hospitals had a paternalistic information approach, where clinicians were the gatekeepers of information, and the patients had restricted access to their electronic health records. Furthermore, most patient-clinician communication is done verbally, a method reported as inadequate and challenging for patients (Schlindwein, Slowther, & Fritz, 2019; Thomson, Cunningham, & Hunt, 2001).

Yet, patients need to rely heavily on conversations and verbal communication with their care team to perceive and understand their health situation. Patients and their family caregivers receive the majority of updates verbally from their care team, including information about their health progress, such as new diagnoses, new test results, treatment regimens, and more (M. Smith, 1991; Stein, Nagy, & Jacobs, 1998). Consequently, verbal communications with clinicians can become overwhelming and taxing because of the implicit assumption that the patients will understand and remember the verbally communicated medical concepts and terms. More challenges can arise from coordinating between care teams, accessing limited resources, and dealing with the cognitive and physical impairments that might occur as a result of their condition or treatments.

Thus, it is noteworthy that a patient's perception of the current course of their treatment often does not match their clinician's plan(Chen et al., 2013; Weeks et al., 2012), leading to communication breakdowns. According to the CRICO report published in 2015, communication breakdowns within the U.S. healthcare system have cost 1,700 lives and 1 billion dollars between 2009 and 2013 and Fifty-five percent of these communication breakdowns happened between patients and their doctor (CRICO, 2015). These miscommunications continuously widen the gap between

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patients and doctors and hinder the engaged and active role that informed patients could play in their healthcare. If a patient is incapable of understanding or recalling details from their conversations with their doctors, they cannot take the necessary actions to play an active role in their care.

1.2 THE ENGAGEMENT DILEMMA

Remembering and understanding medical information is a prerequisite for good therapy adherence. Ley's model on successful communication between patients and clinicians, which is illustrated in Figure1, stresses the importance of memory, understanding, and satisfaction to help patients adhere to their treatment regimen.
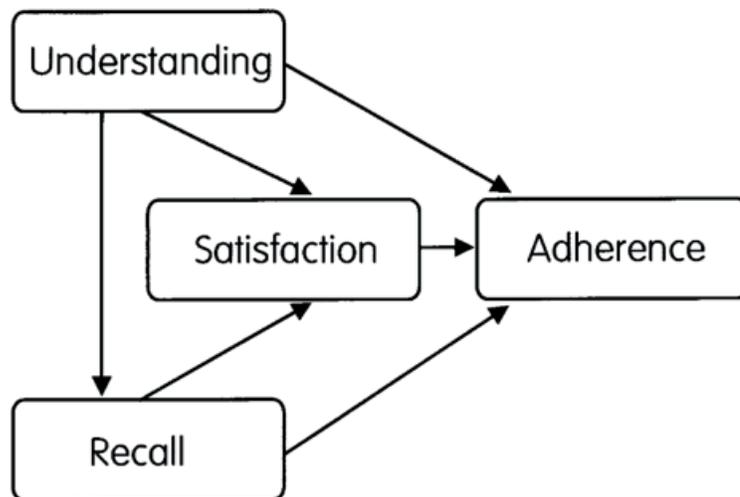
Figure 1 **Overview of Ley's model on the interactions between patient-related factors and therapy adherence (see Ref. 3)**

Figure 1. Ley's model (Kessels, 2003).

However, intricate medical conditions involve longer stays in hospitals, more data, and complex decision making. In fact, the more complex the diagnosis is, the more likely the patients will be subject to impairment and the more intricate the data around the disease will be. This phenomenon is what I call "the engagement dilemma."

Thus, while these situations generate a lot of information that patients need to manage, they also leave the patient in a vulnerable position, unable to recall or understand their medical treatment.

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Furthermore, the greater the amount of information that patients receive, the lower the proportion of information that is correctly remembered (Mcguire, 1996). To play an active role in hospital settings, patients need detailed information to make informed decisions (Kessels, 2003).
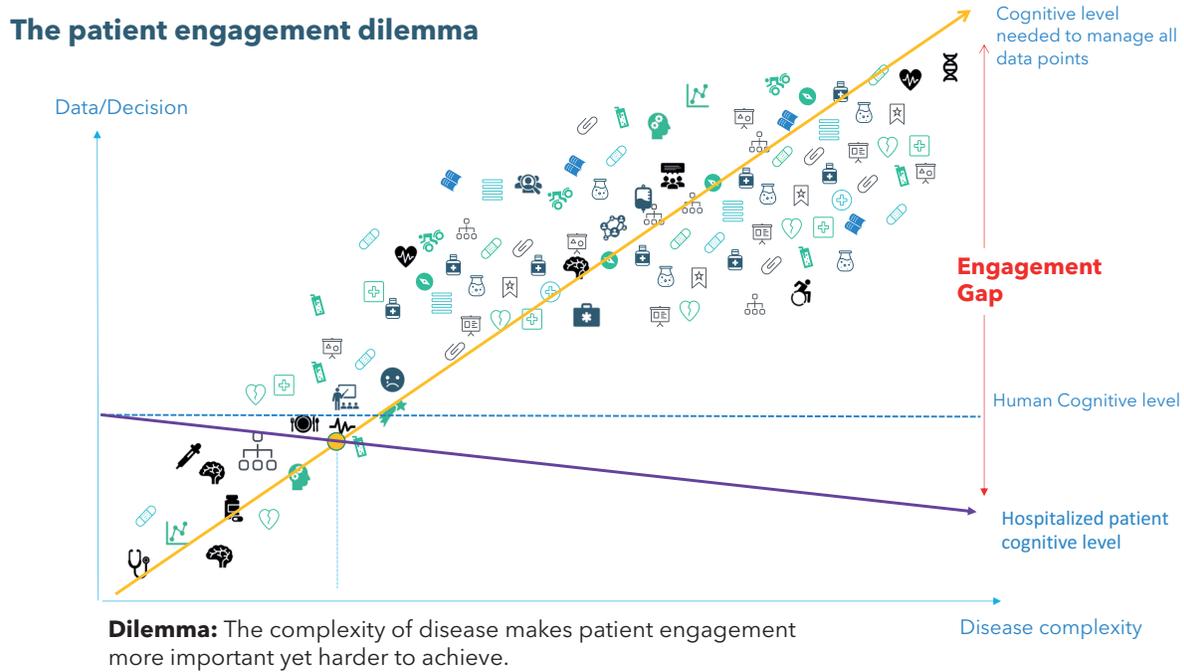
Figure 2. The patient engagement dilemma.

I propose Figure 2 as an illustration of the engagement dilemma. The X axis represents the disease complexity, and the Y axis represents the amount of health data needed to manage the health situation. The yellow line shows that the amount of facts/decisions grows higher as the disease becomes more complex and the data becomes more advanced. At the same time, the more complicated the disease is, the more likely the patient will be cognitively impaired. Thus, the purple line shows that the patient's cognitive abilities decrease with respect to the disease complexity. The intersection between the purple line and the yellow line illustrates the point where the scale of medical data surpasses the amount of data that a patient could manage. Consequently, the red line shows the engagement gap. The more complicated the disease is, the more data that needs to be remembered, the more cognitively impaired the patient will be. Thus, the engagement gap grows bigger with complicated diseases.

As effective patient engagement is becoming the new standard of care, a foundational redesign of patient-facing technologies is needed to overcome the engagement dilemma. An engaged and

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active patient needs to be equipped with the right tools. For that reason, increasing patients' access to information is vital to patient engagement. Artificial intelligence (AI) technologies, especially speech processing technologies, could help overcome this dilemma.

1.3   WHAT IS AI?

AI has several definitions such as "The automation of activities that we associate with human thinking, activities such as decision-making, problem solving, learning'" (Bellman, 1978), 'The art of creating machines that perform functions that require intelligence when performed by people" (Kurzweil, 1990), and the pursuit of computing technologies aimed at imbuing machines with intelligence, where intelligence refers to capabilities that enable an entity to function appropriately and with foresight in its environment (Nilsson, 2009; Stone et al., 2016). Russell and Norvig (2009) organize AI definitions into four categories based on the possible goals to pursue in AI: thinking humanly, thinking rationally, acting humanly, acting rationally. In this dissertation, I use AI to refer to pursuing the use of computing technologies, such as sensing, learning, planning and reasoning, to endow machines with intelligence. I focus on the study of human-centered AI, AI systems that are designed to perform actions that understand and support people. I focus particularly on methods at the intersection between AI and Human Computer Interaction field (HCI). While AI research focuses on making intelligent computational systems, HCI focuses on making these systems user-facing and useful. The merging of ideas from AI and HCI fields grew stronger in the 1990s when several AI researchers, including Eric Horvitz, Sharon Oviatt, Henry Lieberman, Patti Maes, Paul Resnick, Joe Konstan, John Riedl, and Loren Terveen, published work exploring the power of AI methods to address HCI challenges at major venues for HCI research, including the SigCHI conference (Grudin, 2009). The design of AI systems and components could harness the use of physical or digital embodiments that can appear or act as a persona, or "an agent." In this dissertation, I use the term AI agent to refer to these technologies. Specifically, in chapter 3, 4, and 5, I focus on the design of NURI, an AI agent to support hospitalized patients by utilizing their medical conversations.

I define the NURI agent through three points: AI skills, application, and embodiment:

- AI skills: NURI helps hospitalized patients harness the power of speech processing technologies and natural language understanding.

- Application: NURI helps hospitalized patients turn patient-clinician conversation into patient-facing notes.
- Embodiment: NURI is a patient-facing technology presented through an iOS app

NURI is an Arabic name that means "my light". It is also my father's name. My father was born in a small village in Tunisia. The day he was born, a cheikh-a religious leader of his village, chose a random page of a book of names. The page had the name NURI that came with the prophecy that my father should be a scholar, to one day be the light that guides his parents through both the good and hard times. My dad was the first in his family to obtain a University degree in economy and political sciences. By naming the AI agent NURI, I hope to extend the prophecy of learning to build an AI agent that could be the light that guides patients' path during their health journey.

1.4 In the next section, I highlight the need for AI agents in healthcare. THE NEED FOR AI AGENTS

Researchers have explored different ways to overcome the engagement dilemma in the context of patient-clinician conversations. For example, McGuire advises clinicians to reduce the gap by providing medical information to patients, especially the elderly, before asking for their decision (Mcguire, 1996). Furthermore, in the case of sharing bad news with patients, McHugh et al., (1995) recommend providing an audiotape of the interview to help patients go over the information at home. They note that patients will be less stressed and less anxious at home. Thus, having the audiotape will help them understand the conversation with greater accuracy and at their convenience(McHugh et al., 1995).

Several studies have also recommended providing the information in a form other than verbal communication. Houts, Witmer, Egeth, Loscalzo, & Zabora report that only 14% of spoken medical instructions are recalled correctly (Houts, Witmer, Egeth, Loscalzo, & Zabora, 2001). In contrast, patients were able to recall over 80% of medical instructions provided by pictographs.

Yet, providing additional, personalized material to patients could be time-consuming for clinicians, who are often overwhelmed by their workflow (Emani et al., 2015). Emani et al. conducted a study to evaluate the use of after-visit summaries (AVSs) by clinicians and pinpointed several of these workflow issues. In particular, clinicians reported having insufficient time to

integrate AVSs into their clinical workflow or to populate the AVSs with useful information, such as instructions and goals of care. Moreover, clinicians expressed concern about having adequate time especially with the additional task of printing and finding the report at the printing station.

Given the importance of patient participation in healthcare decision making, the complexity of the information that is exchanged verbally in hospital settings, and increases in healthcare data, the need for AI solutions, such as clinical speech processing, is apparent. According to a white paper by Stanford Medicine, the volume of healthcare data increased from 153 exabytes (one exabyte = one billion gigabytes) in 2013 to an estimated 2,314 exabytes in 2020, resulting in an overall rate of increase of at least 48% annually (*Harnessing the Power of Data in Health*, 2017). The scale of medical data is presently shifting from a human scale to a digital scale. Patients now have unprecedented access to a plethora of data types, both personal and general, in groundbreaking ways. In addition to EHR data, new sources of day-to-day data connected to health outcomes are available to patients. These real-world data can come from wireless-enabled wearable technology devices, such as activity trackers and smart watches; direct-to-consumer testing, such as glucometers; genetic testing, such as 23andMe; and medical information websites.

With the digitization of healthcare and the rapidly growing amounts of healthcare information, AI is becoming vital in helping patients understand the meaning of their own data and eliminating the need for patients to get all of their healthcare information from a physician. The McKinsey Global Institute estimates that 15–20% of the healthcare market has the potential to be impacted by AI, making it one of the most affected sectors. Medical experts and scientists are now training algorithms that can analyze vast quantities of data and provide insights.

This dissertation focuses on reducing the engagement gap by building user-centered, AI-powered technologies to support patients and their family caregivers in hospital settings. First, on the basis of user research, I outline technological and design opportunities for supporting hospitalized patients. Then, I report the results of testing an AI agent to help patients remember and understand their medical conversations in hospital settings.

1.5   RESEARCH AIMS

Using patient-centered research methods, I investigated the applications of technologies, especially AI-powered technologies at the bedside of hospitalized patients, that can help patients overcome the engagement gap and play an active role in their healthcare.

Aim 1. Describe how technology and AI agents can best support patients during the hospital stays

To achieve the first aim, I created a new user-centered design method called "Muse cards." Patients interact with different design cards and use them to explore how the technology could support them. Moreover, patients were invited to use unique cards representing "Magic Buttons" and "Avatars" to brainstorm extraordinary technological functionalities. The results of this aim are to produce a user-centered design method that can define hospitalized patients' technological expectations and a list of technological functionalities to support hospitalized patients. This list guided the design of an AI agent app that will be studied in Aims 2 and 3.

The work of aim 1 is detailed in Chapter 2.

Aim 2. Determine which information is important in medical conversations between patients and clinicians from the patients', family caregivers', and clinicians' perspectives

To accomplish this plan, I recruited 22 patients and family caregivers and 9 of their clinicians in Virginia Mason hospital and Seattle Children's Hospital to participate in the NURI study. Participants used the NURI prototype to record, transcribe, and annotate their conversation with their care team. I conducted a pre- and post-survey with the patients and family caregivers and a one-on-one interview with all participants, including the clinicians. In the interview, I invited the participants to a think-aloud annotation exercise for one of their medical conversations' transcripts. Participants reflected on the importance of the information discussed in the conversation and the reason for these perceptions. Moreover, I invited the participants to recommend additional AI services for the NURI prototype, which I used to create an analysis framework that could turn medical conversations into patient-facing notes.

I present the NURI study including related work, the NURI prototype, and the methods in Chapter 3. Then, I present the results of aim 2 in Chapter 4.

Aim 3: Evaluate the impact of NURI on patients', caregivers', and clinicians' hospital experience

To address this aim, I analyzed the patients', caregivers', and clinicians' feedback given during the interviews and surveys in the NURI study. This qualitative analysis of the interviews focused on assessing the acceptance and perceived usefulness of NURI from the patients', caregivers', and clinicians' perspective. Then, I identified the patients' current challenges when conversing with

their doctors in a hospital setting and reported the impact of using NURI to overcome these challenges. Finally, I used the results of this aim to generate design guidelines for improving NURI and implementing similar AI agents at the bedside of hospitalized patients. This work is detailed in Chapter 5.

In chapter 6, I summarize the work done to fulfill the research aims. I highlight the contributions of this work. And, I note the limitations of the studies and results and then describe promising directions for future work.

Chapter 2. USING MUSE CARDS TO IGNITE CREATIVITY IN PATIENT-CENTERED TECHNOLOGY DESIGN

The Muse cards method

2.1 ABSTRACT

In this chapter, I describe a new user-centered design method that aims to help hospitalized patients and their caregivers reimagine in-hospital information technologies. To this end, I created inspirational "Muse cards" to help participants design technologies that could accommodate their evolving roles and needs in hospital settings. The cards aim to limit the preconceptions of the previous in-hospital patient-facing technologies that have failed to meet users' needs and to promote a creative design space for deploying new technological advances that can support patient and caregiver needs. In addition, I delineate the steps that were involved in testing this method with hospitalized patients and their caregivers at Seattle children's hospital and Virginia Mason Hospital. Finally, I offer an analysis to generate some recommended technology specifications.

2.2 INTRODUCTION

When redesigning existing technologies, users, designers, and researchers must overcome the preconceptions inherited from previous efforts, as these past design attempts can create mental models that limit the creativity of the new designs (Chrysikou & Weisberg, 2005). This challenge could slow down innovation, even when it is needed the most, a situation I faced in redesigning the technologies for hospitalized patients. In hospital settings, information technologies have primarily been designed for billing purposes (Evans, 2016). Electronic health records (EHR) are the primary technology that hosts the patient's information. When hospitals are asked to provide patient records, they release personal health records (PHR), with a design and data structure tied to the EHRs (Tang, Ash, Bates, Overhage, & Sands, 2006). Consequently, the building blocks of the patient-facing technologies come from systems that were designed for other stakeholders and different needs. In addition, existing systems put patients in an observer's role with delayed and limited access to their information(Hibbard, 2003; Mishra et al., 2016; Skeels & Tan, 2010). Furthermore, as patients and their caregivers become more active and engaged in healthcare, the gap between this informational support and their information needs has widened (Prey et al., 2014). In the United States, PHRs are only used by 17% of patients (Health Industry Insights Consumer Survey, 2006) and offer patients little assistance during hospital stays (Woollen et al., 2016). Nevertheless, replacing these existing patient-facing technologies, which have failed to support patients' needs, remains challenging. Existing PHR systems have become a reference point for

new patient technologies, slowing progress. Presently, patients, healthcare professionals, user researchers, and designers are curtailed by the existing mental models of patient technologies and will face challenges when trying to break free from these preconceptions.

As a result, I have adopted a new user-centered design method called "Muse cards" to help patients design technologies that are more aligned with their needs and less restricted by current technologies. In the Muse cards method, I have established a design space using two sets of cards. The first set includes the *feature cards,* which involve a feature selection process in a technology-agnostic design space that limits the biases stemming from pre-existing technologies. The second set includes *creativity cards*, which are used to inspire the participants to expand the technological limits of their designs to include more futuristic and AI-powered abilities.

Thus, the Muse card method can help patients and their caregivers create in-hospital technologies with a new design that better aligns with their needs. To create the cards, I determined the users' challenges and needs by referring to the semi-structured interviews and participatory design sessions from prior work conducted by the PAS[1] group. Then, I translated those challenges and needs into a library of feature cards. Afterward, I added inspirational cards, consisting in Avatars and Magic Buttons, to the feature cards to help the participants overcome the design limitations of traditional in-hospital user interfaces. Subsequently, I invited the patients and their caregivers to evaluate and add to the cards.

In this chapter, I describe how this method can be applied to inspire new designs. First, I will introduce the design of the Muse cards and the results of their deployment. Second, I will conclude with the plan to create new technologies for hospitalized patients.

2.3 BACKGROUND

Since the rise of human-computer interactions (HCI) research in the early 1980s, the field has changed drastically (Bannon, 2011). Technology has become more ubiquitous, mobile, and autonomous and is designed in every shape and form. As these new powerful tools emerged, researchers saw an opportunity to study their implementation in every aspect of people's lives,

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[1] NOTE: This work has been conducted as part of Patient-as-Safeguard research study. Hereafter, I refer to the Patient-as-Safeguard as PAS

including their health, finance, travel, and social life. Subsequently, the field has evolved from focusing on optimizing the human-machine fit to guiding the creation of new user-centered technologies (Bannon, 2011).

However, the promise of creating user-centered technologies has become harder to fulfill. The technologies that have been created have shifted human behavior. In this shift, old designs have lost their user-centeredness, because the users have evolved. Thus, HCI researchers and designers need to continue to innovate to fulfill the promise of a user-centered design. How can one change old designs?

> *"… technology is not given. It's not like the sun or the moon or the stars. It was made by people like us. If it's not doing for us what we want, we have a right and a <u>responsibility </u>to change it."*
>
> *–Mike Cooley, Right Livelihood Award Speech, 1981*

One answer could come from Clay Christensen's book The Innovator's Dilemma (1997), which examines the difference between two innovation processes: progress due to sustaining innovations and disruptive innovations. The author recognizes that institutions that follow a sustaining innovation process, where they apply incremental changes based on their product architectures and the existing customer needs, will have a lower product performance over time compared to a counterpart who uses disruptive technologies (Figure 1). This performance will ultimately lead the product to fail and perish, highlighting the innovation dilemma: a failure due to heavy reliance on existing best practices. Instead, smaller institutions who take risks with a disruptive process could end up redefining the whole ecological system of the market segment. The demise of NOKIA™ after the emergence of Apple's iPhones is an illustrative example of this dilemma. NOKIA™ did not fail to understand its users' needs. On the contrary, the company followed best practices. However, they failed to listen to disruptive feedback.
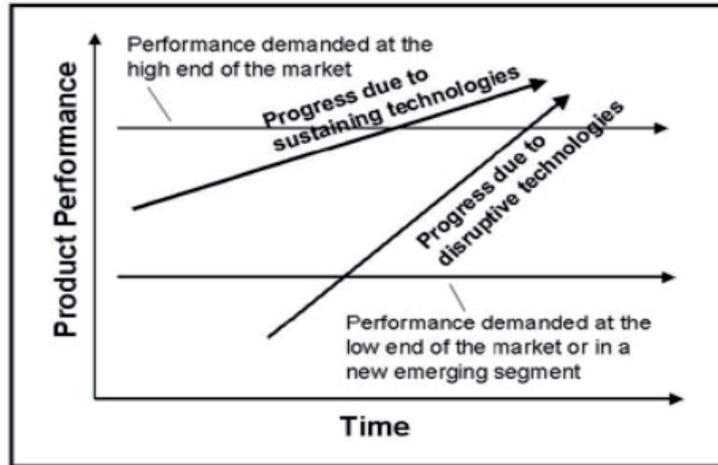
Figure 3. Innovation dilemma (Christensen, n.d.).

However, when it comes to a disruptive innovation, for a long time, user input was even perceived as a hindrance. An old saying attributed to Henry Ford states, "If I had asked people what they wanted, they would have said faster horses" (Vlaskovits, 2011). However, from a user research perspective, the limited innovation in a user's response can be motivated by the questions. To build disruptive technologies, user researchers and designers must go beyond gathering user feedback. Instead, innovators must identify novel ways to collect user opinions about potential future technologies to create parallel streams of innovation, leading to disruptive technologies.

Thus, I created a user-centered approach that uses cards as design prompts to support patients in reimagining the design of their technologies in hospital settings. The cards aim to address two main challenges to break free of my preconceptions based on current technologies.

Challenge 1. Overcoming preconceptions - Overcoming the past: How can I overcome my preconceptions of what patient-facing technology should look like based on previous experiences and popular designs? How can I help participants overcome these biases, too?

Challenge 2. Expanding technology – Building for the future: How can I push the boundaries of existing technology? How can I support patients in creating AI-based futuristic technologies? How can I bridge the gap in understanding AI for adult and child participants?

2.4 RELATED WORK

In this related work section, I further explain the design challenges of overcoming the past and designing for the future. Then, I demonstrate how the HCI research community has approached these two challenges in prior work.

2.4.1 *Challenge 1: Overcoming the ties of the past*

During the prototyping phase, the first design challenge I faced was breaking free from past experiences and previous technologies. The results of previous research had demonstrated that preceding technologies have not supported the new role that patients and their caregivers play in hospital settings (Haldar, Mishra, Khelifi, Pollack, & Pratt, 2019). However, I struggled to translate these needs into a low-fidelity prototype for user feedback. My preconception was that patient technology should look like the patient portal systems that have been widely adopted in hospital settings. Thus, overcoming this preconception was the first challenge I faced. In particular, I worried that a low-fidelity paper prototype could channel biases from people's previous experiences with patient portals. Furthermore, I worried that patient participant would face the same drawbacks. By using a paper sketch of a web platform, the design task could shift from a creativity task to an attempt at incremental change, given participants' preconceptions.

Moreover, research states that researchers and designers can bias the design process through the artifacts they choose to share with participants. In a study by Smith, Ward, and Schumacher (1993), the authors asked the participants to provide sketches of a defined category, such as a creature from another planet. The authors reported that the sketches by participants who had seen experimental examples prior to generating their own ideas contained similarities to conform to these examples(S. M. Smith, Ward, & Schumacher, 1993).

Furthermore, creating pictorial illustrations, such as paper prototypes, could limit one's creativity even more. Research states that the creation of a pictorial solution may lead to a fixation problem (Jansson & Smith, 1991; Purcell & Gero, 1996). Thus, once designers and researchers create a low-fidelity prototype, it could become harder to edit it. Chrysikou & Weisberg refer to some of these challenges as "mental traps": namely, restrictions and mistakes introduced in the design process as a result of previous design tasks (Chrysikou & Weisberg, 2005) .

Thus, while low-fidelity paper prototyping is considered a cheap and pragmatic way of shaping new technologies (Tscheligi et al., 1995), designers and researchers can channel biases from previous experiences and limit participants' creativity by using such prototypes.

2.4.2   *Challenge 2: Disrupting and building for the future*

Innovators must identify novel ways to collect user opinions about potential future technologies so that they can create parallel streams of innovation, leading to disruptive technologies. Mankoff et al. (2013) argue that HCI methodologies, such as participatory design (Muller & Kuhn 1993) or informant design (Scaife, Rogers, Aldrich, & Davies, 1997), fall short in shaping long-term changes and designing technologies that could be part of users' daily lives a decade from now. Mankoff et al. (2013) note that designers and researchers have tended to focus on two main approaches to creating technologies: an inductive approach (using empirical observation to define "what is so") and a deductive approach (using prior knowledge to define "what must be so"). However, they have focused less on predicting the future by adopting a third approach: abductive reasoning or envisioning "what might be so" (Mankoff, Rode, & Faste, 2013).

2.4.3   *Related work: HCI Addressing these challenges*

To address these two design challenges and to help participants imagine new interactions and designs without grounding them in the limitations of current technologies, researchers have explored new approaches to enhance the design process.

For example, Elizabeth Gerber explored a new way to enhance brainstorming sessions. Brainstorming is a process used to generate innovative ideas that involves contributions from participants' pre-existing knowledge. The process facilitates mixing ideas in new creative ways to spawn new knowledge. Gerber proposes adding improvisation techniques and principles to brainstorming sessions to unleash the creativity of the participants, and her work has described how interaction designers have used improvisation techniques to enhance their collaborative design session (Gerber, 2009).

In another work, Stuart Candy used an artistic process and created "bridges of imagination" to take people into alternative possible futures and to help them expand a futuristic abstract into a concrete experience. Candy used two methods: reverse archaeology and the "time machine" method. In the same way archeologists use archeological artifacts of earlier eras to visualize the past, reverse

archaeology encourages participants to create futuristic artifacts to design the future. The "time machine "method consisted of inviting participants to role-play in a futuristic scenario (Candy, 2013).

To add creativity to the prototyping phase of a study aiming to revamp storytelling rooms from children's perspectives, Montemayor, Druin, Chipman, Farber, and Guha engaged children in the design process using innovative physical design artifacts. These child participants created their own interactive environments and design interactions with magic wands to cast magic spells over physical icons. Montemayor reported that the process was very fun for the children and helped generate new insights and designs (Montemayor, Druin, Chipman, Farber, & Guha, 2004).

Similarly, Anderson and Wakkary proposed a "magic machine workshop" as a design process to help participants imagine the design of new things. The two researchers invited users to build hypothetical artifacts or magic non-functional machines out of everyday materials, such as paper and plastic cups (Figure 4). This process aimed to free the participants and researchers from thinking about practical and technical limitations during the workshop (Andersen & Wakkary, 2019).

Figure 6: Demonstrating the finished machine.

Figure 4. A photo from the "The Magic Machine Workshop" The figure illustrates a participant's prototype created during the magic machine workshop.

The previous research illustrates how researchers can expand the limits of creativity and prototyping. Other efforts have been conducted in the HCI community as well, including cultural probes (Gaver, Dunne, & Pacenti, 1999), where researchers presented cards to users to encourage criticism and debate.

While I share the same motivation as the previously mentioned researchers, the Muse cards method is different in two respects: the design goals and the design setting.

The design goals: While previous works focused mainly on the idea generation process, the design sessions for the current study were focused on product specifications. Thus, this design process was more grounded. This process consisted of a feature selection activity that helped participants to cherry-pick features that aligned with their current experiences. Then, I offered creativity cards to the participants to help augment their selection with more futuristic means.

The design setting: The participants in this study were hospitalized patients. Therefore, I created artifacts that could be used at the bedside of the patients and that respected the physical limitations of the design space. For example, medical devices constrained the patients' movement. Thus, I used paper cards for their accessibility.

In consideration of these design goals and design setting, I created the "Muse cards," a new method, to help the participants overcome the biases of the past and design for the future. (Figure 5). Specifically, to overcome the first design challenge, I replaced the low-fidelity prototypes with the first set of Muse cards, which were feature cards. Furthermore, to address the second challenge, I wanted to inspire the participants' creativity. Similar to the magic wand and magic machine approaches, I added a second set of cards: creativity cards. I present the Muse cards in details in Section 2.5.

2.5   MUSE CARDS

In this section, I answer the question, "What are Muse cards?" I explain the process of crafting Muse cards that were used to help patients and family caregivers redesign their in-hospital technologies. Then, I present the principles that were followed during the design sessions.

2.5.1   *What are Muse cards?*

A muse is a person or personified force that is a source of inspiration for a creative artist (Cambridge Dictionary). Muse cards are inspirational cards designed to allow patients and family caregivers to creatively reimagine their in-hospital technologies to be better aligned with their roles and needs in hospital settings. Muse cards aim to inspire users more freedom in reimaging their technologies outside of the biases and limitations of tradition low-fidelity prototypes representing an app or a website (Figure 5).

Muse cards toolkit

Feature   Creativity

- Technology-agnostic
- Fluid (no structure)
- Focuses on the core functionalities
- Support creativity using creativity cards*
  (explained later)

Lo-fi Prototype

TECHNOLOGY-CENTRIC
Conveys structure and interaction

Free   **User's design Input**   **Grounded**
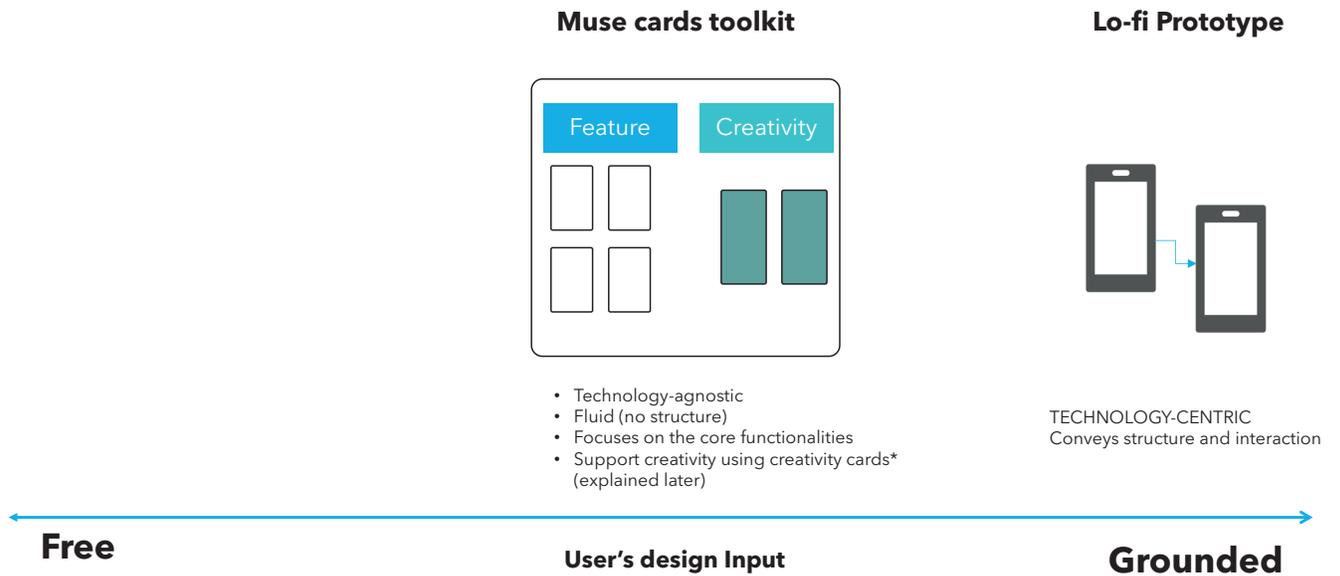
Figure 5. Muse cards and user's input.

To overcome the first design challenge stated in the "background" Section 2.3 and reduce the bias inherited from old technologies, I created feature cards. These cards are designed to help users overcome the constraints and biases of old technologies and focus on short-term changes. As explained in the "Related work" Section 2.4 , pictorial low-fidelity prototypes could channel biases from previous experiences with old technologies. Thus, instead of presenting the prototype through sketches of a web platform or an app, I eliminated the esthetics and structure and presented the prototype through a selection of feature cards. By eliminating the structures and esthetics of the low-fidelity sketches, I created a design space that was technology agnostic, limited the bias that could be channeled through visuals of old designs, and helped the users focus on the feature selection task.

The cards aim to help participants reflect on their needs and pain points and identify potential features that may help their treatment. In addition, the cards illustrate potential technological features that participants can add to a design. By presenting these cards to participants, the design process can be grounded in feature selection, but at the same time keep it free from esthetic and structural limitations.

As for the second design challenge, inspiring futuristic features, I created creativity cards. These cards are inspirational cards to help participants expand on their feature selection with more

advanced technologies, such as AI-powered technologies. The goal of these cards is to help users reflect on the long-term changes that they foresee for their technologies.

The muse cards method

Feature Cards
Expand with new features

Creativity Cards
Push the boundaries with imagination and creativity
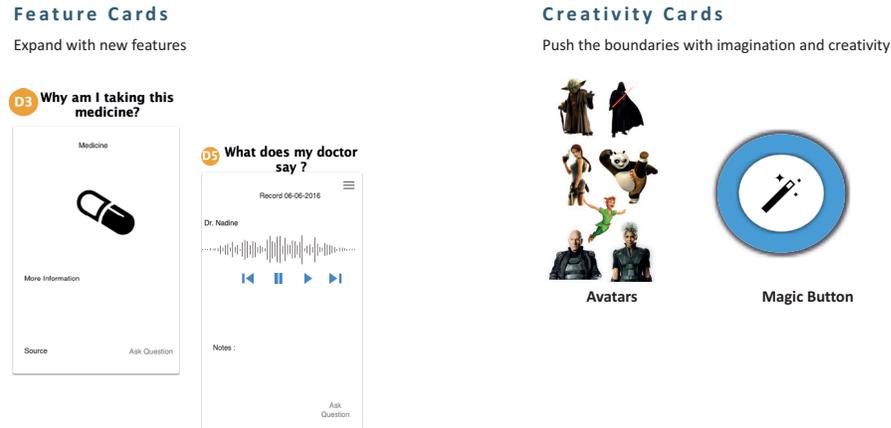
Figure 6. Muse cards.

The cards on the left are feature cards. They present two features: "Why am I taking this medicine" and – "What did my doctor say?" The cards on the right are creativity cards. They showcase avatars and a magic button.

2.5.2   *Crafting Muse cards*

In this section, I detail the process of creating Muse cards. The first step of the process is defining patients' needs based on previous work of the PAS group. Then, the second step of the process consists in translating users' needs into Muse cards

2.5.2.1   Defining patients' needs

The first step in designing Muse cards was to define the patients' needs. Prior to the Muse cards study, I conducted with the Patients as Safeguards (PAS) research team an exploratory research phase using semi-structured interviews and participatory design sessions with hospitalized patients and their caregivers at Seattle Children's Hospital and Virginia Mason Hospital to identify the participants' information and communication needs.

2.5.2.1.1   *– Semi-structured interviews*

Our PAS group conducted interviews with hospitalized patients and their family caregivers to understand their needs and challenges during the hospital stay. In this work, the PAS group

conducted 34 semi-structured interviews. Researchers gathered in-depth insights about the patients' and family members' information needs regarding what type of information would be most useful and desirable during the hospital stay and what communication challenges, needs, and expectations they had experienced. The interviews lasted between 45 and 60 minutes, during which we asked the participants open-ended questions about their hospital stays. The methods and results of these interviews have been described in previous studies(Miller, Pollack, & Pratt, 2016; Mishra et al., 2016; Pollack et al., 2016).

2.5.2.1.2 *Participatory design sessions*

The second step of the exploration phase was to conduct the participatory design (PD) sessions. PD is a user-centered research method based on a philosophy that encourages user involvement at all stages of development, especially in the early stages of conception (Lazar, Feng, & Hochheiser, 2017). The PAS group recruited another group of patients, caregivers, and clinicians to take part in PD sessions. The goal of these PD sessions was to involve the users in the design process and gain a deeper understanding of their technological needs and preferences in hospital settings. PAS ran three PD sessions in the adult hospital and three in the children's hospital, with a total of 30 participants. Each PD session started with a warm-up brainstorming group session, during which PAS research team listed both patients' and clinicians' insights into the challenges related to patient information during the hospital stay. Subsequently, the research team divided the participants into groups to focus on a specific problem and design a technological solution for the problem. A previous study detailed the methods and results of these sessions (Miller et al., 2016).

2.5.2.2 Translating users' needs into Muse cards

From the interviews and the PD sessions, the PAS team generated a list of information needs and communication needs. Furthermore, the team identified users' preferences for technological features. Based on these results, the PAS team created and prioritized a list of technological opportunities to support patients' information and communication needs in hospital settings. Then, I translated these opportunities into feature cards. Subsequently, I created a set of creativity cards to help users expand their respective designs using out-of-the-box ideas.

In this section, I highlight card methods in HCI. Then, I present feature cards and creativity cards.

2.5.2.2.1 *Card methods in HCI*

The HCI research community has created other card toolkits to support aspects of the design process. One example is the Envisioning cards developed by the Value Sensitive Design Research

Lab at the Information School of the University of Washington. This toolkit of preset cards supports exploring the long-term impacts of new designs on stakeholders' values ("About | Envisioning Cards," n.d.). Another example is the IDEO method cards, which are a set of 51 cards to inspire new designs ("Method Cards | ideo.com," 2003). Each IDEO card illustrates one design method to be used in a design session.

Similarly, Muse cards share the same goal of igniting new thoughts from participants. However, while the Envisioning cards trigger thoughts about values and the IDEO cards generate new designs, Muse cards invite participants for a reflection about specific technological features.

Furthermore, in comparison, Muse cards served less as a specific set of cards, but rather as a method to create a contextualized set of cards at the low-fidelity prototyping phase to help researchers define the features that could align with the users' needs. Muse cards represented a set of possible technological features in feature cards, and creativity cards replaced the paper prototyping process and helped the users define the technological supports that would match their needs.

2.5.2.2.2 *Feature cards*

For each feature, I designed a feature card with minimalist aesthetics. The goal for the minimalist aesthetics was to convey the sense of an unfinished design so that the cards appeared to be a draft that could be edited. Each card had a title, a number, and a representative icon or design. Figure 7 illustrates the template I used to design the feature cards.
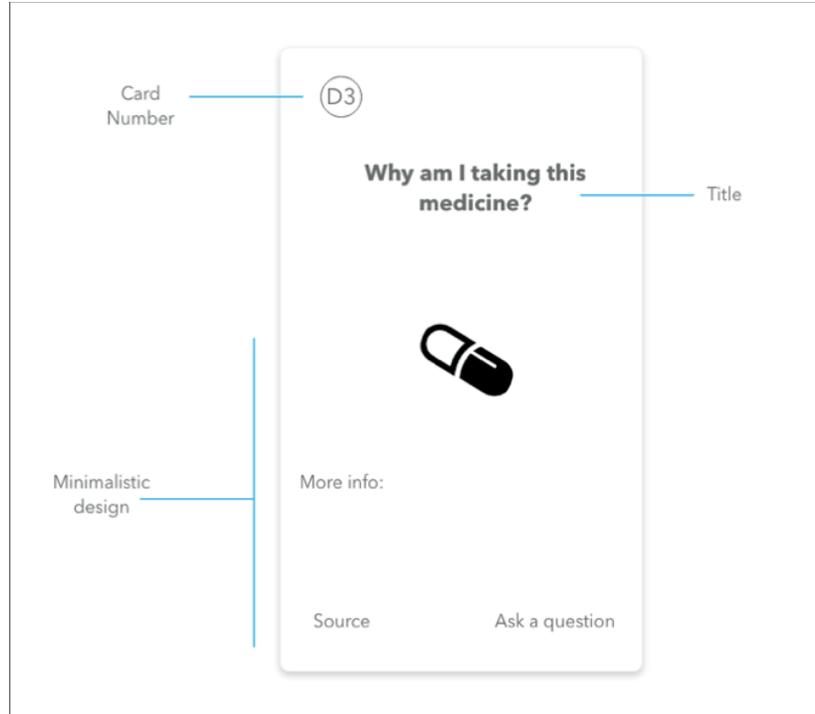
Figure 7. Muse cards template.

I created 46 feature cards illustrated in (Appendix A). Each card represented a feature that emerged from the exploration phase, as explained in the previous section. I grouped the cards into 9 sets based on their content, such as "Information about my care team" and "Learning more about my health." The groups were meant to increase the card's accessibility during interviews. The titles of the feature cards are listed in Table 1. Examples of feature cards are illustrated in Figure 8.

Table 1. Feature cards list

Feature cards	
Feature cards	Information about my care team 1-When is someone coming? 2-Information about my doctor, 3-Who was in my room? 4-What is someone's role in my care?
	Learning more about my health 1-What does my result mean? 2-Doctor's drawing, 3-Why am I taking this medicine? 4-Educational video, 5-What does my doctor say? 6-How does my equipment work?

	Health status 1-My progress toward a discharge goal, 2-My doctor's feeling about my health, 3-My health problems, 4- Ask Jess the Penguin
	Connecting with other patients 1-Advice about being in the hospital, 2-What to do when you notice a problem? 3-Share advice with others, 4-Chat with other patients, 5-Read other patients' stories, 6-Filter patients by
	Notes 1-Take notes, 2-Record Audio, 3-Record video, 4-Take a photo, 5-Draw a picture, 6-Remind me later, 7-Keep track of my symptoms
	More information and safety 1-Learn more about my medicine, 2-Learn more about my lab tests, 3-Frequently asked questions, 4-Personalize my safety checklist
	Doctor-patient communication 1-Get a second opinion, 2-Get a hold of your doctor or nurse, 3-Who should I ask? 4-Tell your doctor/nurse if the question is urgent; 5- Feeling meter: Show the doctor how you feel; 6-Tell the doctor and nurses about yourself; 7-Give feedback to your doctor/nurse
	Hospital 1-Support, 2-Hospital news, 3-Services
	Newsfeed 1-Newsfeed (results, articles, notifications), 2-Calendar (upcoming events), 3-Get updates about medications/health problems/medical tests), 4-Lab results
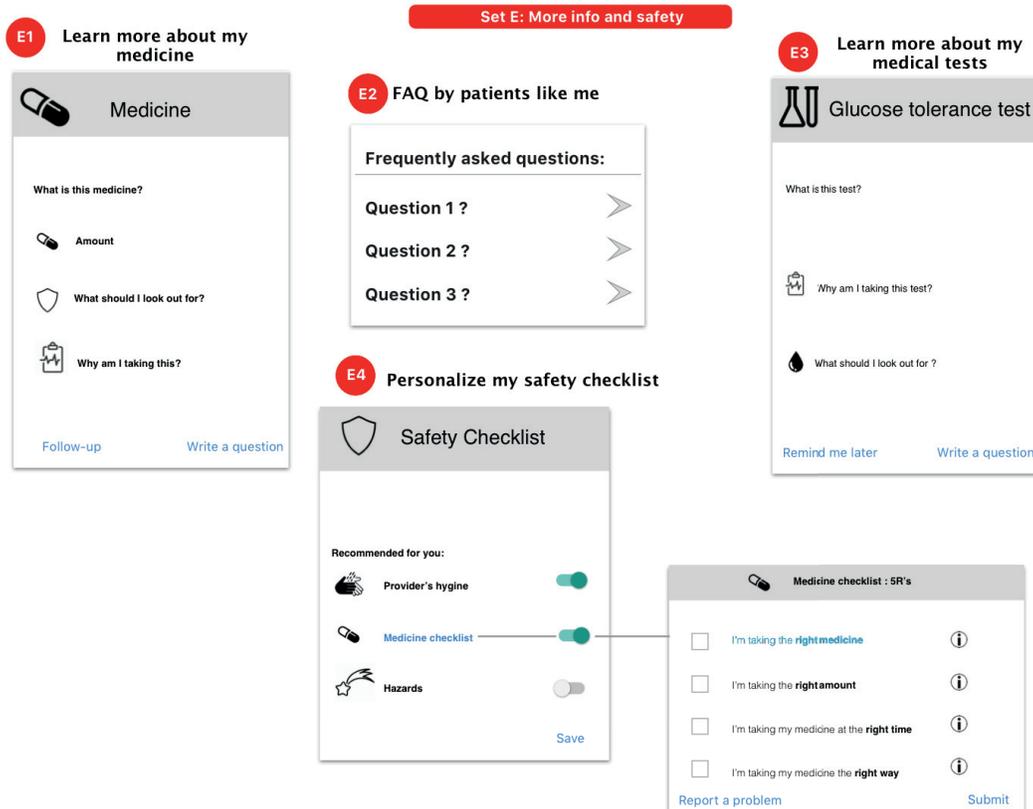
Figure 8. Feature cards.

2.5.2.2.3   Creativity cards – The Avatar and Magic Button cards

I created an additional set of creativity cards to help users think outside of the box of traditional user interfaces. In particular, I created a card illustrating a magic button with a caption stating, "If this button could do whatever you wanted, what would it do?" (Figure 9 – right side). The magic aspect was intended to foreground technology's limitless abilities. This first card was designed for adult participants. As for the child participants, I added another set of cards that depicted avatars of superheroes. I used the latter as a symbol of superpowers. I presented a list of superheroes (e.g., Superman, Wonder Woman, Pocahontas), celebrities (e.g., Selena Gomez), animals (e.g., bears, lions), and cartoons (e.g., Kung Fu Panda). The team brainstormed the avatar selection to create a diverse set that could be appealing to children within a large age range and with different interests. During the design sessions, I invited the participants to pick their favorite avatars and to brainstorm superpowers or technological tasks that the avatar could perform, which I added to the design (Figure 9 – left side).

Creativity Cards

Push the boundaries with imagination and creativity

Avatars   **Magic Button**

Figure 9. Creativity cards: What if technology was magic?

2.5.3   *The design space – Muse card principles*

I defined three principles to set up the design space for the participants.

Design Space Principle 1: Limit the influence of old biases

When presenting the Muse cards to participants, it is essential to limit visual and linguistic cues that may refer to previous technologies, as these cues could create a fixation problem and bias the user's creative process (Liikkanen & Perttula, 2010).

In addition to using feature cards' minimalistic design to limit pictorial bias, I avoided phrases such as "the design of patient portals" and defined the design task as creating a patient-facing technology for patients and caregivers to support them during their hospital stay.

Design Space Principle 2: Focus on the functionalities

I asked the participants to focus on defining the functionalities of the technology, rather than defining other aspects, such as the esthetics and structure. Defining the core technology specifications is more important during this phase. During this research, I invited the patients and

their caregivers to reflect on their hospital experience and focus on selecting features that would support them during the hospital stay.

Design Space Principle 3: Inspire freedom and creativity

I gave the participants the freedom to create their own technology as a way to inspire a sense of ownership. This opportunity allowed the participants to design the technology from scratch to match their current needs. During this research, a whiteboard served as a blank space for the participants to start building their design. The participants selected cards that met their needs and added them to the whiteboard. In addition, I provided the participants with markers to edit the Muse cards, as well as blank cards that they could personalize.

2.5.4   *The process for using the Muse cards*

I conducted a one-on-one design session with each participant (Figure 10). For each session, I followed these steps:

Step 1: I explained the design task and I invited the participants to reflect on their current experience in the hospital.

Steps 2: I presented a catalog of 46 Muse cards in random order to the participants. Then, I invited the participants to select the technological features that could support them during their hospital stay. I instructed participants to think aloud during the selection process and add their selected cards to a whiteboard. Finally, I gave the participants white cards and invited them to create new features cards or to edit the existing cards with markers, if they desired.

Steps 4: I invited the participants to use the two creativity cards – the Avatars and the Magic button – to expand on their design. Participants could use creativity cards to add magic and futuristic capabilities to their design.

Steps 5: I invited participants to reflect on their final designs. Then, I noted of the participant's selections and took pictures of the final results.

The Muse cards method
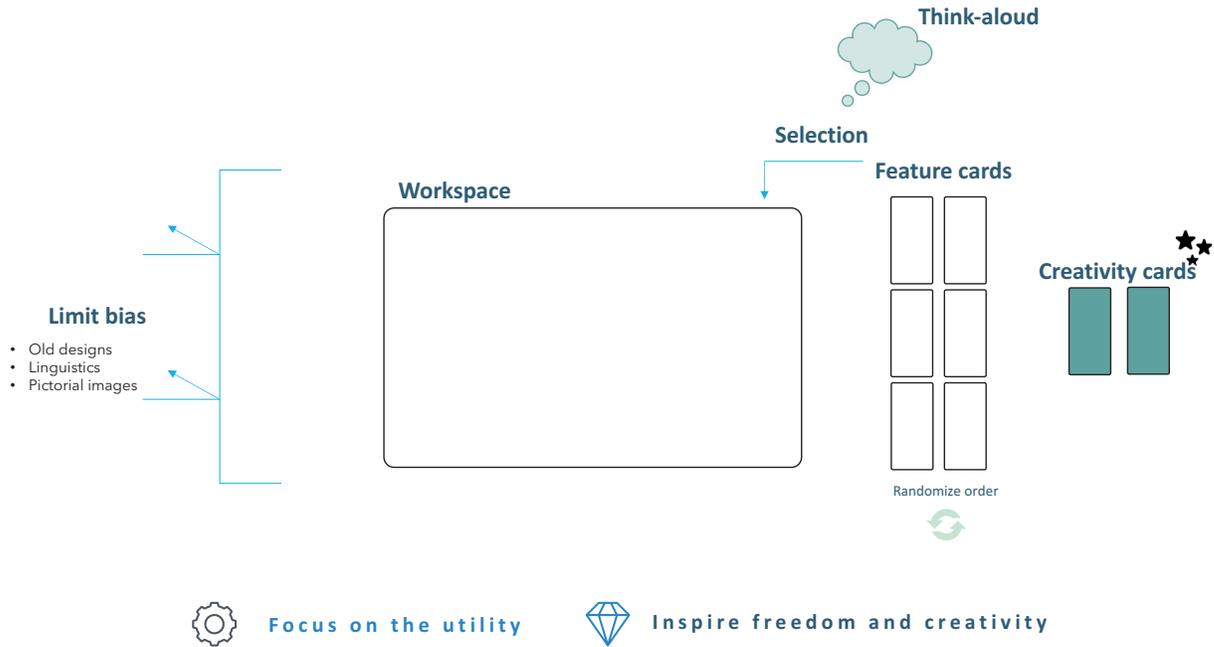
Figure 10. The design space: Blocking biases and inspiring the user with Muse cards.

2.6 APPLICATION: USING MUSE CARDS TO DESIGN PATIENT-FACING TECHNOLOGIES

In this section, I report the details from using Muse cards in the design sessions with the hospitalized patients and their family caregivers. I recruited a total of 30 participants: 13 children, 2 caregivers at Seattle Children's Hospital, and 15 adults at Virginia Mason Medical Center. I invited the participants to think aloud during the design sessions. I conducted the design session s in the hospitals in which the interviews and PD sessions took place. Sessions lasted up to 60 minutes with the individual patients or caregivers (Figure 11).
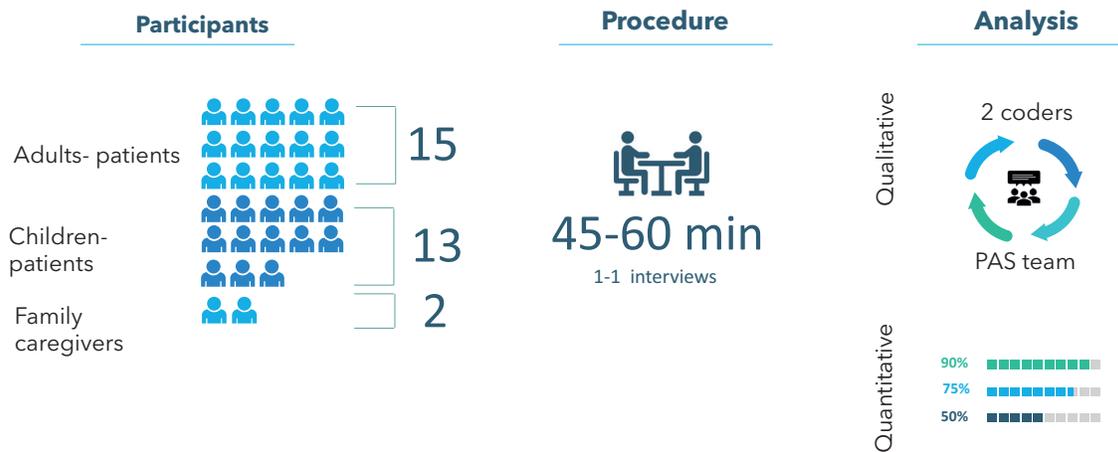
Figure 11. Muse cards method summary.

I printed and presented a catalog of 48 cards (46 feature cards + 2 creativity cards) to the participants. Each page of the catalog embodied a different group of cards. I presented the pages to the participants in random order. The process consisted of choosing a card, taking the card from the catalog, and putting it on top of the whiteboard, which represented the final technology. The participants were also able to edit the existing cards with markers. I kept a record of the cards that the users included in their own individual apps. At the end of the session, I invited the patients, families, and caregivers to think beyond the limits of existing technologies. To this end, I gave them Magic Button and Avatar cards and invited them to use either or both to brainstorm superpowers and functionalities that they would add to their prototype. The cards catalog is attached in (Appendix A)

2.7 DATA COLLECTION AND ANALYSIS

We used a mixed methods approach, whereby I collected and analyzed both quantitative data consisting of the card selection data and qualitative data consisting of the participants' feedback and thoughts during the feature selection (Appendix A).

Quantitative analysis

During the design sessions with the participating patients and caregivers, I kept track of their feature card choices. The participants placed their selected cards on the whiteboard and discarded

the cards that they thought were irrelevant to their experience. Subsequently, I used descriptive statistics to define which feature cards were the most desirable for the participants.

Qualitative analysis

In addition to the card selection data, I analyzed the patients' feedback and think-aloud data from the design sessions. To do so, I followed several steps. First, I transcribed the audio recordings of the interviews. Second, another coder and I independently analyzed the patients' and caregivers' interviews. In particular, we independently analyzed five interviews to identify main themes in the patient's perspectives on Muse cards. The coders and the rest of the PAS research team met regularly to review and iterate the codebook. When disagreements occurred, the coders held further discussions to reach consensus and make the final decisions.

2.8   HIGHLIGHT OF THE RESULTS

2.8.1   *Highlights of the quantitative analysis results for Muse cards*

Based on the rate of selections among the feature cards, I highlighted three distinct groups of features: cards selected by at least 50%, at least 75%, and at least 90% of the participants, respectively (Table 2). This analysis helped identify the most desirable features to add to the participants' technological support.

Table 2. Feature card selection results

At least 50%	At least 75%	At least 90%
When is the doctor coming?	What is someone's role in my care?	Calendar
Who was/is in my room?	Remind me later	Why am I taking this medicine?
Keep track of my symptoms	Get updates about	Learn more about my medicine
Educational video	What does my result mean?	
Feeling meter: Show the doctor how I feel	Doctor's feeling about my health	My progress toward discharge goals
Give feedback to your doctors/nurses	Advice about being in the hospital	Hospital services
Share your advice with others		Tell the doctors and nurses about myself
Chat with other patients		
My health problems		
Learn more about my medical tests		

Highlights of the qualitative analysis results for Muse cards

2.8.2.1   The feature cards analysis

The participants reported nine benefits and ways that the technological features on each feature card could augment their experiences in a hospital setting: Supporting patients in evaluating their care, supporting recall, supporting safety, supporting access to information, including patients in teamwork, providing emotional support, supporting decision making, supporting personalized communication, and supporting accessibility. Concomitantly, some participants expressed concern that the technology could negatively impact their current hospital experience such as information overload and reducing direct contact with clinicians.

Table 3 illustrates the benefits and drawbacks analysis of the following cards: Calendar, Doctor's feeling about my health, and Audio recording. Note: NV = negative value | V= positive value.

I use the following nomenclature when referring to participants: the first letter (M) refers to the Muse cards study. (VM) or (SCH) indicates the participant's presence at the adult hospital Virginia Mason Hospital or the children's hospital: Seattle Children's Hospital. The letter (P) refers to patient participant. The numbers that follow are unique identifiers for each participant.

Table 3. Muse cards benefits and drawbacks analysis and participants' quotes

Card	Benefits and drawbacks analysis	Representative Quote
Calendar	V- Improve recall	***Organize and Schedule:***
	V- Improve patient's autonomy	*M.VM.P.05:"– "– what I would like to know is,*
	V- Ease of scheduling & planning	*because I work when I'm in the hospital a lot,*
	V- Improve communication	*I work while I'm in the hospital – I would like*
	V- Support emotional readiness	*to know when I have a big block of*
	V-Support patient's information perception	*uninterrupted time – a bigger block. Because I think one of the things that happens when*
	NV - Information overload	*you're in a hospital is there's just a continuous*
	NV - Increase in clinicians' workload	*stream of people in and out, and of course somewhat at the convenience of the facility."*

Doctor's feeling about my health	V- Better understanding V- Evaluate care V- Personalized communication V-Teamwork V- Informed patient NV- Reducing direct contact with clinicians NV- Emotional distress	*NV- Better in Person* M.VM.P.01*: "I don't think that one's good because what it means for your status, if he puts up a frowny face."*
Audio recording	V- Improve data ownership V- Better accessibility V- Improve recall V- Improve team work	M.SCH.P.12: *"That way I could listen to them talk about it over and over, instead of having them being here and talking about it over and over, because I think that would irritate them a bit. And a remind-me-later thing, because sometimes I forget things, and I don't really use a remind-me-later thing, so I think that would be pretty helpful."*

2.8.2.2 Creativity cards analysis

Another researcher (Emily Bascom) and I identified several themes when coding the interview sections related to the Magic Button & Avatar cards: AI informational support such as smart contextual information and predictions. Furthermore, participants wanted AI emotional support and AI communication support.

AI informational support: In addition to wanting access to information like test results, the side effects of medications, diet requirements, and things to do after leaving the hospital, the patients and caregiver participants wanted more advanced information support:

- **Smart contextual information:** The participants wanted their technology to simplify their medical information and provide only contextual information based on their current health progress. Moreover, the participants needed assistance in identifying their own knowledge gaps, as well as ways to recognize relevant information and understand it.

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- **Predictions:** Some participants wanted better estimates of their discharge dates. They wanted a dynamic estimation that changes based on the progress of their care.

AI emotional support: Several participants expressed a desire to receive emotional support. They wanted a conversational agent to talk to them when they were lonely or to provide encouraging messages.

AI communication support: The patients have been offered communication channels, such as emails or call-buttons. However, they wanted a smarter communication option that would be more sensitive to their preferences, including them in care team conversations and helping them to reach out for help. Moreover, the participants wanted new ways to communicate with their care team and caregivers. For example, one participant wanted an enhanced call button that could understand the urgency of the message and convey it the receiver. They hoped that such technology could help their care team adjust their response time to the urgency of the message.

AI usability support: The participants requested assistance in how to use the technology. For example, one adult participant requested assistance in navigating the hospital app through voice interactions. In this scenario, according to the participant, the "technology would ask me, 'What do you want to do today?'"

2.9   INTERPRETATION OF THE USE OF MUSE CARDS

After conducting this qualitative and quantitative analysis and associating each card with its selection rate, benefits and potential drawbacks for a user, I propose two ways of utilizing the results.

2.9.1   *Feature analysis*

The first way to interpret Muse cards is to report the benefits and drawbacks for each feature. For each card, I documented the associated benefits and risks from the user's perspective in a feature report. For example, in Figure 12, I illustrate the audio recording feature report. It includes the name of the feature, the adoption rate (the percentage of users who picked this feature), the benefits and drawbacks of the feature, and a sample quote from a participant.
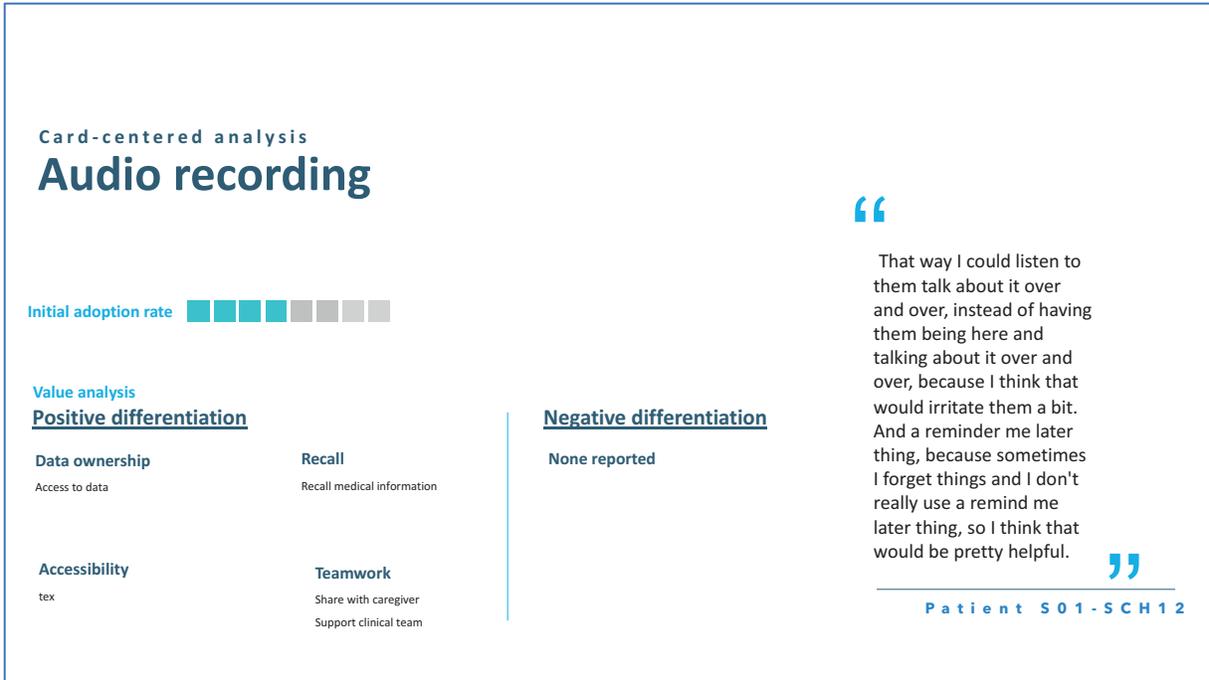
Figure 12. Feature report: Audio recording.

This analysis helps with highlighting the desirability of each feature cards in comparison with all feature cards presented to the participants. Thus, researchers and designers could rank the features from the most desirable to the least desirable from the user perspective. Furthermore, this analysis highlights the benefits and the drawbacks of adopting each feature. Thus, researchers and designers could acknowledge these factors in the design process by presenting the feature in ways that support the benefits and mitigates the risk of the drawback.

2.9.2 *Framework for innovation*

The second way to interpret Muse cards is to generate a summary framework for innovation to guide the design of future patient-facing technologies (Figure 13). This framework must highlight the different technological benefits reported by the participants. The advantage of this interpretation is its focus on the technological opportunities rather than the features. In this way, Muse cards play the role of an example rather than a feature that should be implemented. Thus, in this analysis, we focus on the high-level technology benefits reported by patients, rather than the desirability and the usefulness of each feature card. For example, while interacting with Muse cards, patient wished that the technologies could offer more emotional support, better teamwork tools, and support recall.

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After analyzing feature cards and creativity cards, I identified nine pillars of technological support in hospital settings: Supporting patients in evaluating their care, supporting recall, supporting safety, supporting access to information, including patients in teamwork, providing emotional support, supporting decision making, supporting personalized communication, and supporting accessibility.

The innovation framework is presented in Figure 13. For example, to support the informed patient pillar, participants wanted technological support to ease their access to information, especially in delicate situations, such as the transition between home and hospital. The participants reported difficulty in transitioning between the two environments and desired new ways to enable continuous comfort with information support. Furthermore, the participants wanted information about hospital resources and services before making this transition to overcome the intimidation caused by moving to an unknown environment. Further details can be found in the publication "Beyond patient portals," where the PAS research team highlighted main technological supports that could revamp inpatient portals (Haldar et al., 2019).
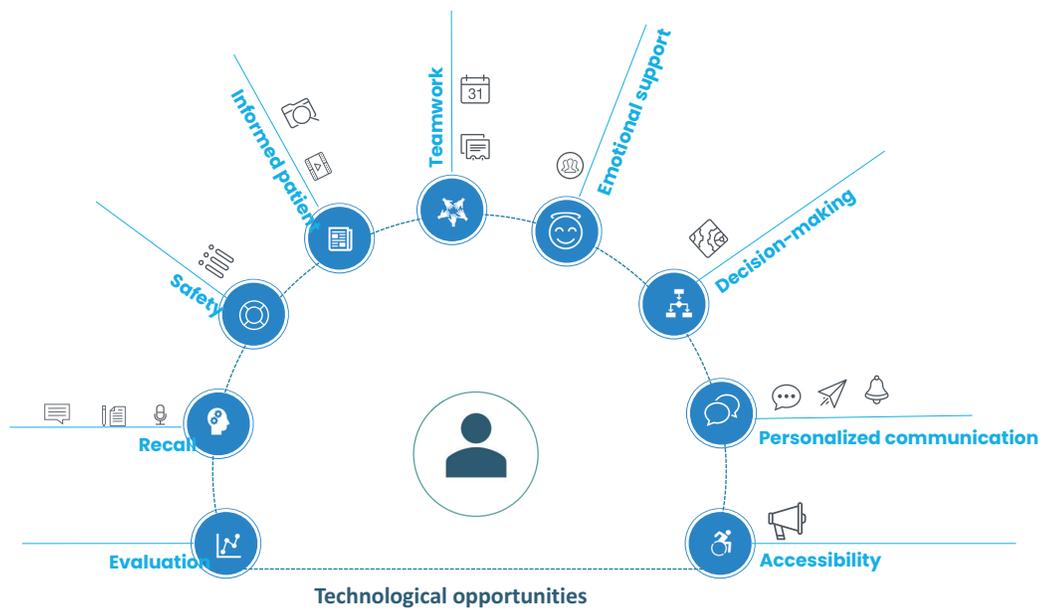
Figure 13. Innovation framework.

Additionally, using creativity cards, patients identified more futuristic features to help them disrupt their attachment to existing technologies (Figure 14). For example, the participants wanted emotional support through AI agents that could chat with them and keep them company.
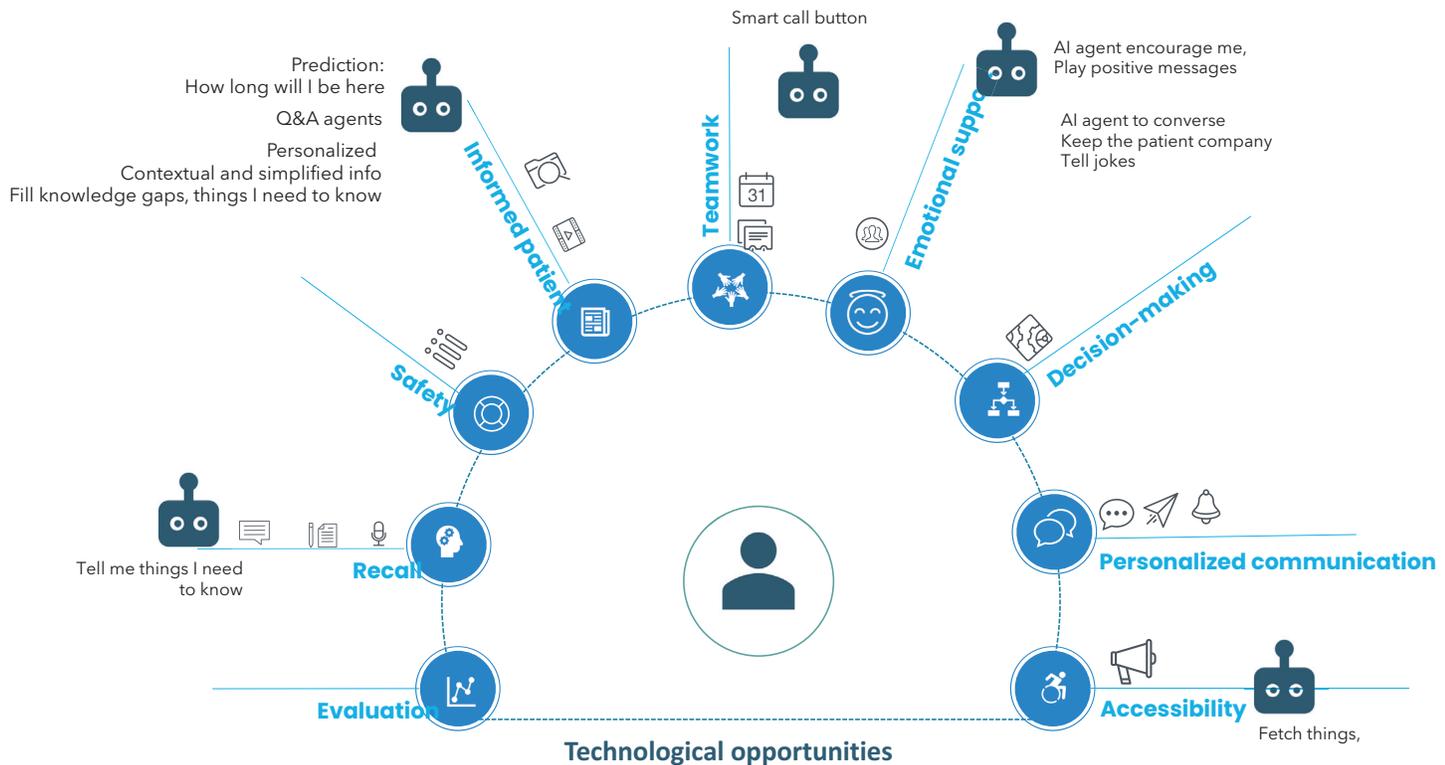
Figure 14. Futuristic Innovation Framework.

2.10   FROM THE MUSE CARD TO THE DESIGN OF NURI[1]

As explained in chapter 1, remembering and understanding medical information is a prerequisite for good adherence to a treatment regimen and better satisfaction (Ley, 1979). Thus, from the Muse card results, I chose to focus on features that improve patients' recall of information.

The results of the Muse cards study show that patients perceived the following features as tools that could help them recall medical information during the hospital stay (Figure 15).

- **F1**: "What did my doctor say?": This feature plays an audio recording of the clinician's instructions and advice.
- **F2**: "Audio recording": This feature records conversations during a patient's hospital stay.

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[1] As mentioned in the introduction, NURI is an Arabic name that means "my light".

- **F3**: "Notes": This feature allows patients to take notes about their care.
- **F4**: "AI agent" – "Tell me the things I need to know": The patients requested an AI agent that could tell them the information they needed to know.

Thus, I used these recall-support features as an inspiration to create the NURI prototype:

> NURI, is an AI agent that highlights important information for patients(**F4**). NURI utilizes audio recording of medical conversations(**F2**) to help patients remember their clinicians' instructions and advice **(F1)** and create patient-facing notes (**F3).**

In the next chapters, I will provide more details about the design of NURI (Chapter 3), I will describe which information is important in medical conversations between patients and clinicians from the patients', family caregivers', and clinicians' perspectives (Chapter 4), and I will report the evaluation the impact of NURI on the patient's hospital experience (Chapter 5).

Figure 15. Technological support for recall.

2.11   CONCLUSION

Using the Muse cards method with the participating patients and their caregivers at Virginia Mason Medical Center and Seattle Children's Hospital has allowed me to identify new opportunities for technology to offer support to hospitalized patients. The findings of this chapter illustrate that patients need technology to offer more support as they adjust to the hospital experience and to play an active role in their care. Furthermore, the participants identified several support gaps between the assistance they wanted or needed and the assistance they currently received to manage their hospital stay. Moreover, Muse cards provided patients with a tool to inspire new designs and technologies that align with their needs. Participants created new designs that would help with patients' evaluation of care, recall, safety, staying informed, teamwork, emotional support,

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decision making, personalized communications, and accessibility. These findings inspired the design of NURI, an AI agent to support the recall of medical conversations. In the next section, I present the design and evaluation of NURI.

Chapter 3. THE NURI STUDY: RELATED WORK, DESIGN OF NURI, AND THE PROBE STUDY METHODS
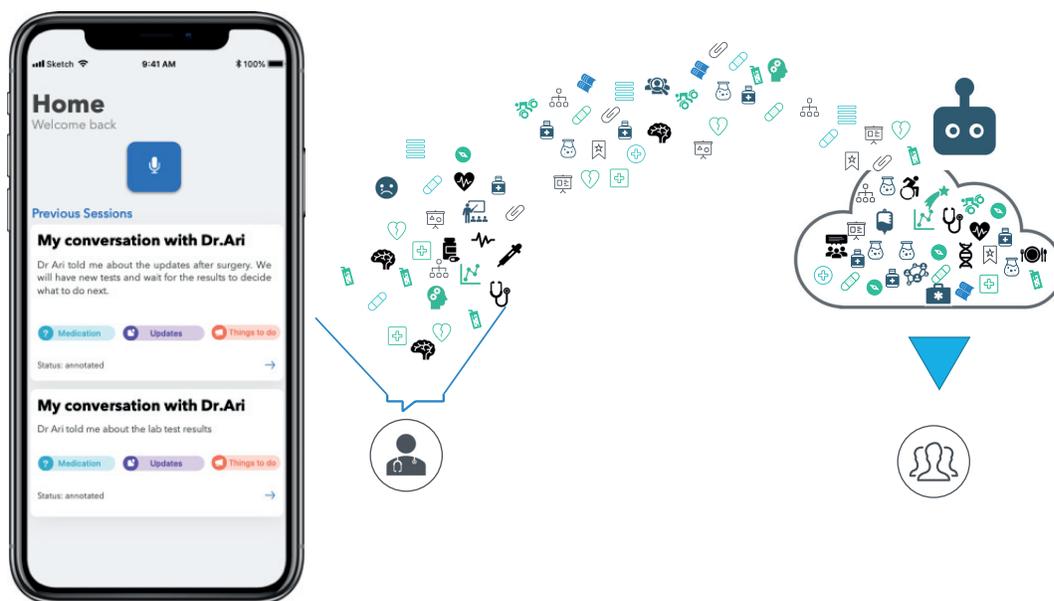
In **Chapter 1,** I described the patient's engagement dilemma. Patients with complex health problems are cognitively and physically impaired because of their pain, stress, and medications. At the same time, the information related to their health situation is more abundant and more complex. Thus, hospitalized patients face an engagement gap that grows deeper with the complexity of their health problems.

In **Chapter 2,** I discussed technological ways to overcome this engagement dilemma. In particular, I presented Muse cards study, a new user-centered method to investigate technological opportunities to help patients better manage and utilize their medical information during a hospital stay. I also discussed the steps for using this method with hospitalized patients and their caregivers at Seattle Children's Hospital and Virginia Mason Hospital. Then, I offered an innovation framework highlighting nine pillars of innovation to support hospitalized patients. Based on these findings, I designed NURI, an artificial intelligence (AI) agent that can turn patient-clinician conversations into patient-facing notes.

In the rest of this thesis, I will detail the results of the NURI study. In **Chapter 3**, I present the NURI prototype, feature the background and related work, and outline the methods used to investigate NURI's impact on the patients' hospital experience. In Chapters 4 and 5, I present the results of the NURI study. Specifically, **in Chapter 4**, I identify the factors that define which pieces of information from a medical conversation are considered important from the patients', family caregivers', and clinicians' perspectives. Then, I provide design recommendations to utilize these factors. **In Chapter 5,** I evaluate NURI's acceptability and usefulness in the hospital setting from the patients', caregivers', and clinicians' perspective. Finally, based on these results, I provide design recommendations to successfully implement NURI into hospital settings.

3.1   BACKGROUND AND RELATED WORK

In this section, first, I discuss the culture change in medical institutions that has led to increases in patients' access to medical information, as this culture change motivated the development of the NURI prototype. Second, I present research investigating patient information needs and patient-facing technologies in hospital settings. This work helped clarify the value NURI, using advances in AI technologies, could have in fostering patients' access to medical conversations. Third, I discuss examples of AI agents supporting hospital patients to showcase the success of similar technologies. Fourth, I present the promising solution of digital scribes in healthcare. Fifth, I

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address the challenges of implementing AI agents in hospital settings. These challenges helped refine the research questions for the NURI project that are answered in Chapters 4 and Chapter 5.

3.1.1 *A new culture of information transparency: Motivation for the NURI project*

In "To Err Is Human," the Institute of Medicine (IOM) pinpointed patient-centered care as one of 6 strategies to reduce medical errors, a problem leading to 44,000 to 98,000 deaths every year (Donaldson, 2008). To help patients manage their health, the IOM recommended improving information transparency and patients' access to medical information. Since then, several health institutions have followed these guidelines and started shifting from a paternalistic approach to care to a patient-involved approach. For example, the American Academy of Pediatrics (Eichner et al., 2012) has recommended making bedside medical rounds more family-centered. Family-centered rounds are "multidisciplinary rounds that involve medical teams partnering with patients and families in daily medical decision-making" (Mittal, 2014). The practice encourages patients and their family caregivers to actively participate in the discussion happening at their bedsides (Sisterhen, Blaszak, Woods, & Smith, 2007). Family-centered rounds have been shown to positively impact the patient experience in hospital settings, improving patients' relationship with clinicians (Lewis et al., 1988) and supporting shared decision making (Rosen, Stenger, Bochkoris, Hannon, & Kwoh, 2009). In addition, to optimize the impact of patient-centered rounds, clinicians should provide a checklist with information about the care team, assessment, daily plan, and goals for discharge, according to Cox et al. (Cox et al., 2017). Patients should be included in the decision-making process and asked for information related to their inpatient medication schedule and adverse drug reactions (Benjamin et al., 2015).

In addition to showing the positive impacts of family-centered rounds, a growing body of evidence has shown the benefits of the IOM strategy, confirming that an informed patient is more likely to have a good relationship with their care team and be more engaged, safer, more satisfied with their care, and less likely to sue their clinicians (Bell et al., 2017; Tang & Newcomb, 1998). Furthermore, in the 21st century, patients have become more involved in their hospital care and have demanded better clarity and transparency in their medical information. Patients and their family caregivers want to be included in medical discussions and decision making (Benham-Hutchins, Staggers, Mackert, Johnson, & deBronkart, 2017).

However, despite clinicians' efforts to keep patients and caregivers informed, in-person communication is not enough to give patients full access to their information (Tang & Newcomb, 1998). Thus, hospital settings have implemented technical and non-technical resources to support hospitalized patients' bedside access to information.

Among the non-technical resources now being implemented, hospitals have installed tools like whiteboards to highlight patients' medical information at their bedsides. Tan, Hooper Evans, Braddock, and Shieh reported that whiteboards significantly increased the proportion of patients who knew their physicians, care goals, and estimated discharge date. However, these whiteboards provide only a limited amount of information due to their space constraints. Moreover, they can present outdated information if not regularly updated (Tan, Hooper Evans, Braddock, & Shieh, 2013).

Therefore, even more resources have been developed. Hospitals have paid considerable attention to health information technologies at the bedsides of patients that can streamline the patients' access to information and promote a patient-centered model of care.

In the next sections, I talk about in-hospital health information technologies and highlight studies on hospitalized patients' information needs and bedside patient-facing technologies.

3.1.2 *Information and technologies at the bedsides of hospitalized patients: Where does NURI fit in?*

As hospitals have been digitized and patients have been encouraged to access their health information, several research efforts have started exploring how to optimize patients' access to information during a hospital stay. Moreover, a growing body of research asserts that information technologies are crucial in giving patients better hospital experiences (Caligtan, Carroll, Hurley, Gersh-Zaremski, & Dykes, 2012; Kelly, Hoonakker, & Dean, 2017; Prey et al., 2014; Skeels & Tan, 2010; Vawdrey et al., 2011). Thus far, these studies have focused on answering two questions:

- Q1: What kind of information do patients need at their bedsides?
- Q2: How can we develop patient-facing technologies and patient-centered technologies?

3.1.2.1 Patient information needs in hospital settings

To answer the first question, our PAS research team investigated hospitalized patients' information needs. To this end, Kendall et al. (2015) conducted a mixed-method research study, including questionnaires and observations of patients' experiences in hospital settings (Kendall, Mishra, Pollack, Aaronson, & Pratt, 2015). They reported that hospitalized patients wanted information about (1) their medications, (2) the next visit from their clinicians, and (3) their lab and imaging results. In addition, Haldar et al. identified further information needs to be included in patient-facing technologies in hospital settings, particularly those related to adjusting their schedules, receiving status updates, understanding and remembering their care, asking questions, and flagging problems (Haldar et al., 2019).

In another study conducted by Mishra et al., hospitalized patients and their family caregivers requested additional information to help them play active roles in their care during their hospital stays. For example, to play a "team manager" role, some participants requested information about their care team members, interactions, and the information flow in their hospital settings. Furthermore, this study showed that the participants did not want to be merely information recipients; they wanted to be an active source of information to help the care team. For example, the participants wanted to communicate information to help their clinicians prescribe medication that matched their preferences, to support the decision-making process by providing their medical histories, and to help the care team members identify and correct discrepancies in their medical information (Mishra et al., 2016).

Other research groups have also studied patients' information needs in hospital settings. For example, Caligtan et al. (2012) conducted a study to identify the data elements needed to populate a bedside communication tool in an acute care hospital setting. To this end, the researchers conducted individual interviews with patients and clinicians. The patients and clinicians reported five categories of information requests at the bedsides of patients: (1) plan of care, (2) patient education, (3) communication of safety alerts, (4) diet, and (5) medications (Caligtan et al., 2012). Woollen et al. (2016) conducted observations and semi-structured interviews with post-operative cardiac surgical patients and their family caregivers to investigate their information needs. The researchers reported that the patients had unmet information needs in the hospital setting. In particular, the patients and their family caregivers wanted to receive information about their diagnoses, laboratory test results, radiology reports, and procedure notes in patient-friendly

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language. In addition, the participants wanted to view the daily progress reports about their hospital stay and to have access to the educational information about their post-acute recovery (Woollen et al., 2016).

Furthermore, Wilcox et al. interviewed hospitalized patients and nurses in a cardiology unit to investigate the patients' medication-related information needs. This study reported that the patients had problems keeping track of their therapies, despite their desire to do so, and needed technology to help them manage their medication information during their hospital stays and to display their medications list and educational information summaries(Wilcox et al., 2012).

Relatedly, after conducting semi-structured interviews with hospitalized patients and family caregivers, Skeels and Tan (2010) proposed a redesign of the call button at patients' bedsides to improve nurse-patient communication. Furthermore, the researchers reported that participants wanted more information about their overall progress, upcoming events, pain scale data, and billing information (Skeels & Tan, 2010).

Similarly, Wilcox, Morris, Tan, Gatewood, and Horvitz (2011) studied patients' information needs in emergency rooms. This study highlighted the beneficial impact of providing short "micro-explanations" of medical events through web-based resources for hospitalized patients (Wilcox, Morris, Tan, Gatewood, & Horvitz, 2011).

Grossman, Creber, Restaino, and Vawdrey investigated the potential impact of patients' access to physicians' notes. This research effort is part of the OpenNotes efforts. The OpenNotes project started in 2010, supporting a movement to reduce the gates between patients and their data and provide patients with access to their medical notes1. The project started in Beth Israel Deaconess Medical Center in Boston, Geisinger Health System in rural Pennsylvania, and Seattle's Harborview Medical Center. In 2012, the first results of the OpenNotes research were published, putting clinicians' worries at ease. The results found that doctors report little change in their workload. Furthermore, patients noted that reading their notes helped them feel more in control(Leveille et al., 2012). Thus, after seeing patients' interest in getting clinicians' notes in an outpatient setting, Grossman, Creber, Restaino, and Vawdrey investigated patients' desire for their clinicians' notes during a hospital stay. The team employed a mixed-methods approach, including surveys, telemetric data analysis, and qualitative interviews, to evaluate the patients' perspectives on receiving and using their clinical notes. The study confirmed that sharing clinical notes with hospitalized patients is feasible and beneficial. Furthermore, patients reported several benefits,

including having better insight into their conditions, feeling less anxiety, appreciating their clinicians more, and feeling more engaged with their care (Grossman, Creber, Restaino, & Vawdrey, 2017).

The NURI study focused on identifying patients' information needs in the context of medical conversations. Patient-clinician conversations are an essential source of information for patients. However, these conversations are often misrepresented in clinicians' electronic health record (EHR) notes and can lack important details for the patient's use (Weiner, Wang, Kelly, Sharma, & Schwartz, 2020).

3.1.2.2   Patient-facing technologies in hospital settings

As for the second question, "How can we develop patient-facing technologies and patient-centered technologies?" several research efforts have studied technologies for communicating medical information at the bedside of hospitalized patients. With the proliferation of ubiquitous and smart technologies, researchers have tested tablet computers, phone applications, video recordings, virtual nurses, virtual reality applications, and more. In this section, I highlight a selection of these studies.

For example, gaming and simulation videos have been used to support patients in hospital settings. Bers, Gonzalez-Heydrich, and DeMaso (2003) conducted a pilot in which they provided children undergoing dialysis treatment and their nurses with "Zora," a computer-based application that allowed the patients and nurses to communicate virtually. The participants could create avatars to inhabit a virtual city and interact with each other in real-time. The participants found the experience enjoyable and reported that the application helped them voice their concerns without the burden of face-to-face communication. Furthermore, the authors stated that the virtual environments helped the patients cope with chronic physical illnesses. The technology engaged both patients and staff in the creation of a virtual community-support network (Bers, Gonzalez-Heydrich, & DeMaso, 2003).

Mahler & Kulik, (1998) conducted a randomized controlled study to investigate the use of another form of technology: educational videos. The researchers showed patients videos in preparation for their surgeries. The results of the study found that the patients who viewed the videos felt "significantly better prepared for the recovery period" and had higher reported self-efficacy beliefs (Mahler & Kulik, 1998).

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In the Muse cards study, highlighted in Chapter 2, Haldar et al., (2019) conducted semi-structured interviews with 30 inpatients and caregivers in an adult hospital and a children's hospital to investigate patients' and caregivers' perspectives on how future inpatient portals could be designed to meet their needs during a hospital stay. The study noted that the hospitalized patients wanted their portals to support "(1) transitioning from home to hospital, (2) adjusting schedules and receiving status updates, (3) understanding and remembering care, (4) asking questions and flagging problems, (5) collaborating with providers and caregivers, and (6) preparing for discharge and at-home care" (Haldar et al., 2019).

In addition, Vardoulakis, Karlson, et al. (2012) studied the use of mobile phone applications in emergency departments to display patients' medical progress, care plans, and care team members. The study noted that the technology helped with improving patients' awareness, supporting patients' empowerment, and enhancing patients' ownership of their medical information. The participants valued the educational application and reported feeling less anxious(Vardoulakis, Karlson, et al., 2012).

Similar to the research efforts of Vardoulakis, Karlson, et al. (2012), Vawdrey et al., (2011) (Vardoulakis, Karlson, et al., 2012), ran a pilot test with five hospitalized patients to study their use of a patient-facing tablet computer application. The system displayed information from the patients' EHRs and personal health records. The participating patients stated that the application helped them remember their medical information, track their medication, communicate with their care team(Vawdrey et al., 2011).

In another innovative approach, Cimino, Patel, and Kushniruk (2002) studied the use of PatCIS, an interface that allows patients to add to and review their medical data. Additionally, the technology provided educational resources and automated advice programs. The researchers evaluated the use of PatCIS with thirteen subjects over 36 months. They found that patients used the system mainly to review laboratory results. Furthermore, in the study, patients and their physicians noted that the use of PatCIS enhanced the patients' understanding of their conditions and improved their communication with their physicians (Cimino, Patel, & Kushniruk, 2002).

Dykes et al. (2013) also ran a usability study on an electronic bedside communication center that helped patients access their information in hospital settings. The patients and their family caregivers appreciated receiving tailored educational content though the prototype. Furthermore, the participants valued having information about their care team, such as the team members'

profile pictures and bio links. In the future, the participants asked for video conferencing features to communicate with out-of-town family members, access to the hospital's menu, and the ability to text/email their clinicians(Dykes et al., 2013).

Wilcox, Morris, Tan, and Gatewood, (2010) conducted a Wizard-of-Oz study exploring the usefulness of delivering information through a patient-centered display during emergency department (ED) visits. The research team displayed information extracted from the patients' medical records on a manually compiled paper poster. The poster showed information such as "Your medication," "Your care team," and "What's completed." The research team interviewed patients, family members, and clinicians to gather their insights into the intervention. The participants felt the resource could be useful as a memory aid, as a tool to discuss their progress with family caregivers and clinicians, and as a tool to help archive their data to build an extensive medical record (Wilcox, Morris, Tan, & Gatewood, 2010).

In another study, our PAS team evaluated three different display types (timeline, categorical, and goal-oriented) for patient-facing technologies based on the experiences of 21 hospitalized patients. The results showed that patients used each display for different purposes. For example, the timeline prototype, displaying information in a calendar-like fashion, helped the hospitalized participants gain more control over their schedules and ensure a caregiver was present during medical rounds. Furthermore, the goal-oriented display helped pinpoint conflicting opinions between the patients and providers. The study findings suggested that hybridizing the presentation of medical information optimizes the information's usefulness at the bedside of patients (Haldar, Khelifi, et al., 2020).

In addition, Haldar, Mishra, et al. 2020 studied a technology that connected hospitalized patients to an online community. Using the technology, patients could exchange advice about their hospitalization. The participants reported positive experiences using the prototype. Furthermore, they noted that the technology improved their safety and overall hospital experience (Haldar, Mishra, et al., 2020).

Bickmore, Pfeifer, and Jack (2009) also took an innovative approach and investigated the use of relational agents in hospital settings to prepare patients for discharge. In the study, the patients received educational materials from an animated, empathic virtual nurse interface. The participants found the system was easy to use. Plus, most of the participants preferred receiving information from the virtual nurse over their actual doctor or nurse (T. W. Bickmore, Pfeifer, & Jack, 2009).

As a bedside patient-facing technology, NURI differs from the previously mentioned technologies in content and format. It differs in its content since NURI displays a new type of information: the verbal medical conversation between a patient and clinician, presented as an audio recording, transcript, and notes. Furthermore, it differs in its format since NURI is an innovative AI agent that deploys speech processing technologies to turn medical conversations into patient-facing notes.

In the next section, I highlight a selection of research work focusing on the use of AI agents to support patients.

3.1.3 *Examples of AI agents in healthcare*

To push the boundaries of existing patient-facing technologies, several academic and commercial efforts have studied the value of introducing AI agents to the bedsides of patients. An AI agent, as defined by Russell and Norvig, is anything that can be viewed as perceiving its environment through sensors and acting upon that environment through effectors (Russell & Norvig, 2009). AI agents have become easily accessible to many users and have helped users with several tasks, including autonomous delivery, diagnostic assistance, tutoring, and trading (Poole & Mackworth, 2010). Furthermore, human-centered AI agents have appeared in many different technologies, such as smartphones, smart speakers, the IoT, tablets, and computers (McTear, Callejas, & Griol, 2016). I define NURI as an AI agent that leverages text and speech processing to turn medical conversations into patient-facing notes.

The history of agent-leveraging text and speech processing services can be traced back to the 1960s. In 1966, Weizenbaum published the details of an early natural language processor, "ELIZA," that simulated a text-based conversation with a psychotherapist (Weizenbaum, 1983). Since then, AI, speech processing, and natural language processing (NLP) have evolved immensely. These advances have reignited efforts to integrate AI services into medical practices to solve long-existing problems, such as shortages of healthcare professionals, affordable remote and continuous patient monitoring methods, and more (Tian et al., 2019).

These efforts have also led to the development of more diverse conversational agents. In particular, researchers have explored the use of agents to support healthcare professionals, patients, and at-risk populations. Examples of this work include AI agents for self-management and chronic pain (Hauser-Ulrich, Künzli, Meier-Peterhans, & Kowatsch, 2020), oncology (Bibault et al.,

2019), depression and anxiety (Fulmer, Joerin, Gentile, Lakerink, & Rauws, 2018), cognitive behavioral therapy (Fitzpatrick, Darcy, & Vierhile, 2017), teen sexual health (Crutzen, Peters, Portugal, Fisser, & Grolleman, 2011), autism (Tanaka, Negoro, Iwasaka, & Nakamura, 2017), and hypertensive patient management (Rojas-Barahona, Quaglini, & Stefanelli, 2009).

These recent experiments in using AI agents to support patients' needs have had promising results. However, studies into implementing AI agents at the bedsides of patients have been limited. One exception is the work done by the Relational Agents Group led by Timothy Bickmore, which explored the use of agents at the bedsides of hospitalized patients. This group worked on simulating face-to-face counseling interactions between patients and agents, primarily in health education and health behavioral change interventions.

In 2009, Bickmore, Pfeifer, and Jack studied the use of relational agents to educate patients before discharge, particularly in regards to the agents' ability to mimic and streamline one-on-one patient education, a gold standard of care. Within this innovative study, AI agents helped patients overcome challenges related to costs, convenience, logistics, and stigmas (Bickmore, Pfeifer, & Jack, 2009). As the results showed, the patients expressed a high level of satisfaction after using a virtual nurse to prepare them for discharge. Moreover, most patients said they preferred receiving the discharge information from an agent over their care team. The patients also felt that the virtual nurse provided an additional authoritative source for their medical information.

Furthermore, Bickmore, Bukhari, Vardoulakis, Paasche-Orlow, and Shanahan (2012) built a hospital companion agent to provide emotional support to patients throughout their hospital stay. The patients could chat with the agent about their hospital experience, including their feelings about specific events, and the agents would provide empathetic feedback. The participants found the agents to be effective and easy to use(T. Bickmore, Bukhari, Vardoulakis, Paasche-Orlow, & Shanahan, 2012).

In addition, the Relational Agents Group explored other use cases for relational agents, such as using AI agents as social companions for older adults (Vardoulakis, Ring, Barry, Sidner, & Bickmore, 2012) and to promote teen sexual health (Gardiner et al., 2013).

More recently, several commercial enterprises have started using AI agents in hospital settings to improve patient accessibility and communication. In 2019, Cedars-Sinai Medical Center in Los Angeles, California installed Amazon Echos with the Alexa-powered healthcare platform, Avia, in over 100 patient rooms. Avia is a patient-centered voice assistant that allows patients to inform

their care team of their needs by forwarding their request to the proper care team member ("Virtual Health Assistant | Aiva Health," n.d.). The Avia system also allows patients to utilize the standard Alexa features and control the television in their rooms. This system allows patients who may have limited mobility or use of their hands to contact their care team. It also provides clinicians with an interface to manage their patients' needs and feedback metrics.

These efforts show the immense promise of AI agents to overcome the shortcomings of traditional patient-facing technologies in hospital settings. The Relational Agents Group led by Timothy Bickmore demonstrated that AI agents could increase patients' accessibility and use of rich and contextual information. Thus, in this work, I describe a new application for AI agents at the bedsides of hospitalized patients: turning medical conversations into patient-facing notes. In the next section, I present similar research efforts for turning medical conversations into clinician-facing notes.

3.1.4 *The promising solution of digital scribes in healthcare*

Digital scribe or automated clinical documentation system have become the focus of several academic and commercial research efforts into reducing the notetaking burden on clinicians. Researchers have taken different approaches to automating medical notes. For example, Wilcox, Feiner, Lu, Jordan, and Lai, (2009) built a prototype called "ActiveNotes" that adds contextual patient data into clinical notes. Their study noted that physicians found the prototype to be useful (Wilcox, Feiner, Lu, Jordan, & Lai, 2009). Since then, promising advances has been made in clinical speech processing. Hodgson and Coiera note that the accuracy of speech processing for medical use has reached 88.9% to 96% and appears to improve 0.03% per year (Hodgson & Coiera, 2016). Thus, several academic and industrial research efforts have also started creating digital scribes to turn medical conversations into medical notes (Figure 16).

However, creating digital scribes is a gigantic challenge. Quiroz et al.(2019) reported that unstructured medical conversations, ambient noise, and multiple speakers create challenges for digital scribes (Quiroz et al., 2019). Nonetheless, several studies have proven that these challenges can be overcome. In a study on automatic speech recognition (ASR) models that can transcribe patient-clinician conversations, Chiu et al. (2017) reported that the speech recognition models performed well when extracting key medical utterances, though errors occurred during casual conversations. Thus, they believed that ASR models can provide reasonable results in medical

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practice (Chiu et al., 2017). Similar research efforts have reported promising results as well (Wallace, Laws, Small, Wilson, & Trikalinos, 2014; Yim, Yetisgen, Harris, & Sharon, 2016).
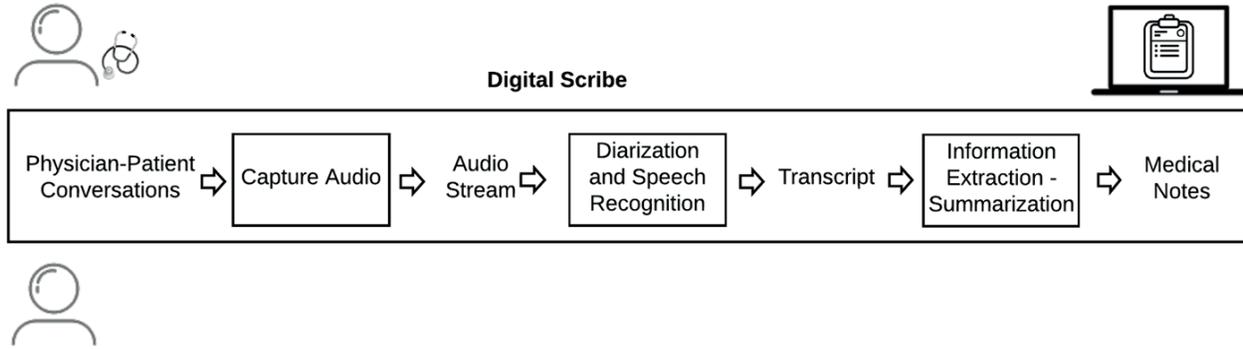
Figure 16. Digital Scribe (Quiroz et al., 2019).

On the industrial side, several big tech companies, such as Google[1], Amazon[2], and Microsoft[3], are developing technologies to turn medical conversations into medical notes to reduce clinician burnout. For example, as of May 2020, a research team in Microsoft Health-NeXT is building a service called "EmpowerMD" to generate medical notes and billing codes from patient-clinician conversations. Moreover, startups like Saykara[4] and DeepScribe[5] are working toward the same goal.

Thus far, these research and industrial efforts have focused on turning medical conversations into medical notes to populate EHRs and support billing. In contrast, this work aims to generate a better understanding of how to turn these medical conversations into patient-facing notes. To this end, in Chapter 4, I identify the factors that define which information in medical conversations is important for patients' use.

Though having a patient-centered digital scribe at the bedsides of patients has many benefits, it also comes with design challenges. In the next section, I present the potential design challenges related to using AI agents for this purpose.

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[1] https://ai.googleblog.com/2017/11/understanding-medical-conversations.html

[2] https://aws.amazon.com/transcribe/medical/

[3] https://www.microsoft.com/en-us/research/project/empowermd/

[4] https://www.saykara.com

[5] https://www.deepscribe.ai

3.1.5 *Design challenges for AI agents: NURI design and implementation challenges*

To create responsible technologies, it is crucial to anticipate the potential risks for users. Thus, in the design of NURI, two main potential challenges were faced: concerns about privacy and concerns about disrupting clinicians' workflow.

3.1.5.1 Concerns about privacy

While speech processing services can offer a lot of informational support to help patients remember and understand their medical conversations, these services can be challenging to implement due to privacy concerns related to audio recording medical information. In particular, smart assistants, such as Alexa and Google Home, are perceived as a threat to user privacy since they continuously record audio. In the article "Alexa, are you listening?" Lau et al. investigated users' privacy perceptions of smart speakers and found that users felt there was a tradeoff between the convenience of using the technology and their security, which prevented some users from purchasing the smart speakers since they felt they could not obtain the security they desired, even after altering the speaker's settings (Lau, Zimmerman, & Schaub, 2018). In addition, patients are not the only ones with these perspectives on audio recording in clinical settings. Although providing audio recordings of initial oncology consultations to patients is largely commonplace and a generally accepted practice (Hack, Ruether, Weir, Grenier, & Degner, 2013; Knox, Butow, Devine, & Tattersall, 2002; McClement & Hack, 1999), some clinicians resist this practice as they find it intrusive. Furthermore, studies have reported that clinicians fear the audio recordings could be used against them in the form of malpractice suits (Tattersall & Butow, 2002). A recent research effort that was launched by Barr et al. (2018) reported that only 8% of clinicians (n = 456 survey participants) reported that they had recorded a clinic visit for a patient's personal use. Moreover, among the clinicians who had not recorded a clinic visit, only 49.5% would be willing to do so in the future, while 66.0% of patients would be willing to record in the future(Barr et al., 2018).

3.1.5.2 Disrupting clinician's workflow

In recent years, clinicians have had to adjust their work habits in response to a growing number of technologies expanding patients' access to medical information. At the forefront of this movement is the OpenNotes project. At first, physicians expressed concern about OpenNotes' potential to disrupt their workflow. For that reason, Delbanco et al. investigated the impact of patients having

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access to their physicians' notes (Delbanco et al., 2010). The study involved over 100 primary care physicians and 20,000 of their patients in three hospitals throughout the United States. The results of this study were profound; a majority of the patients read their physicians' notes and reported increases in their engagement, comprehension of their care, likelihood to take their medication as prescribed, and ability to recall events from their visit. In addition, the participating physicians reported limited to no disruption to their workflow, though some physicians commented that they were unsure if their patients were actually reading their notes because of how infrequently the notes were brought up during the visits. Some clinicians also noted an overall improvement in the patient-physician relationship. Many physicians, both participating and non-participating, initially expressed concern about OpenNotes' potential to disrupt their workflow. However, these concerns did not materialize during the study(Bell et al., 2017).

Thus, reflecting on this research around users' perceptions of the impact of AI agents on their privacy and the implementation of new technologies such as OpenNotes between patients and clinicians, I acknowledge that implementing NURI comes with potential risks, which I will address in Chapter 5. Furthermore, in the same chapter, I will report the benefits of using NURI from the patients', caregivers', and clinicians' perspectives.

In summary, this research on NURI adds to the literature of patient-facing technologies in hospital settings by offering an innovative technology to support the patient-clinician conversation. Specifically, this research adds to the literature on the use of AI agents in hospital settings by studying the design and use of NURI, an AI agent to turn medical conversations into patient-facing notes.

The rest of Chapter 3 will further describe the NURI prototype and the methods used in the NURI study.

3.2   NURI, AN AI AGENT

NURI is an AI agent designed to record, transcribe, and annotate medical conversations for patients' use. The NURI prototype is composed of a patient-facing iOS application for recording and reviewing the conversation and a researcher-facing web platform to manage transcription correction and annotation.

Using NURI, patients can record their medical conversations with their clinicians. Then, they can play back the audio recording of the conversation and read its transcript. Moreover, for each conversation, NURI highlights topics, questions, and online resources that can help users revisit their medical conversations without having to read and/or listen to the totality of the conversation. Before accessing the transcript, patients need to read a statement that the transcript might contain errors even after human annotation and press the "I understand" button.

The NURI service was inspired by the results of the work described in Chapter 2. In the Muse cards study, patients identified the following features as the most important for supporting their ability to recall information in a hospital setting (Figure 17).

- (F1)- What did my doctor say?: This feature plays an audio recording of the clinician's instructions and advice.
- (F2)- Audio recording: This feature allows patients to record conversations during their hospital stay.
- (F3)- Notes: This feature allows patients to create personal notes.
- (F4)- AI agent - Tell me things I need to know: This feature allows patients to ask the agent to highlight the information that they need to know to manage their care in hospital settings.

These features inspired the creation of the NURI app to support patients recall of medical conversations. NURI, is an AI agent that highlights important information for patients (F4). NURI utilizes audio recording of medical conversations (F2) to help patients remember their clinicians' instructions and advice (F1) and create patient-facing notes (F3)
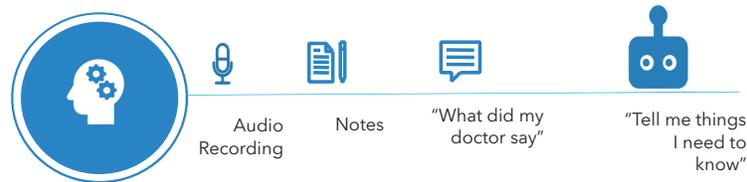
Figure 17. Recall features from the Muse cards study.

3.2.1 *The NURI Service*

The patient-facing app features

In this section, I present the features of the NURI patient-facing app, including the home page and patient-facing notes function.
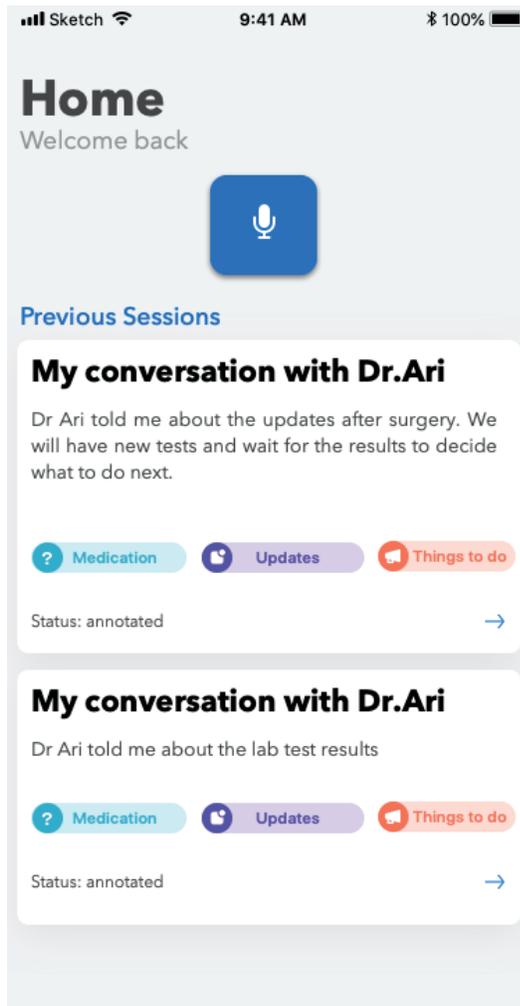
3.2.1.1   Home page features

Through the home page, users can access the recording features and their list of patient-facing notes.

• **Recording feature:** The recording feature offers users the option to record and transcribe a medical conversation. Users can submit the recording by adding a title, optional short description, and tags (e.g., medication, diagnosis, or updates).

• **List of patient-facing notes:** On the home page, patients can see a list of notes generated from their medical conversations. The note widget shows the title, short summary, tags of topics discussed in the conversation, and status of the speech processing (e.g., submitted, transcribed, or annotated).

3.2.1.2   Patient-facing notes.

In each note, patients have access to an indexed transcript, a list of questions, a list of topics, and a list of resources.

- **Indexed transcript:** Patients can read the transcript of their conversations with clinicians. The first version of the transcript that patients receive is generated automatically. Usually, it contains transcription errors. Therefore, our research team uses the researcher-facing web platform (explained in the next section) to fix the errors in the transcripts. Before they can access the transcript, patients need to press a button to acknowledge that they understand the possibility that the transcript might contain transcription errors, even after human verification (Figure 18).
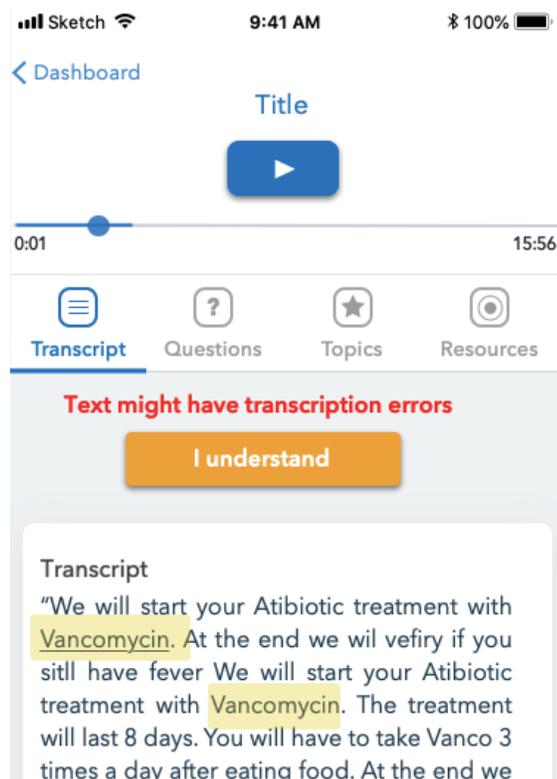
Figure 18. NURI patient-facing notes.

- **Topics:** NURI offers patients a list of the topics they discussed with their clinicians. This feature aims to reduce the cognitive load involved in finding specific topics. Instead of reading the whole transcript, patients can read and/or listen to specific parts (Figure 19, left screenshot).
- **Questions:** This feature offers patients a list of the questions they asked during the conversation to help them read and/or listen to the question and the answer again (Figure 19, middle screenshot).

- **Resources:** This feature gives patients relevant educational links to key topics discussed in the conversation. The topics, questions, and educational material were added manually by our team through a web platform that supports the NURI app (Figure 19, right screenshot).
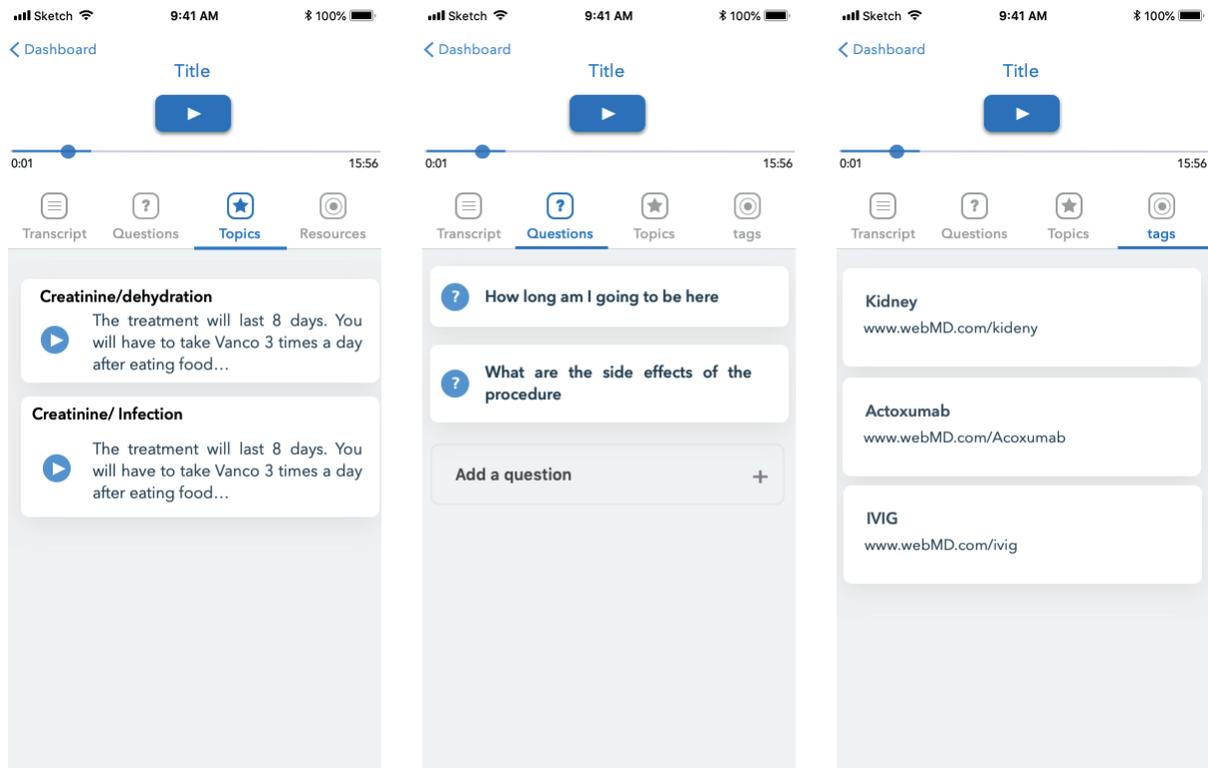
Figure 19. NURI design: topics, questions, and resources.

3.2.1.3   NURI backend

NURI is an iOS application that works in sync with a web application. To generate patient-facing notes, the NURI team (Will Kearns, Chen Chieh, Daniel Lee, and myself) built a backend service to record, transcribe, and annotate patient-clinician conversations.

For the transcription process, we used the Google Cloud Speech API[1] to turn the conversation into timestamped, tokenized text. Furthermore, Will Kearns developed a clinical language understanding (CLU) pipeline using Unified Medical Language System (UMLS)[2] to highlight

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[1] Google Cloud Speech API - Powerful Speech Analysis

[2] https://www.nlm.nih.gov/research/umls/index.html

medical terms in the transcripts (Figure 20). This service was built by Will Kearns to highlight the medical terms in the transcripts of patient-clinician conversations. Furthermore, Chen Chieh and Daniel Lee, in addition to building the patient-facing app, built a researcher-facing platform to manage the annotation of the transcripts. This web platform was built to correct mistakes in the transcript and to annotate topics and questions in the conversations. Once the changes are submitted, the researcher-facing platform sends the updated information to the patient-facing iOS app.
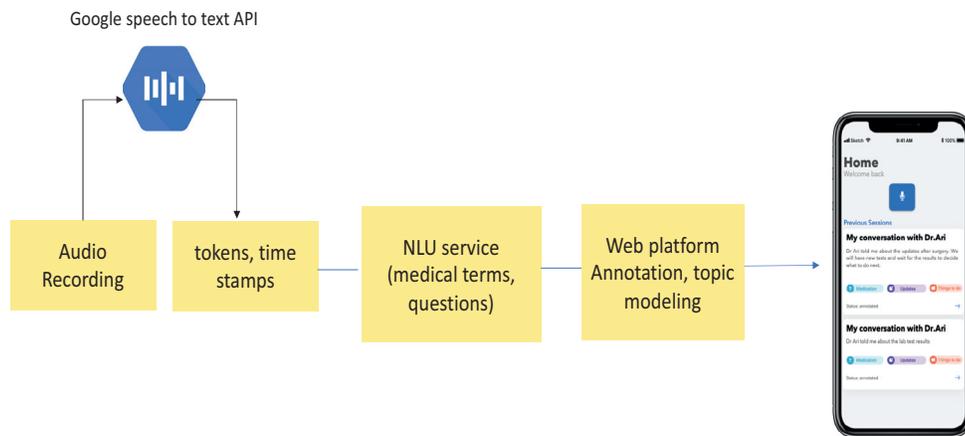
Figure 20. The NURI backend.

3.2.1.4   Researcher-facing web platform

We built a researcher-facing app as a part of the NURI service to help researchers access the transcripts, correct the transcription errors, and annotate the medical conversations by identifying the topics, highlighting the questions, and adding relevant resources.

During the annotation process, the research team generated topics manually for all transcripts. In particular, we split the text into short paragraphs and added a title that highlighted the key terms in each paragraph. For example, a title could be "The part about: new antibiotic." We highlighted the keywords in this way to easily generate titles without adding biases or interpretations.

3.3   NURI STUDY METHODS OVERVIEW

I used NURI as a technology probe to understand the needs of hospitalized patients. I tested NURI with patients, their caregivers, and their clinicians in Virginia Mason Hospital and Seattle

Children's Hospital. In this section, I present the processes for recruitment, using the prototype during a hospital stay, data collection, and interviewing the participants. The data analysis is detailed in chapter 4.3 and chapter 5.3 to highlight the analysis conducted to fulfill aim 2 and aim 3. The study was granted an IRB approval by the Human Subjects Division at the University of Washington.

3.3.1   *Recruitment process*

First, I recruited clinicians working in Virginia Mason Hospital and Seattle Children's Hospital. Then, I recruited the clinician's patients who were at least 7 years old and/or the patients' family caregivers. Individuals were excluded if they were not proficient in the English language. Patients were also excluded from the study procedures if they were not physically able to participate in a conversation about their care; were disoriented in person, place, or time; or were not recommended for inclusion by the attending staff.

I collaborated with the participating clinicians to identify potential patients for the study. Once a potential patient was identified, a research coordinator approached the patient during a convenient time and explained the research process and the potential risk. Patients and/or family caregivers provided written informed consent to allow us to shadow their clinicians and record at least one of their conversations with their care team. Patients and/or family caregivers also agreed to use the NURI app, answer a pre-survey, answer a post-survey, and participate in a 45–60 min audio-recorded interview.

3.3.2   *Process for using the prototype during the hospital stay*

Once both the clinicians and participants consented, a team member shadowed the clinicians during their meetings with the participating patients. At the beginning of each meeting, the researcher or clinician reminded the participants about the study and asked them to confirm that they still wanted to proceed with the recording. I recorded at least one medical conversation for each patient. I conducted a brief training session to familiarize the participants with the iPad and the NURI app. Then, I provided them with an iPad to revisit their transcripts. A team member visited the patient and their family to make sure that they understood how to use the NURI app. The researcher used antiseptic wipes to clean the iPads between uses.

In case of technical problems occurring in the iOS app, I provided the patients with secure links to their audio recordings and transcripts via Microsoft Business OneDrive, which is a HIPAA-compliant cloud service.

3.3.3   *Data collection*

In this section, I highlight the data I collected from the patients, caregivers, and clinicians in the NURI study. First, I present the patient and family caregivers' data, which was collected through one-on-one interviews and surveys. Then, I present the clinicians' data, which was collected through one-on-one interviews.

3.3.3.1   Patients and family caregivers' data

After using the app to record and review at least one conversation, I interviewed the patients and their family caregivers in their hospital rooms. The interviews lasted between 45 and 60 min and consisted of two parts: an annotation exercise and an assessment interview. Moreover, I asked the patients to answer two surveys: a pre-test survey before using NURI and a post-test survey after using NURI. In this section, I present the patients and family caregivers' NURI assessment interviews, the patients and family caregivers' annotation exercises, and the patients and family caregivers' surveys. The interview scripts are attached in Appendix B and the survey questions/answers are attached in Appendix C.

Patients and family caregivers' NURI assessment interviews

In this part of the interview, I asked the participants open-ended questions about the impact of NURI on their hospital experience. The questions included the following: In what ways did you find Nuri helpful? Do you have any examples of that? In what ways did you find Nuri not helpful/harmful? Do you have any examples of that? How comfortable were you using NURI? How comfortable do you think your doctors and nurses were with you using NURI?

Patients and family caregivers' annotation exercises

During this part of the interview, I reviewed a transcript generated by the prototype with each participant. First, I invited the participants to read their transcripts. Then, I asked them to reflect on the importance of the topics they discussed with their clinicians. Finally, I asked the participants to consider how they would summarize and simplify the transcript (Figure 21).

The script for the patients' and family caregivers interviews, including the assessment interview and the annotation exercise, is detailed in Appendix C

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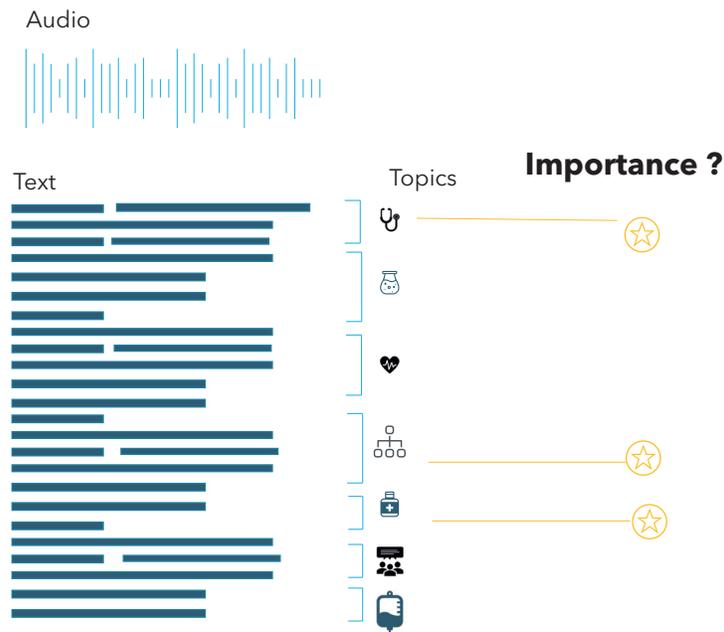
Figure 21. Annotation exercise.

Patients and family caregivers' surveys

The patients and caregivers completed a survey before and after using our application. The first survey had questions about demographics, the friendliness of the technology, and their ability to recall and understand the medical conversations. We used SurveyGizmo to collect the survey data. (The survey questions and answers are attached in Appendix B.)

3.3.3.2 Clinicians' data

After using the app to record and review at least one conversation, I conducted one-on-one interviews with the clinicians that lasted between 30 and 60 min. Each interview consisted of two parts:

Clinicians' NURI assessment interviews

I conducted the same assessment interviews with the clinicians as I did with the patients and their family caregivers. The questions included the following: In what ways did you find Nuri helpful? Do you have any examples of that? In what ways did you find Nuri not helpful/harmful? Do you have any examples of that? How comfortable were you using NURI?

Clinicians' annotation exercises

I conducted the same annotation exercise with the clinicians as I did with the patients and their family caregivers. I went through at least one of the transcripts that I recorded with them. I asked the clinicians which information they found valuable, what external links they would recommend to explain the technical terms in the transcripts, and how they would summarize and simplify the transcript.

The script for the clinicians interviews, including the assessment interview and the annotation exercise, is detailed in Appendix C.

3.3.4   *Participants*

A total of 31 people participated in our study across the two sites: 22 patients/caregivers and 9 clinicians (4 attending, 1 surgeon, 1 fellow, 2 residents, and 1 med student). The 22 patients for the study included 10 hospitalized adults, 5 hospitalized children and their caregivers, and 7 adult patients, all of whom were recruited through pre-hospitalization clinic visits. I recorded at least one medical conversation for each patient. Not all patient participants completed the entire study. The participation details are listed below:

- Pre-survey + recording (22 participants)
- In-person interviews: (19 patients): For the other 3 interviews, which were with adult patients, technical challenges with the application forced the clinic visit to end early.
- Post-survey (15): Seven post-surveys were left incomplete for the following reasons: 1 technical issue, 3 drop-offs, 2 patients who could not use the app and received audio and text summaries, and 1 patient who could not complete the survey due to a worsening clinical condition.

Our recruitment methods focused on maximizing the diversity of the participants in regard to age, gender, ethnicity, and medical/surgical care services. Figure 22 shows the age distribution of the patients and family caregivers. Table 4 and Table 5 show the ethnicity and gender distribution of the patients.

Value	Percent	Count
25 to 34	11.8%	2
35 to 44	17.6%	3
55 to 64	35.3%	6
65 to 74	23.5%	4
75 or older	11.8%	2
	Totals	17

Value	Percent	Count
7 to 12	20.0%	1
13 to 17	40.0%	2
18 or older	40.0%	2
	Totals	5

Value	Percent	Count
35 to 44	40.0%	2
45 to 54	20.0%	1
55 to 64	20.0%	1
65 to 74	20.0%	1
	Totals	5

Virginia Mason

Seattle Children's
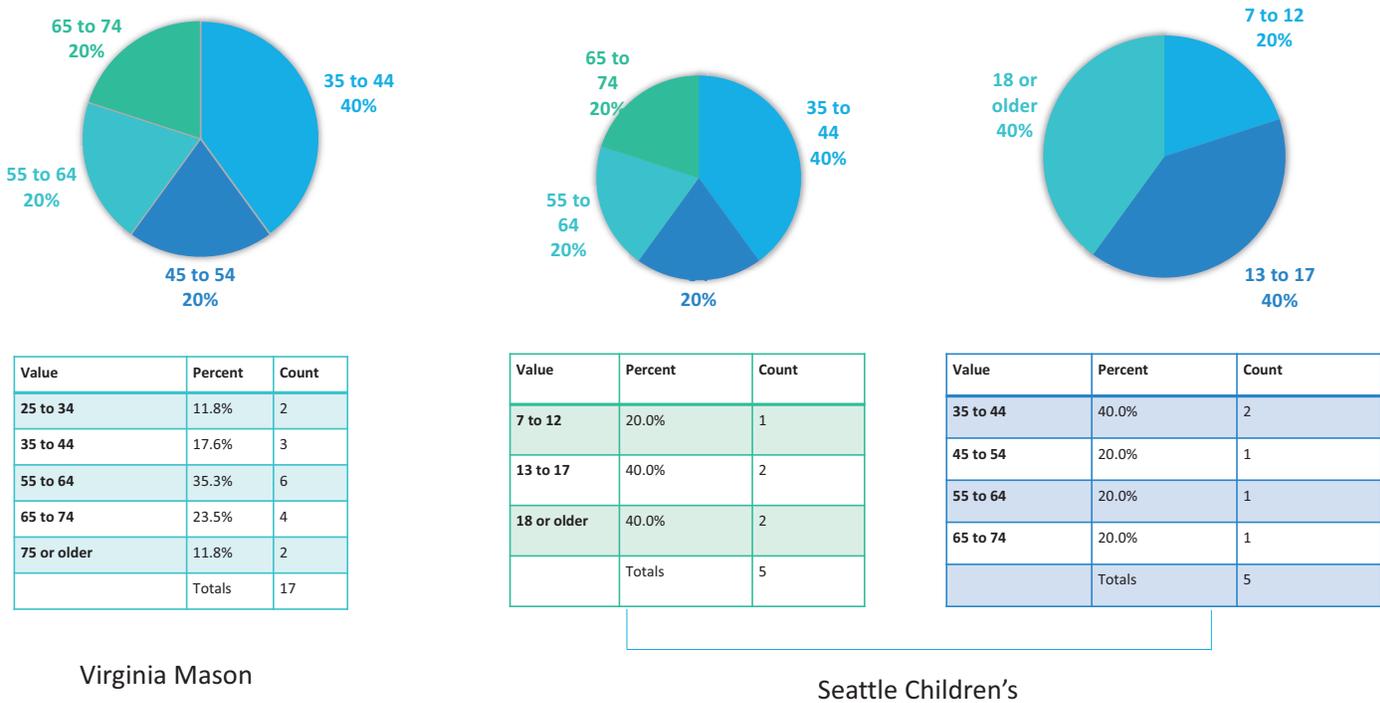
Figure 22. Age distribution of participants.

Table 4. NURI study ethnicity distribution (Select all that apply)

Value	Percent	Count
Native Hawaiian or Other Pacific Islander	4.5%	1
Black/African-American	4.5%	1
White	86.4%	19
American Indian/Alaska Native	4.5%	1
Write In	4.5%	1
Prefer not to answer	4.5%	1

Table 5. NURI study gender distribution

Value	Percent	Count
Male	40.9%	9
Female	54.5%	12
Transgender	4.5%	1
	Totals	22

Note: In the next sections, the participants' IDs are divided into 4 sections:

[Study. Hospital_code. Category. Participant_number]

- Study: N for NURI
- Hospital code: "SCH" for Seattle Children's Hospital and "VM" for Virginia Mason Hospital
- Participant category: "P" refers to the patients and family caregivers. "Dr" refers to the participating clinicians.
- Participant number = 2-to 4-digit number

In the next two chapters, I report the results of the NURI study (Figure 23). In Chapter 4, I detail the results of the annotation exercise. I report the patients', caregivers', and clinicians' perceptions on which kinds of information in medical conversations are important. Furthermore, I generate an annotation framework to help turn patient-clinician conversations into patient-facing notes. In Chapter 5, I summarize the results of the NURI assessment interviews to highlight the impact of NURI on our participants' hospital experiences. I detail NURI's acceptability and perceived usefulness as reported by patients, caregivers, and clinicians. Then, I make design recommendations to mitigate the risks and support the benefits of using NURI.
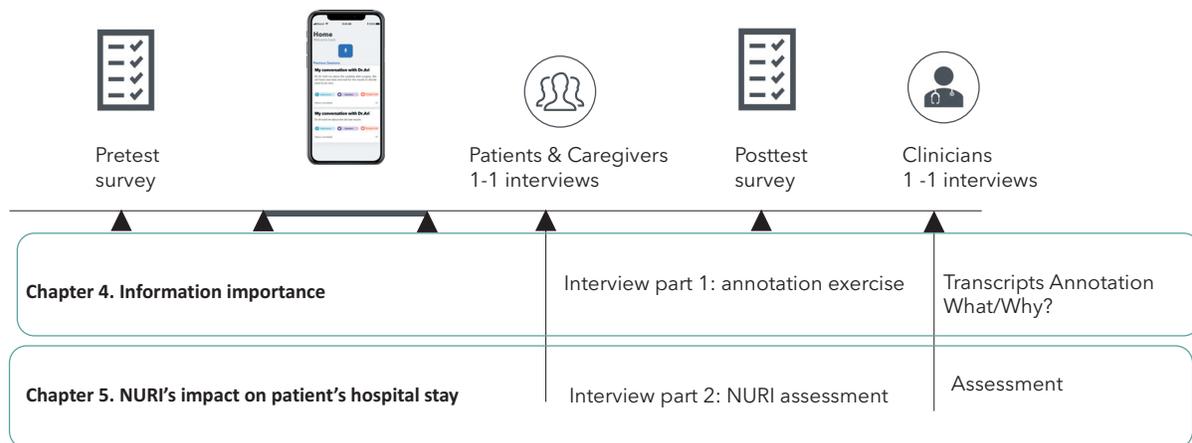
Figure 23. NURI study summary.

Chapter 4. TOWARD AUTOMATIC ANNOTATION OF THE PATIENT-CLINICIANS' BEDSIDE CONVERSATIONS FOR PATIENT USE

In this chapter, I report the patients', caregivers', and clinicians' perspectives on the importance of different types of information in medical conversations within hospital settings. Next, I define the factors that influence participants' perceptions of informational importance. Then, based on these factors, I build a framework to annotate medical conversations at the bedsides of hospitalized patients. Using this framework, I also provide guidance on labeling the information in patient-clinician conversations for researchers and developers generating patient-centered notes. Furthermore, I provide design guidelines for using the annotated data and specify the patients', caregivers', and clinicians' wishes for future artificial intelligence (AI) applications documenting medical conversations. Finally, I provide design guidelines for addressing these wishes.

4.1 ABSTRACT

Clinical speech processing represents a promising approach to helping hospitalized patients remember and understand their conversations with clinicians. Such technologies can automatically turn verbal medical communications into searchable audio notes and summaries that patients and their family caregivers can access at their convenience. While most research efforts are focused on turning these conversations into clinical notes and billable codes to reduce clinician burnout, researchers lack the guidance to generate notes that patients can use. Thus, in this chapter, I apply a user-centered approach to study patients' and clinicians' perspectives on the importance of verbally communicated information in hospital settings. To this end, I conducted a technology probe study of NURI, an app that generates transcripts, topics, and resources from patient-clinician conversations. Then, I interviewed patients, caregivers and their clinicians to annotate the recorded medical conversations. Finally, I report their perspectives on the importance of different types of information.

4.2 INTRODUCTION

Holding patient-clinician conversations at patients' bedsides to inform them and their family caregivers about their care progress is the standard of care. In these conversations, clinicians and patients exchange key information about the patients' health problems, medications, lifestyle changes, plan of care, and more. Unfortunately, it remains challenging for patients and their family caregivers to remember and understand the details of these numerous verbal exchanges. These challenges can come from their unfamiliarity with the technical jargon, the length of the conversations, and their cognitive impairment from their pain and treatments (Unruh, Skeels, Civan-Hartzler, & Pratt, 2010). Furthermore, the challenges can grow for patients who require unfamiliar and complicated treatments and procedures managed by an expanded team of clinicians. Research shows that patients forget up to 80% of what their clinicians tell them, and they incorrectly report 50% of what they do remember (Bradshaw, Ley, & Kincey, 1975; McGuire, 1996; Schuller, Rigoll, & Lang, 2003). Thus, patients' perceptions of the current course of their treatments might not match their clinicians' plans and could lead to communication breakdowns. These miscommunications can also lead to several undesirable outcomes, such as poor clinical outcomes, lower satisfaction with care, and malpractice lawsuits (CRICO, 2015). In addition, patients who aim to engage in their care actively will remain powerless, as they will lack an accurate perception and understanding of their progress or memory of their verbal exchanges with their clinicians.

AI, especially natural language processing (NLP) technologies for semantic searching, question answering, machine reading, and semantic indexing of audio files, could help patients remember and understand their bedside conversations. Such technologies could capture patient-clinician conversations and provide AI services so that patients can have better access and comprehension of what their clinicians have told them.

To my knowledge, no research to date has focused on generating patient-centered notes from medical conversations. Thus, this work represents the first step in automatically generating patient-centered notes from medical conversations and augmenting the notes with patient-centered AI applications. Several other research efforts have also extracted medical information from patient-clinician conversations, but these efforts have primarily focused on obtaining clinical notes to reduce clinician burnout (Arndt et al., 2017) and free them from the burden of entering medical

notes into EHRs (Finley et al., 2018; Shafran et al., 2020). In contrast, the medical context that patients need these notes for is different from the billable context that physicians create the notes for (Mishra et al., 2016).

Therefore, I applied patient-centered research methods to understand how to turn medical conversations into patient-centered notes and developed "NURI," a prototype that can record, transcribe, and annotate medical discussions between patients and clinicians in hospital settings. Then, I invited patients, caregivers, and clinicians to annotate the transcripts of their conversations by highlighting the critical information and explaining the reasons why they perceive those pieces of information as essential. Moreover, I asked all participants to reflect on their technological needs so that I could simplify the accessibility of the information for the patients. From these results, I created a framework to annotate patient-clinician conversations at the patients' bedside and to improve their usefulness to patients and family caregivers. Furthermore, I provide design guidelines for using the labeled data and for designing applications that can help patients understand their conversations with their clinicians.

4.3 METHODS

As explained in Chapter 3, I conducted a probe study in Seattle Children's Hospital and Virginia Mason Hospital in the Seattle area. I tested NURI, a service that can generate transcripts from patient-clinician bedside conversations, and highlighted the topics, questions, and medical keywords in the conversations. Then, I conducted a think-aloud annotation exercise with the patients, caregivers, and clinicians. In particular, I asked the participants to identify the information that they perceived as important and to describe why they thought that information was important. In this chapter, I focus on the results of this annotation exercise (Figure 24).
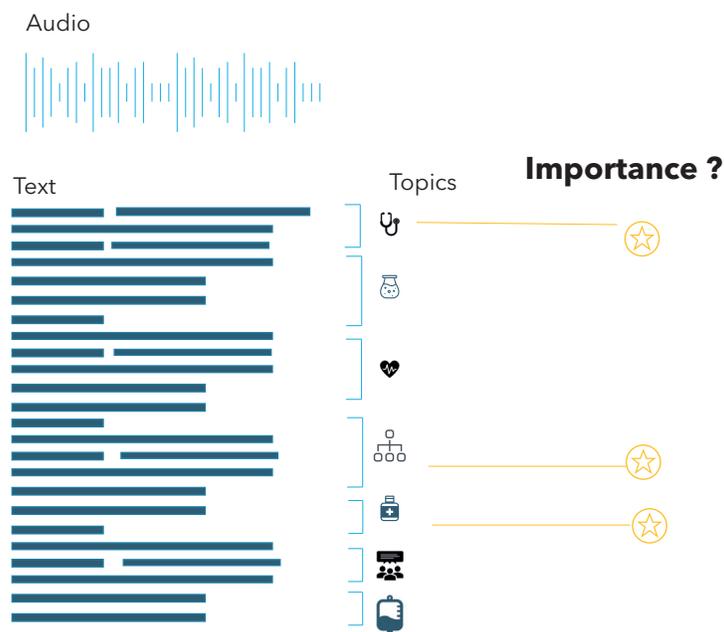
Figure 24. Annotation exercise.

4.3.1 *Qualitative analysis*

We used a professional service to transcribe the audio-recordings of our interviews with the participants. We imported the transcripts into Atlas.ti Version 8.4.4 for a thematic analysis. Two authors with training in qualitative methods analyzed the transcripts in multiple steps.

- *Qualitative analysis of the patient and caregivers' interviews*

The two coders (Emily Bascom and I) started by coding the patients' and caregivers' interviews. First, they independently analyzed the transcripts of five patient interviews (one-third of the interviews) to identify the themes regarding the patients' perspectives on the importance of different types of information. The coders and the PAS research team met regularly to review and iterate the codebook until reaching a consensus. Then, the two coders examined each other's work. Any discrepancies were discussed and resolved.

- *Qualitative analysis of the clinicians' interviews*

The coders followed the same process for the qualitative analysis of the coded physicians' interviews. All team members reviewed the coding procedures to ensure the dependability and credibility of the results.

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4.4 RESULTS

The qualitative analysis produced two main findings that are discussed in this section. First, I identify the factors that define which information in medical conversations is important for patient use from the patients', caregivers', and clinicians' perspectives. Second, I discuss the stakeholders' wishes for future speech processing and AI applications documenting bedside conversations.

4.4.1 *The factors that define informational importance*

In this section of the results, I identify the factors that influenced the participants' perceptions of a piece of information's importance. To this end, I analyzed all participants' feedback and identified the characteristics that defined the importance of the topics discussed between the patients and their clinicians. Based on this data, I identified three types of factors: information quality factors, patient-independent factors, and patient-dependent factors. The quality factors described the data, particularly the accuracy and validity of the data. The patient-independent factors were related to the clinical situation independent of the patient's background, particularly the novelty, utility, and criticality of the information. The patient-dependent factors related to patients' knowledge gaps and emotional value[1] (Figure 25).
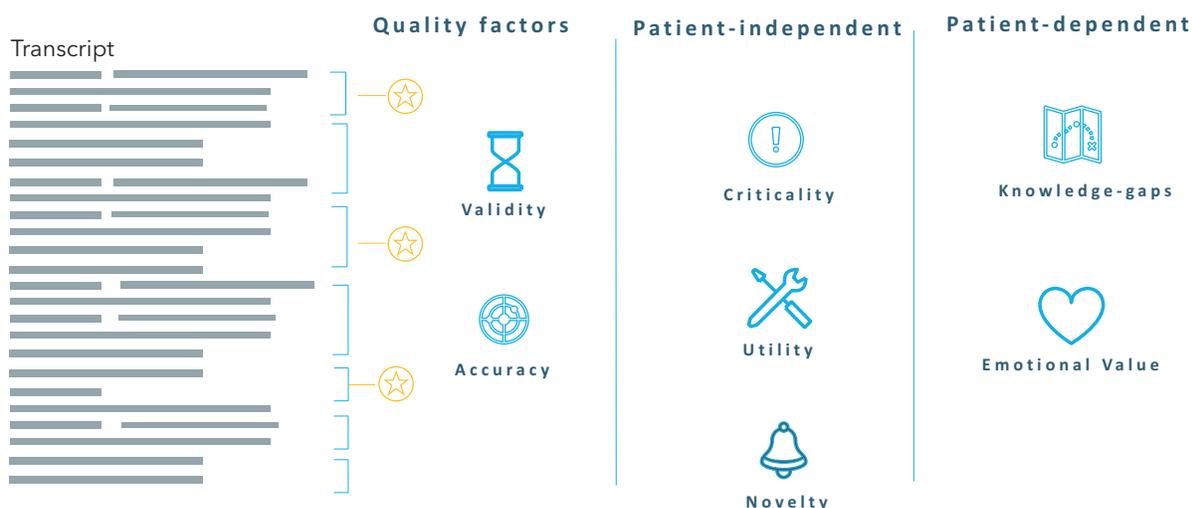

Figure 25. Importance factors.

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[1] The emotion value refers to the emotional perception of the information of being pleasant, neutral, or unpleasant for the patient

4.4.1.1 Quality factors

The quality factors related to the accuracy and validity of the data. They were metadata about the quality of the information communicated in the medical conversations.

- **Accuracy:** Is the data the right value?

Clinicians sometimes express uncertainty about the accuracy of the data given during their conversations, and clinicians reported that the accuracy of the information affected their perceptions of its importance. They believed there was no need to remind the patient of inaccurate or approximate data that were shared at their bedside. For example, a clinician might state that the patient's renal function is getting better and blood creatinine levels are getting close to normal. However, the clinician might forget the exact value of the creatinine and give a best guess. On this subject, one participating clinician at Seattle Children's Hospital noted the following:

> N.SCH.Dr.01: *"I feel like me personally, those types of little **details, like what was their weight today or what was their creatinine today** or what was their calcium today – if I am in a room and I'm not actively looking at the computer, those are the **small things I'm much more likely to be like oh, I think it was about this,** and then I wouldn't want that to cause confusion for the families"*

Inaccuracies might also happen when sharing information about other team members' work. Clinicians might express their thoughts about the most likely next steps in the patient care, but that might not be the way it works out; for that reason, they might want to deemphasize any statements made about uncertain care plans.

Moreover, patients and their caregivers can be presented with contradictory information. For this reason, the clinicians felt that NURI should be able to reconcile these discrepancies. For example, with future NLP and speech processing work, NURI could be connected to a patient's EHR data to verify and correct lab values. Furthermore, these inaccuracies could be captured from the clinician's speech if the clinicians express uncertainty by saying things like "*I think it was about this*" or by triggering a verification process by saying "Hey NURI, please verify the following."

Of note, our participating patients and family caregivers did not report accuracy as a factor in informational importance.

- **Validity**: Is the data still valid?

The validity of data changes over time. For example, old test results will not be valid when newer test results are available. The patients, caregivers, and clinicians in this study reported that the

validity of a piece of information defined its importance, because once data is invalid, it becomes less relevant to the current status of the patient's health and future care. The state of a patient's health, diagnosis, and treatment is often dynamic during a hospital stay. Thus, the information that is exchanged between patients and their clinicians is always evolving. With new information comes new interpretations of the information, leading to new decisions regarding the patient's care plan. These conversations are essential for improving the effectiveness of the patient's care, making the validity of the information exchanged extremely important. The clinicians worried about the potential of invalid information creating confusion for their patients.

Furthermore, the patients and family caregivers felt that invalid information was irrelevant. For example, clinicians had to cancel important medical follow-ups for Patient N.VM.P.7914 and that patient's caregiver because a new medical situation emerged that required a different plan.

> **N.VM.P.7914** "It ended up not being important because the real information wasn't ……… so by the time we got close to the date, like now, Dr [name] makes a very informed decision and tells us not to go."

4.4.1.2   Patient-independent factors

The patient-independent factors relate to the clinical importance of the information, independent of the patient's background. The patient-independent factors are the novelty, utility, and criticality of the information. In contrast, the patient-dependent factors (explained in 4.1.3) are linked to the patient's profile: specifically, their knowledge gaps and emotional values.

The patients, caregivers, and clinicians valued the clinical aspects of their bedside conversations, as those aspects were more directly related to the care progress. However, clinicians commonly spend time socializing with the patients and their family members. For example, the clinicians might joke with patients and discuss hobbies and movies. While these social interactions are very appreciated by patients, they are not perceived as essential.

Both the patients and clinicians felt the same about these social interactions and agreed that they could be discarded from the transcripts, stating that only clinical information should be processed and annotated. In addition, the participants reported that the novelty, criticality, and utility of a piece of information determined its importance.

- **Novelty: Is the information new?**

The patients and caregivers expressed great interest in information that was new or provided a clinical update because it helped them stay up to date with their care progress. In particular, the patients felt that having access to new information was critical to being more in control and involved in the decisions about the course of their care. During the course of a patient's care, a clinician usually gives several updates, such as lab results and changes to a patient's care plan. This news is some of the most valuable information patients receive, as it keeps them informed and allows them to take proactive steps in working toward being discharged. Once this information becomes old news, it loses its importance, other than for potential longitudinal tracking of the patient's hospitalization. For example, after listening to a conversation that they missed in person, the caregiver of Patient N.VM.P.0218 did not see any value in re-listening to the things they knew before. Therefore, they thought that some parts of the audio recording could be deleted so that they could focus on the new updates.

N.VM.P.0218: *"Well, it's kind of what I heard before, though. Clinicians kind of have the same message."*

However, the caregiver saw a huge value in listening to updates about the care team's work. After listening to the updates, they realized that they do not need to give the patient any heartburn medicine since the care team already took care of that.

N.VM.P.0218: *"Just because they're maybe upping his heartburn medicine. I wouldn't have known that without reading that, for him. Because he was saying he's having really bad heartburn. It just helps to know, because I went to get him some more – just what I had in my car, just over the counter stuff, and he said no, that they were giving him some, and I wasn't sure he was comprehending what the doctor was going to do, so by me reading this, then I can say okay, we don't give you none of that"*

- **Utility:** Is the information useful?

Patients, clinicians, and family caregivers reported that the utility or practical aspect of each piece of information was a significant factor in defining the importance of the information. The clinicians, patients, and caregivers noted several practical values that could make a piece of information important, particularly if it helped in: understanding care, supporting decision making, improving planning, supporting safety, evaluating progress, planning, and providing instructions. Information with these utility aspects allowed the patients and caregivers to have a better understanding of the treatment plan and to play an active role in the patient's care. In Table,

I summarize the utility aspects reported by the participants and I provide examples of the participants' quotes.

Table 6. Information utility and participants' quotes

Utility subtypes	Quotes
Understanding care One clinician emphasized the importance of information that helps patients understand their care progress, as that information can help patients feel that their care is advancing.	N.SCH.DR.04: *"....I still think that's helpful to families because oftentimes they get so much information during the 15 minutes or whatever we spend with them, it's easy to forget what are we watching for today? What are they going to do? What tests am I going to be expecting? So if they had that well delineated, it would be helpful for them. And I feel like their care is advancing."*
Supporting decision making N.VM.P.19, an adult patient, felt that information that helped in making informed treatment decisions was very important. For example, part of the patient's discussion with a surgeon concerned the pros and cons of a surgery and, thus, was very important in the decision-making process.	N.VM.P.19: *"No, it's going through the checklist of things I had. It was nice because this will be my fourth surgery in two years. I don't want to have any more surgeries, but it's sort of a pro and cons list. It's nice to just have that there to be like look, you do qualify for this, it is recommended. Here are the reasons why. That's handy for me to have to sort of – no one wants to get an unnecessary surgery, no one wants to go through that if they don't have to. So to have that like – no, here are some legitimate reasons you should have this? That's helpful."*
Improving planning Patient N.VM.P.780 highly valued any information that helped with treatment planning. Since the patient was going through recovery and was feeling disoriented, having	N.VM.P.780: *"Yes. I think it's important for there to have – I just want to know that I need these things done by then. How long in between can I really wait? Because who knows when they're going to be available, who knows that I'm going to go home and still be in a fog maybe for a couple of*

access to this kind of information helped with planning the next steps of the treatment plan.

days. Who knows. The procedure that I've had, depending upon how each of us recover differently. But if that's something that you need to see them within the week, I'm going to want to know that right away."

Supporting tracking	N.SCH.P.04:
N.SCH.P.04, a child patient, reported creatinine values as a very important indicator of care progress. Thus, the patient perceived any information that helped in tracking creatinine values as very important.	*"Especially with my condition and everything, my creatinine is my kidney function so it's like the most important thing we're watching, and having the numbers, we were talking about 2.9 and 2.4, how my creatinine was raising but we're trying to get it back down to where it's supposed to be, like .7 to .9. As it goes up, it's showing my kidney function failing so they're really big important of what we're watching out for. It's big indicators of like my condition coming back. So creatinine is always the biggest important thing we talk about with me, creatinine and blood pressure."*
Supporting safety	N.VM.P.780:
N.VM.P.780 described clinician warnings and safety tips as very important, since that information helped patients avoid any behavior that could hurt their recovery.	*"... Important that she came back with a warning for me. Don't lift heavy things. That's what I walked away with. Now here's the part – she told me there were two things. She told me don't lift heavy things.*
	……. Yes, please. [plays audio] So for me, being reminded, the second point was only take Tylenol. Because they'd been giving me aspirin here, thinking it was a heart issue, but that can cause leaks because the walls are thin where they've done it. So not taking the Tylenol, or only taking Tylenol is a really critical piece of recovery and – I forgot it already. That's something I knew from Day 1 from the surgery, and I still forgot it. "

	..So I think things like that, those really big bullet points, do not do this, do not do that. Those are pretty important to highlight in a significant manner."
Providing instructions Patients N.VM.P.7914 and N.VM.P.0918 felt that clinician instructions were very important. They valued having lists of things to do and explanations for why these steps were necessary.	N.VM.P.7914 *"I'm not speaking their language as far as what they do when they come in and do that discharge dialog, but maybe there's a certain protocol that's going to come in and then kind of mirroring what that looks like in here. Like here's your to-do, this is the follow ups we need, and then being able to also upload"* N.VM.P.0918 *"So more of a guide as to why things are happening the way they are and why I need to do what I need to do"*

- **Criticality**: Is the information critical?

The clinicians, patients, and family caregivers perceived the information that was more critical to the patient's care as more vital for the patient to recall and notice in the transcript. Some information is crucial in expediting recovery, avoiding readmission and treatment complications, and more. Thus, from the clinicians' perspective, it is essential that their patients understand the criticality of particular instructions. For example, N.VM.Dr.01, a clinician, discussed the symptoms that might indicate an urgent need for a patient to seek emergency care. During a bedside conversation, she verified that the patient and caregiver had understood the information. Moreover, the clinician emphasized the importance of the information.

> N.SCH.Dr.03: *"It's important because you want them to go home and be able to carry out the plan so that they can manage the treatment and the disease process at home, and not end up back in the hospital. You also want a kid to be safe, that's the big thing when they go home, they need to be carrying out the plan so they stay safe and can get the treatment they need."*

Thus, the clinician felt that NURI should highlight the criticality of this information in the transcript given to the patient.

Similarly, the patients such as N.SCH.P.04 and N.VM.P.780 valued any information that was critical to their care progress and wished the NURI app could help them highlight this information.

> N.SCH.P.04: *"I was talking how the numbers are really important for me with my condition, watching my different levels – being able to highlight that and put that aside. Like on this date, me and the doctor talked about my creatinine, it was on this number and we could put that into a folder."*

> N.VM.P.780: *so these are the things the doctor wants to talk about, A, B, C, like these are things you need to follow up."*

4.4.1.3 Patient-dependent factors

This section identifies the patient-related factors that affected the patients' perception of a piece of information's importance, including their knowledge gaps and emotional value.

- **Knowledge gap (Knowledge-based)**

The patients reported that their understanding and familiarity with the information presented to them impacted their perception of its importance. In particular, the patients had knowledge gaps when presented with new health information, such as new diagnoses, health procedures, and medical terms. Thus, they sought out information to help them understand this new information. Over time, the patients tended to develop expertise over their health information, making some of the information related to certain aspects of their health less critical.

> N.SCH.P.01: *"No, I find that actually really important because I like to understand as a parent, what does this medication do, how does it work and that kind of thing. So I find that important because – and my son had never actually had those. I knew kind of what they did, but the way he explained it to me was so nice, so I think that was important."*

Similarly, the clinicians felt that any information that could help their patients understand new health information was very important. N.SCH.Dr.05 noted that it is crucial to highlight new information that patients are not familiar with since this information could be easily forgotten or misinterpreted.

N.SCH.Dr.05:" *If we make changes in their medications, if we are starting new medications, those are things you always worry that might be something that doesn't get translated properly and they might go home with the wrong instruction or the wrong memory of what they heard. So if it's just continuing the normal care, that's usually not much of a problem. But any kind of new thing that we do, that can get missed.*"

- **Emotional value**

Our participating patients and caregivers valued any information that reassured them, such as information about their discharge date and good progress. Therefore, the information in the patient-clinician conversations associated with positive emotional experiences was valuable to the patients.

For example, N.VM.P.20, who was deciding whether or not to have a surgery, shared that having information about a surgery's risks and benefits helped in managing the emotions involved in the decision-making process.

N.VM.P.20: "*But listening to that this morning, it's like a little bit of reassurance instead of like well, do I need to have this done or can I live without getting the surgery?*"

Furthermore, the caregiver of N.VM.P.0218 stated that information about new treatments helped in feeling reassured during the decision-making process.

N.VM.P.0218*: "Yes, just to know that they were changing his medication. They finally found something that kind of is working. So yeah.*"

Moreover, the clinicians stated their belief in the importance of a piece of information's emotional value and wanted to highlight information that would enhance their relationships with their patients and strengthen transparency and trust. For example, the clinicians recommended keeping a record of the caregivers' and patients' complaints about the care team performance to review later. They felt that highlighting such parts could convey their transparency and lead to a better relationship. Furthermore, one clinician reported that fun interactions are important and should be highlighted, believing they could strengthen their relationship with their patients.

N.SCH.DR.3: "*I think it is important. I guess it just is more comfortable. It's less I'm the doctor, you're the patient, and I'm going to tell you what to do. It's more of a collegial, joint – I don't know, I have fun with my patients. It's part of what I like about my job. That's why I'm a pediatrician, not an adult doc so I can play with the kids and have fun*".

4.4.2 *Participants' wishes for AI improvements*

This section describes the clinicians', patients', and caregivers' wishes for better AI-powered services. In particular, I report the participants' desires for less transcription errors, speaker identifications, and better topic summaries and highlights.

4.4.2.1 Transcription errors

During the interviews, we asked the patients to discuss their feelings about transcription errors. Of note, the patients were aware of the technical challenges in turning speech into text. They often referred to the natural language processors that they were familiar with, such as Apple's virtual assistant, Siri, and how the transcriptions of voice messages spoken to these assistants were often flawed. In addition, the participants recognized that this technology still needed time to be optimized.

> N.VM.P.6414: *"When you talk to Siri and you say something, she doesn't answer you back right all the time, right? So there's always going to be that. But if you can listen to it and proof it, you're good to go. If you've got somebody that goes through and proofs it."*
>
> N.VM.P.01: *"I think it needs fine-tuning, but I think it is a really great start, really good. Having the audio files as well was really good."*
>
> N.SCH.P.04: *"Sometimes if we mumbled or weren't loud enough or clear enough, it kind of jumbles up some of the words. Other than that, there wasn't really anything else I would say was bad about it. Maybe going and understanding you're going to be using an app that's voice recording, to kind of speak up a little more clearly."*

Nevertheless, the patients expressed their wish for better speech recognition in the future. Moreover, they stated that having access to the NURI-indexed transcripts and being able to play the corresponding audio while reading the transcript could help with identifying transcription errors.

> N.VM .P.708: *"loved that you have the whole transcript, that I can hear it as well as see it. Even when it missed, the translation missed some stuff, it was clear enough that I could understand and follow along, and I felt that the segments pulled out surprisingly really important stuff."*

In contrast, the clinicians were especially worried about the potential for transcription errors. They felt that these errors could lead to misinterpretations of the information presented in a visit, which

could harm their patients. Therefore, N.SCH.Dr.01 recommends proofreading the transcript with the help of a human until speech to text technologies reaches a better performance.

> N.SCH.Dr.01: " ... *but my impression of where the technology is at, it might need a quick – like if the doctor says this, then at the end they can turn to their computer, and there it is and they can do a quick proofread. Even when we do our dictations on the phone, there's a person hearing them and transcribing them, and it's nice because sometimes if you add in too many "uh's" or have a run on sentence, they kind of sometimes will help you out there a little bit. But we still always review them at the end to make sure we agree with what we said and the type makes sense and everything. So it might be at this stage we'd still need that quick overview, but that takes no time – that's much quicker than typing it all out. You have a document, you look at it really quick, it looks okay.*"

4.4.2.2   Speaker identifications

Clinicians, patients, and caregivers wanted speaker identifications within the transcripts. When they were reading portions of the transcripts without context, it was often difficult for them to identify who was speaking. Such a feature could help separate the clinician from the caregiver and patient during the conversation and make the transcript more comprehensible.

> N.VM.P.708: *"Especially if you just did that general highlighting, like anytime the doctor talks it's typed in red and my language is typed in black and then you can still do the highlighting? That cuts down by 50 percent better"*

4.4.2.3   Better topic summaries and highlights

The patients and family caregivers also wanted better topic summaries from NURI, highlighting the knowledge and insights from their medical conversations. Furthermore, the participants hoped for more highlights related to urgency and criticality in the text. For example, one patient recommended highlighting the text with different colors to reflect the level of criticality. Some patients expressed their need for clinically verified summaries that could simplify the transcript.

> N.VM.P.708: *"I thought it would be neat if there would be a way that the things that you need to follow up on, if the doctor regulated things – so these are the things the doctor wants to talk about, A, B, C, like these are things you need to follow up. If those specific items were to be highlighted in say, red. Like an urgent color. Or green, like these are the*

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things that you need to really – this is what the doctor says, you're going to follow up with GI, follow up with bariatric."

Similar to the patients and their caregivers, the clinicians stated that adding summaries and highlights could help reduce the cognitive load of reading the transcript and ease the task of understanding the whole conversation. The clinicians also hoped the application could produce automatically generated discharge goals and to-do lists in the future, which could help emphasize the key points of their communications with patients. As clinician N.VM.Dr.01 explains,

N.VM.Dr.01: *"The benefit for my patient is like, especially the one we were discharging, like okay, she told me all this stuff I was supposed to do in follow up or were supposed to come back if something happens, but look, it's written right here, the doctor said that. So we're going to do that. Or very specific instructions on – oh yeah, we're supposed to take that medicine tonight and we're going to do it for four more days and it's going to stop. Very specific things."*

In addition, one clinician desired an innovative way for highlighting important topics: automatically generated teach-back questions. Teach-back is a method used to help patients understand their care by asking them questions about the conversations they have had with their clinicians. For example, a clinician might ask, "Which medication will you take?" Then, the patient must teach-back their clinicians what they learned about their care. This clinician was wondering if NURI could help patients exercise the teach-back methodology,

N.VM.Dr.01: *"Yeah, I don't know if the technology's smart enough to pull that out of what the residents tell them unless you could have like three pat questions, do I need a follow up lab test? Yes or no. And then if yes, can you tell me when or whatever. And then what symptoms do I call the doctor about or go to the ER. What symptoms do I seek medical attention? Some basic ones that they would fill out and then if they had their pads, they could turn in the pads when they leave"*

4.5 DISCUSSION

Based on the themes found in the analysis, this section highlights three implications for NURI's design. First, I utilize the importance factors highlighted in Section 4.4.1 to propose a patient-clinician annotation analysis framework. The framework aims to guide the annotations of bedside conversation transcripts and improve their relevance for patient and caregiver use. Second, I

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describe the design implications of the annotation framework for the NURI patient-facing app. Third, I utilize the results from Section 4.4.2 to provide further design recommendations that address the participants' feedback on how to improve the AI applications and help the patients use the information with fewer cognitive challenges.

4.5.1   *Patient-clinician conversation analysis framework*

Since the gold standard for NLP systems is to use human annotation to train the automatic speech understanding algorithms (Coiera, Kocaballi, Halamka, & Laranjo, 2018), I propose this framework for guiding the annotation process. Based on the importance factors identified in the results section, I have created a framework to annotate patient-clinician conversations and generate patient-facing notes (Figure 26). This annotation framework could be used to manually annotate conversations from the technology probe. Moreover, this framework could be used to train future AI systems to automatically or semi-automatically annotate conversations.
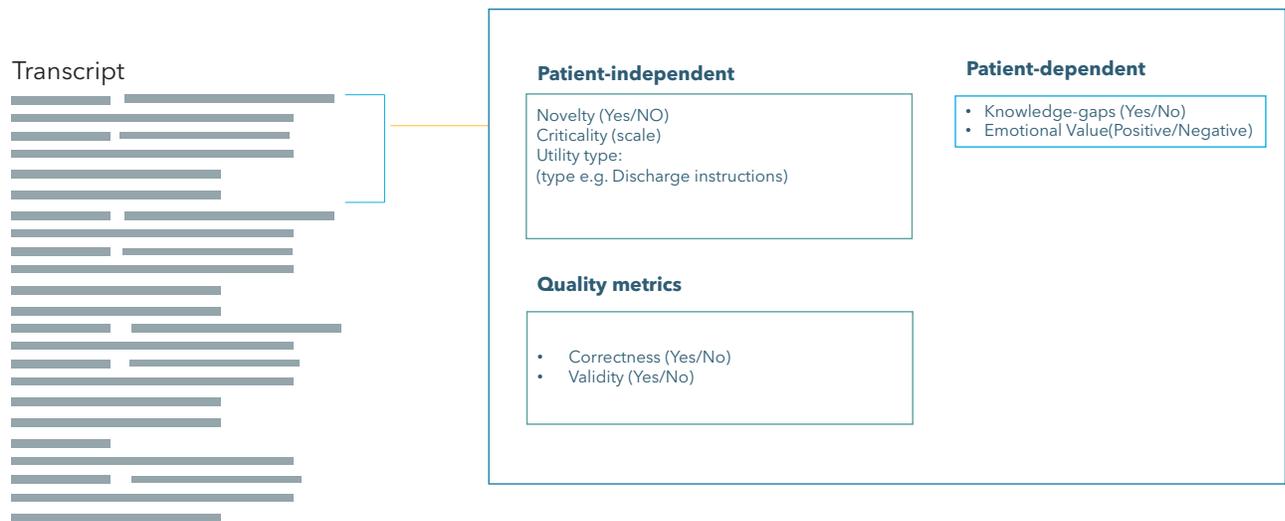

Figure 26. Analysis framework.

In the results section, the patients, caregivers, and clinicians in this study identified several factors that define the importance of a piece of information from a medical conversation. In Table 7, I explain how these factors could be used to annotate medical conversations.

Table 7. Annotation analysis framework

Factors	Explanation	Labels
Quality metrics	Annotator should verify the accuracy and validity of the information.	• Accuracy [Yes/No] • Validity [Yes/No]

Patient-independent factors	Annotator should assess the novelty, criticality, and utility of the information. For example, a clinician's instructions for recovering from surgery should be annotated as "Utility type: Instruction."	• Novelty
		• Criticality
		• Utility
		   ○ Understanding care
		   ○ Supporting decision making
		   ○ Improving planning
		   ○ Supporting safety
		   ○ Evaluating progress
		   ○ Planning
		   ○ Instructions

Patient-dependent factors	Annotator should identify the emotional value of the information (bad news/good news) and pinpoint potential new concepts to be explained to the patients. Patients should provide their feedback to validate these assumptions.	• Emotional value [Positive/Negative] • Knowledge Gap [New Concept]

During annotation, the quality factors (accuracy and validity) and patient-dependent factors (knowledge gaps and emotional value) require contextual information. For example, to be able to identify information that supports patients' knowledge gaps, the human or the machine annotator requires information about the patient's familiarity and knowledge with their health problems. However, these knowledge gaps can be inferred from the questions that patients ask during the conversations with their clinicians.

The patient-independent factors (novelty, criticality, and utility) could be annotated by capturing context clues from what the clinicians say when delivering news to patients or by highlighting the utility or criticality of the news.

Table 8 highlights several potential ways for identifying the importance factors in a transcript.

Table 8. Annotation framework support

Importance factors	Labeling tips
Is it novel? [Old/New] [Redundant/Unique]	• One way to define informational novelty is to analyze the clinician's speech and assess the linguistics used to announce the news to the patient. Example: o "I have some good news for you." o "We got back your lab results." • Another approach is to conduct a longitudinal comparison across the patient-clinician conversations.
Is it clinical? [Chitchat/clinical]	Annotator could identify non-clinical discussions between patient and clinicians such as chitchat and social interactions. However, it is essential to capture what patients will consider medical information to help them filter the conversation without losing topics of importance. Example: • "Are you enjoying any of the new shows on TV?"
Is it critical?	One way of capturing critical information is to capture the clinician's way of highlighting critical information in their conversations. Clinicians tend to emphasize things that they want the patient to pay attention to. Example: • "There are two things that I'm concerned about. One is your blood pressure, which is higher than I would like to see it." Another way to capture criticality is the medical context. For example, one patient said creatinine updates are very critical to them since they had a Kidney transplant.
What type of utility?	Annotators could capture the utility of the information from the context.

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Example:

- [Decision making]: "*Yes, and the Lisinopril you're off. Right now. So I am debating on starting either another longer acting blood pressure medicine. There is something called metoprolol.*"
- [Understanding care]: "Yes, but the one concern is I cannot comfortably send you home with it [creatinine] going up."

This proposed framework will help highlight the information from the conversation that matters the most to patients and clinicians. In the next section, I propose design features for the patient-facing app that could be developed based of this annotation framework.

4.5.2   *The design implications of the annotation framework for the NURI patient-facing app*

In this section, based on the annotation framework, I propose design features to add to the patient-facing app. For example, after annotating the medical conversation, we could display the data in new designs to help users access the information more easily. In particular, I present two design proposals: a filtering feature and Q&A agent.

- Filtering feature

The filtering feature illustrated in Figure 27 could help highlight specific topics for the patient, such as news, clinical data, and actionable information. After annotating the text and identifying the information that is most valuable for the patients from their and the clinicians' perspectives, we could create designs that will make it easier to find this information. For example, the filtering feature could highlight parts of the transcript to convey that information's criticality and utility (Figure 29). This design feature would answer the users' wishes for better topic summaries and highlights.
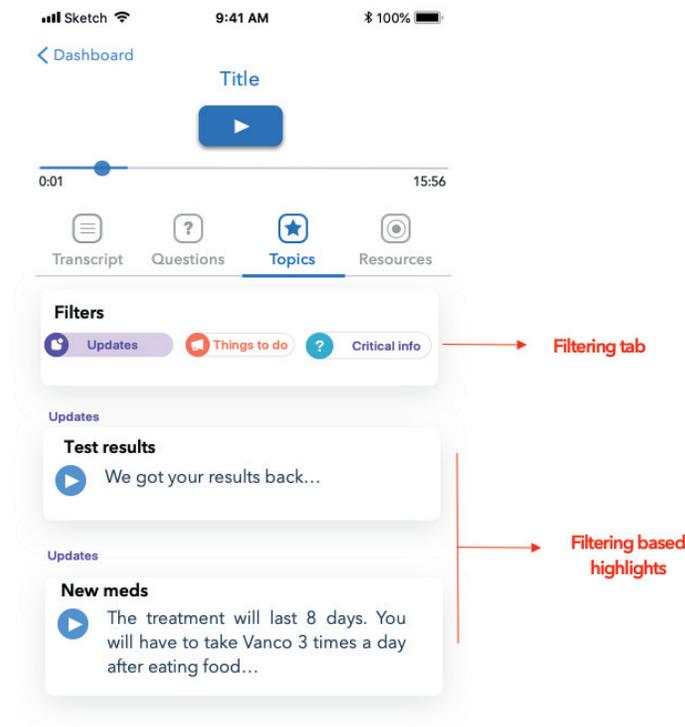
Figure 27. Filtering feature.

- Q&A agent

To make the filtering feature more accessible, especially for physically impaired patients, we could also build a question-and-answer function into the NURI app. For example, patients could ask questions like "Hey NURI, what did my doctor tell me to do?" (Figure 28), and NURI could pull up audio/transcripts annotated as "Utility type: Instruction" and play them back to the patient. By being voice-based, this feature could provide better accessibility to hospitalized patients.
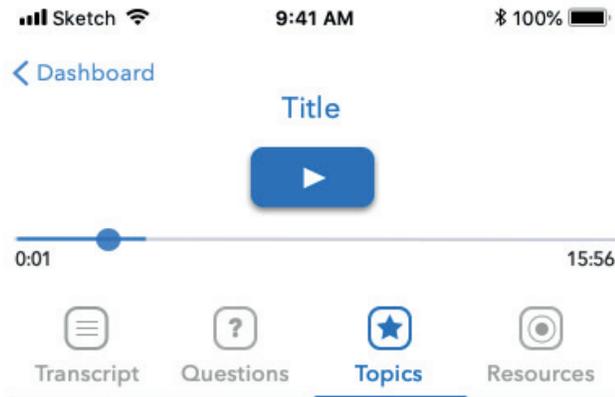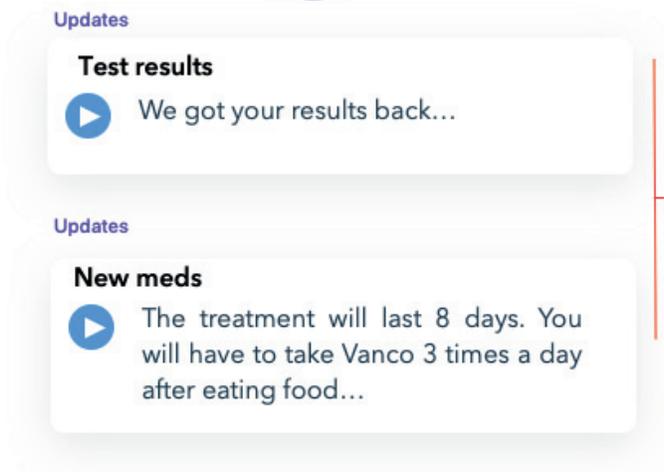
Figure 28. Q&A feature.

4.5.3   *Design features to provide better AI transcriptions*

While the patients did not mind that transcription errors were possible due to the current technical limitations of speech processing services, they did wish for fewer transcription errors. At the same time, the clinicians worried about the clinical impact of transcription errors. Thus, NURI could

hide the part of a transcription text that had a high error rate. The app could also offer patients a way to see these parts if they chose to and an option to play the audio part corresponding to the text and correct it or request human verification of it on their behalf if they wished. For example, in figure 29 to highlight and play text with high probability of transcription errors. In figure 30, I propose a feature to help users correct a transcription errors in their transcripts.
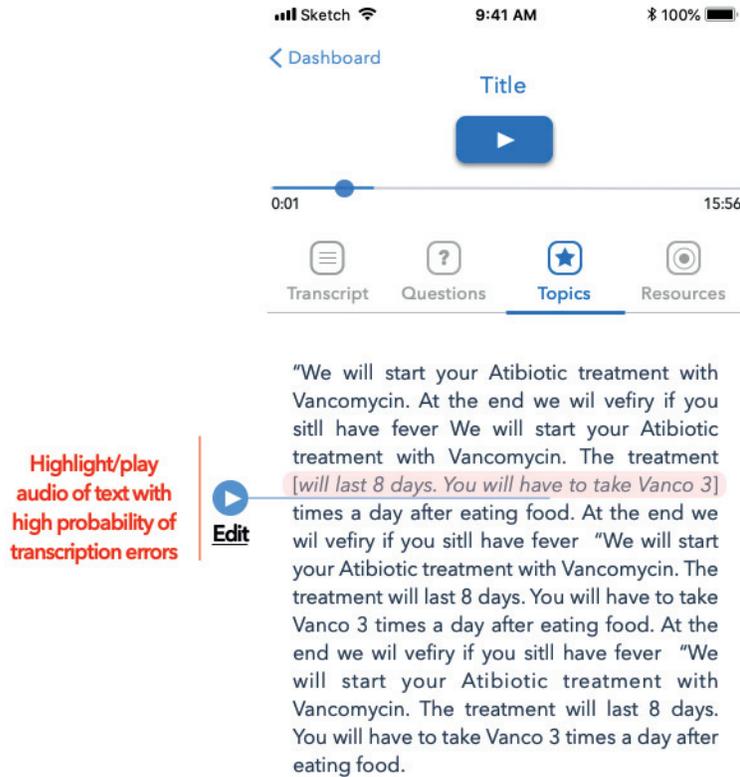

Figure 29. Highlight/play text with transcription errors.
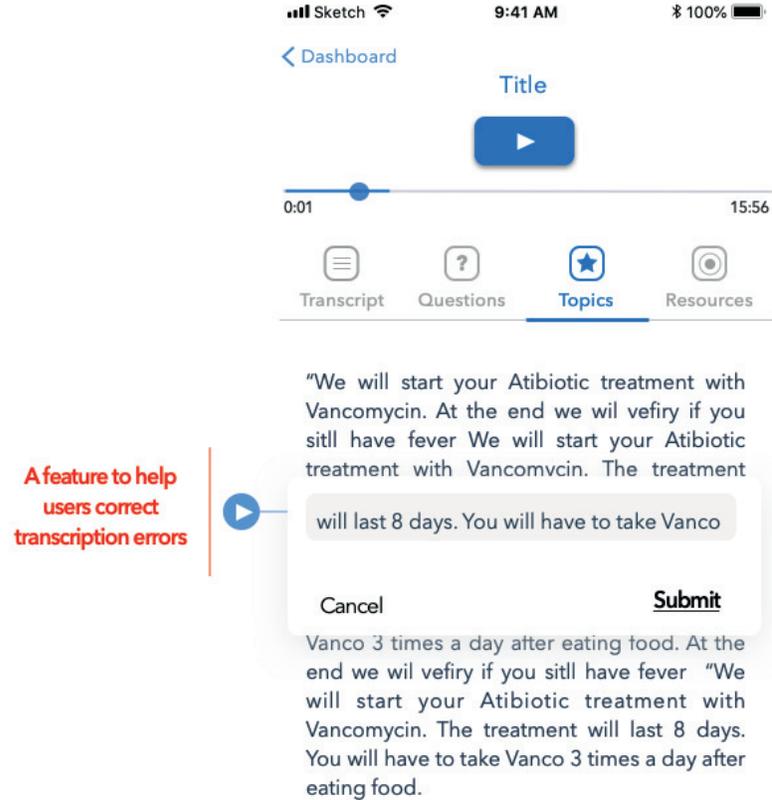
Figure 30. Design recommendation of a feature to help users fix transcription errors.

4.6 CONCLUSION

As the scope of medical information continues to grow, patients need greater AI support to identify, understand, and use information critical to their health. Healthcare is moving toward adopting mainstream speech recognition to reduce the burden of taking clinical notes. Thus, researchers should focus on building NLP models that are patient-focused. Such models could help preserve medical conversations as a patient-focused source of information. Research, such as the OpenNotes study, has emphasized the relationship between informational access and quality of care and support. Along these same lines, the NURI project aims to put a spotlight on patient-clinician conversations as a key information resource that should be at patients' fingertips anytime they need it.

In the next chapter, I present the perceived usefulness and acceptability of NURI in a hospital environment.

Chapter 5. THE DESIGN OF AI AGENTS TO SUPPORT PATIENT–CLINICIAN MEDICAL CONVERSATIONS IN HOSPITAL SETTINGS

5.1   ABSTRACT

In this chapter, I study the introduction of NURI, an AI agent implemented to assist patients in remembering and understanding their verbal communications with their care teams in hospital settings. The agent helps patients to re-access audio recordings of their medical conversations, transcripts, and highlights. In this chapter, I delineate patients' current pain points concerning verbal communication without NURI. Furthermore, I report patients', caregivers', and clinicians' perceived usefulness of using NURI. Especially, I detail participants' perceptions of the value of speech-processing services at the patients' bedside and I examine the impact of NURI on their experience. Additionally, I describe the acceptance of using NURI by patients, caregivers, and clinicians. Finally, based on the results, I specify design guidelines to address participants' feedback.

5.2   INTRODUCTION

When struggling with health problems compounded by being confined to a hospital bed for multiple days, patients face cognition problems in perceiving and utilizing their medical information (Morris & Karlson, 2011). Challenges arise from multiple factors: complicated medical terminologies, a changing care team, limited access to information resources in hospital settings, and the cognitive and physical impairments that might occur as a result of treatments and stress (Anderson et al., 1979; Klasnja, Civan Hartzler, Unruh, & Pratt, 2010). Consequently, patients who aim to play an active role in their care could remain limited by not remembering or understanding critical information about their care.

One of the information pieces that patients struggle with is remembering their conversations with their clinicians (Bradshaw et al., 1975; Kessels, 2003; Ley, 1979). Anderson et al. (1979) state that patients remember only 40% of their communications with their clinicians, and half of what they do remember is incorrect (Anderson et al., 1979). These conversations

between patients and clinicians are key exchanges of information that contain details about the diagnosis, treatment plan, test results, and most importantly, information to help patients manage their care. Therefore, patients in hospital settings rely heavily on these medical encounters to perceive and understand their health progress—not remembering them could lead to harm (CRICO, 2015).

To address this challenge, AI agents offer a promising solution. While patients struggle to remember and understand medical conversations, such agents could turn these conversations into searchable notes that patients could access and process at their own pace. They could provide a new means of accessing information that matches each patient's cognitive abilities.

However, researchers know little about patients' desires for such technology throughout their hospital stay, especially in the context of patient–clinician communication. In this chapter, I report the existing limitations that patients face when conversing with their clinicians in hospital settings. Moreover, I detail their attitudes toward using an AI agent to overcome these challenges. I invited patients and their family caregivers to use NURI, an AI agent that transcribes, summarizes, and annotates medical conversations at two hospitals with nine clinicians and 22 of their patients, studying their use of the prototype. I evaluated the impact of NURI on their hospital experiences through a pre–post survey and interviews. Moreover, I interviewed their clinicians to collect in-depth insights into their experience using NURI in the patients' rooms.

5.3 METHODS

As explained in Chapter 3, NURI is an iOS application designed to help patients capture the medical information relayed in medical conversations they have with their clinicians. In this chapter, I focus on reporting the results of one-on-one interviews and surveys that I conducted with patients, family caregivers, and clinicians to capture their insights and feedback on using NURI.

5.3.1 *Interviews*

In this chapter, I focus on NURI assessment interviews that I conducted with patients, family caregivers, and clinicians. Here, I asked participants open-ended questions about the impact of NURI on their experience. Some examples of the questions asked include "In what ways did you find Nuri helpful? Do you have any examples of that? In what ways did you find Nuri not

helpful/harmful? Do you have any examples of that? How comfortable were you using NURI? How comfortable do you think your doctors and nurses were with you using NURI?"

I conducted similar interviews with clinicians, asking them to reflect on their interactions with NURI, such as, "In what ways did you find NURI helpful? In what ways did you find NURI harmful? What concerns do you have about using NURI?". The totality of patients' interview questions are highlighted in Appendix C

5.3.2 *Survey*

Of the groups involved, only the patients and caregivers completed a survey before and after using my application. The first survey contained questions about demographics, technology friendliness, and perception of ability to recall and understand the medical conversations. I used SurveyGizmo to collect the survey data. In this chapter, I report the survey answers that assessed respondents' use of NURI. For example, "Would you rather have a conversation with the doctor with NURI or without NURI? Rank your preferences for follow-ups after medical conversations (NURI, paper summary, audio recording, nothing)." The complete list of survey questions and answers are available in Appendix B. In this chapter, I focus on survey question numbers 37, 40, and 33

5.3.3 *Qualitative analysis*

Two coders analyzed the patients' and caregivers' interviews. First, they independently analyzed five patient interviews to identify themes regarding NURI's impact on the users' experiences. The coders and the research team met regularly to review and iterate the codebook until reaching a consensus. The two coders analyzed the rest of the transcripts separately and examined each other's work. Any discrepancies were discussed and resolved.

My colleagues and I conducted the same qualitative analysis process to code the clinicians' interviews. We did not use the codebook from the analysis of the patient interviews—instead, we began the coding process from scratch. All of the members of the research team reviewed the coding procedure to ensure dependability and credibility.

5.4 RESULTS

In this section, I begin by highlighting some of the survey results assessing the use of NURI in hospital settings. Second, I summarize the results of the qualitative analysis of the interviews with patients, family caregivers, and clinicians. Specifically, I report the challenges in capturing medical conversations without NURI, the value of using speech processing in the context of patient–doctor conversations, the benefits of using NURI, and the risk analysis of NURI.

I present the participants quotes using the following nomenclature: **N** for NURI study, **VM** or **SCH** for Virginia Mason and Seattle Children's Hospital, **P** for patients and caregivers, **Dr** for clinicians, and an **X** number for the participant ID.

5.4.1 *Survey highlights*

The patient and family caregivers ranked NURI as their preferred tool for post conversations follow-up (figure 31), comparing it to a paper summary (ranked 2), audio recording (ranked 3), and nothing (ranked 4), (n = 15).

A total of 93% of participants (14 out of 15) said that they would rather have their medical conversations with NURI; only one participant said that he would rather not (Figure 34). Moreover, 80% of patients and family caregivers reported that NURI made their conversations with their clinicians better, 20% said it had no effect, and no participants reported that NURI made their conversations worse (Figure 32). All of the participants reported that they were certain/very certain that they were able to understand their medical conversations with the help of NURI. Only 36% said that they were certain/very certain they could understand the conversation without NURI (Figure 33).

Q40. Rank your preferences for follow-ups after a medical conversation.		Q37. Having NURI made communication with my doctors and nurses (worse, the same, or better).
Item	**Overall Rank**	
NURI	1 (highest)	
Paper summary	2	

| Audio recording | 3 |
| Nothing | 4 (lowest) |

Figure 31. NURI ranking.
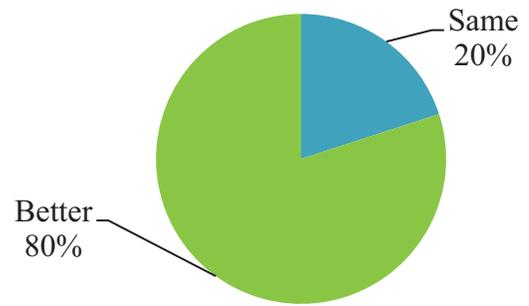
Figure 32. NURI's impact on patients' satisfaction with their medical conversations.
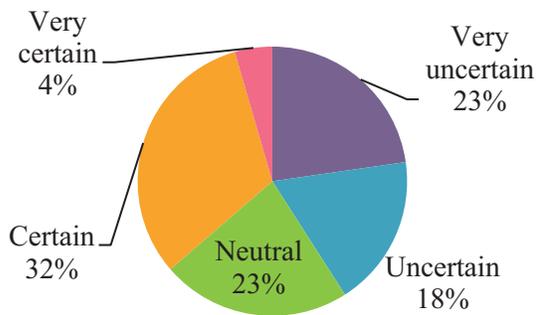
Perception of understanding pre-NURI
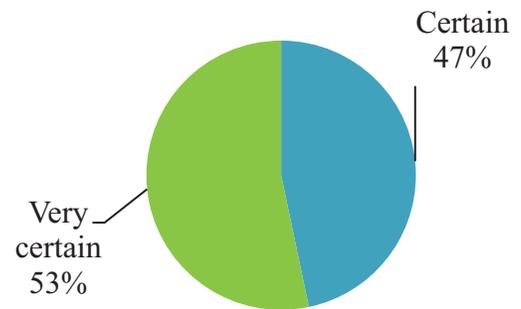
Perception of understanding post-NURI

Figure 33. NURI's impact on patients' understanding of medical conversations.
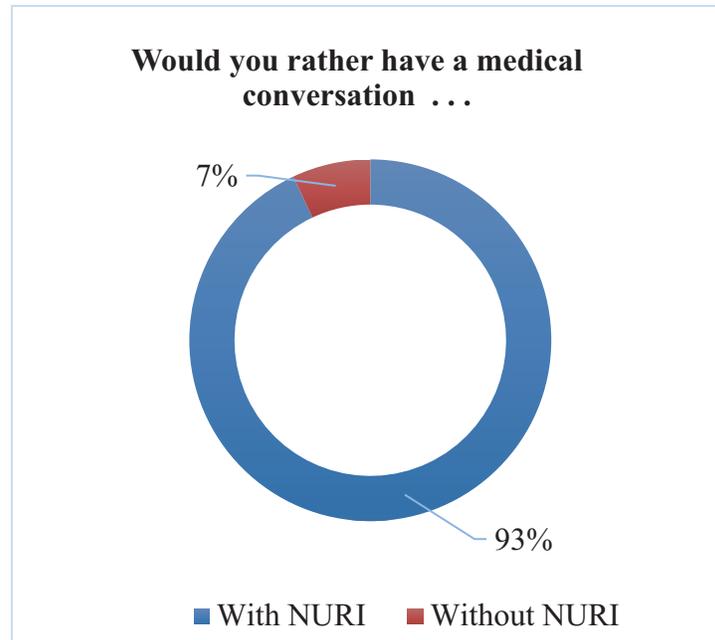
Figure 34. Answer to the survey question, *"Would you rather have a medical conversation with NURI or without NURI?"*

5.4.2   *Challenges in capturing medical conversations without NURI*

The results show that patients and their caregivers faced several challenges gathering and using information that was verbally communicated to them by their clinicians. I divided the challenges into two groups. The first set comprised **perception challenges**, which are related to problems that patients and caregivers face in gathering information. The second set of issues are **processing challenges**, which reflect difficulty in utilizing the information.

The clinicians, patients, and family caregivers reported similar challenges. However, the patients and family caregivers reported additional challenges that were related to their clinicians' communication style.

5.4.2.1   Perception challenges

Patients, caregivers, and clinicians reported three factors that prevented patients from fully perceiving their medical conversations: patient/caregiver cognitive impairments, clinicians' communication style, and simply missing the clinicians when they came into the room.

5.4.2.1.1   *Perception challenge 1: Cognitive impairments*

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The patients reported being cognitively impaired due to age, stress, medications, and exhausting procedures. They noted that this caused them to have a hard time focusing and remembering the details of their conversations with their clinicians. Patient N.VM.P.708 reported that, during the hospital stay, they felt fuzzy and had a hard time processing their medical conversations.

> N.VM.P.708: *"...and maybe they did and my head was fuzzy, like I'm not in my normally focused state of mind when I'm in that kind of pain and frightened*
>
> *....but you feel like you're in a fishbowl and you hear these things being spoken, but it's like they're talking about somebody in another room. It's happening around you, it's not you"*

N.VM.P.7914 reported that they had a hard time remembering information due to their age. They stated,

> N.VM.P.7914 : *"It's just hard to assimilate. Especially for an old person. As I've aged, I notice my mind doesn't keep up the way a young person makes a point. And the doctor tends to talk very rapidly anyway."*

Similarly, clinicians cited cognitive impairment as one of the problems their patients struggled with during verbal communication.

5.4.2.1.2 Perception challenge 2: Clinicians' communication style

Several patients reported challenges in understanding and remembering their medical conversations due to their clinicians' communication styles. Specifically, SCH.P.06 and SCH.P.04 reported challenges with their clinicians' communication style during family-centered medical rounds. While these rounds are highly recommended so families are included in the medical conversations to encourage shared decision-making (Rosen, Stenger, Bochkoris, Hannon, & Kwoh, 2009), N.SCH.P.06 as well as N.SCH.P.04 reported problems being part of the medical conversation due to several factors: the complexity of the conversation, the pace, and even the low volume of the conversation. The communication challenges can become greater when patients have multiple clinicians in the room. In these situations, clinicians tend to talk to each other in medical terms, which is more intimidating for the patients and makes it harder for them to follow the discussion. SCH-P04, a 14-year-old patient, told us that she tried to be actively involved in her care by attempting to participate in the medical decision-making during rounds; however, sometimes, she failed to chime in:

N.SCH.P.04: *"Yeah. And there was like seven people in here, so it's like, how are you going to remember all that information they're throwing at you and all the different medications and options they're talking about?"*

SCH.P.06 reported problems hearing their clinicians during family-centered rounds,

N.SCH.P.06: *"When they come? A lot of it I didn't hear, I was overwhelmed with that many people at once. They talk very lowly so it was really kind of frustrating, I didn't hear exactly what – I think the doctor was mainly talking so I missed a lot of it because I was over there. I think it would have been helpful if they kind of speak up, knowing what was going on"*

Furthermore, both patients and caregivers reported that they sometimes received conflicting information from different team members. Having different data about the same issue makes the task of managing information even more challenging.

The clinicians did not report their personal communication styles as being a factor that could affect patients' recall and understanding of medical conversations. Additionally, the data showed a difference between the patients' perceptions and the clinicians' perceptions of the quality of the conversation. For instance, one of the clinicians stated that they had a good communication style that included providing rich information and details; however, their patients had a different opinion. They appreciated the richness of the details, but they complained about the pace of the conversation. They reported that the clinician talked very quickly, and that they had trouble asking them to slow down.

5.4.2.1.3   Perception challenge 3: Scheduling

Another problem with perceiving information is simply missing the clinicians' visit to the room. The patients and caregivers stated that the clinicians tended to make unscheduled visits to the patients' rooms due to the nature of the workflow in the hospital setting. Thus, the caregivers missed updates if they left the room, even for a short amount of time. Moreover, the patients could be more overwhelmed at specific times of the day when their pain was higher or when they had taken medication that affected their thinking. If a medical encounter happened during these times, they were more likely to miss what the clinician told them. For instance, the caregiver of Patient N.VM.P.0218 said that they were always worried when they left the room, as they would

sometimes miss important updates from the clinical team. Additionally, they worried that the patient would not be able to remember the conversation to explain it back to them.

> N.VM.P.0218: *"…Because I just am always afraid to leave and not know what they said, because he forgets what they say and stuff"*

5.4.2.2 Processing challenges

The participants reported three processing challenges: encoding new terminologies, recall, and information overload.

5.4.2.2.1 Processing challenge 1: Encoding new terminologies

Patients reported that they faced problems understanding certain medical concepts during the short encounters they had with their clinicians. During hospital stays, the patients and their caregivers encountered new concepts of care such as new procedures, interpretations of diagnoses, rationales for a care plan, and medical terminologies. To remember these new notions, patients must first understand them.

> N.VM.P.708: *"Some of these guys come in here, you see them. All these big words and walk off. Well, what does that mean? No matter how many times you ask them, they didn't tell you a thing. I like the way she explains it."*

5.4.2.2.2 Processing challenge 2: Recall

The hospitalized patients reported challenges remembering information they received verbally. Recalling information is an overwhelming cognitive challenge that both patients and caregivers face in hospital settings. Patients must rely on their memories to store information communicated to them verbally. My results echo those of several research studies highlighting that patients remembered only 20–40% of what their clinicians told them (Kessels, 2003). One of the patients reported having memory challenges in general; thus, for them, remembering medical conversations was very challenging. N.VM.P.538 noted that they have problems remembering their medical conversation due to their memory problems that started after a concussion.

> N.VM.P.538: *"I had a concussion about eight months ago and I'm actually going in to see a neurologist, because I am having some memory problems. So I might have a memory that's more like an 80-year-old right now than my age of 55."*

Furthermore, one of the clinicians estimated that her patients retained at most three pieces of information out of any conversation. She acknowledged that they would forget the rest. Thus, she tried to emphasize the three points that mattered the most from her perspective.

N.SCH.Dr.5: *If we make changes in their medications, if we are starting new medications, those are things you always worry that might be something that doesn't get translated properly and they might go home with the wrong instruction or the wrong memory of what they heard."*

5.4.2.2.3 *Processing challenges 3. Information overload*

The clinicians, patients, and caregivers reported that during medical conversations, the patients and caregivers could become overwhelmed with the amount of information they received. It should be noted that the volume of information is usually proportional to the complexity of care.

In addition to the challenge of encoding new information, the parent-caregiver of patient N.SCH.P.01 mentioned that the information overload added an additional challenge to their ability to manage all the information.

N.SCH.P.01: *"I am not someone that went to college for medical, and so sometimes I think that's really overwhelming for parents and scary."*

The patients tried to stay informed to play an active role in their care. They tried to capture as much data as they could to make informed decisions. However, because most of these data were communicated verbally, the patients struggled to remain fully informed. As child patient N.SCH.P04 explains,

N.SCH.P04: "*Yeah. And there was like seven people in here, so it's like, how are you going to remember all that information they're throwing at you and all the different medications and options they're talking about?"*

Similarly, clinician N.SCH.Dr.05 noted that, sometimes, their patients could miss some of the important key points from long conversations.

N.SCH.Dr.05: "*…sometimes when you are discussing, you might not always remember the key points, even though we try to summarize everything at the end of rounds, but instead you're talking for 15, 20 minutes, and multiple people talking, so they might miss some of those important things…"*

5.4.3   *The value of speech processing*

In this section, I highlight the value of speech processing from the participants' perspective. The participants valued their prompt access to richer notes, their ability to search spoken dialogue, and their ability to read and assimilate complex discussions at their own pace.

5.4.3.1 Prompt access

The patients perceived a benefit in having automatic generated annotated transcripts of their therapeutic conversations as a way to have prompt access to medical notes. Patients' access to medical information in a hospital setting, if allowed, is usually delayed by 24 hours. With NURI, the team provided an indexed audio file with a non-verified transcript in less than 10 min. For instance, N.VM.P.7914 said that having prompt access to the conversation was very valuable since some of the information, such as symptoms to watch for, was time-sensitive, and waiting for a highly edited summary could take up to three days.

> N.VM.P.7914: "*Again, for me, a written record that I can read and take with me after that visit would be way more valuable than a highly edited one three days later.*"

5.4.3.2 Richer notes

The clinicians and patients perceived the transcripts as more meticulous notes compared to simply viewing the clinicians' notes and the patients' notes. In some hospitals, patients have access to EHR clinicians' notes through OpenNotes. These notes are a high-level summary of their conversations with the patient. For instance, clinicians could note that they explained a new diet to the patient, but they do not have to write out the details of the diet. In addition, clinicians are not required to provide detailed summaries for their patients, especially for bedside conversations. The clinician in this study reported that sometimes, they invited a nurse to help patients take extensive notes for outpatient visits. Unfortunately, this was not always an option, as the nurses are already overwhelmed with other tasks.

> N.SCH.Dr.2: '*It can be quite a complex discussion which we sometimes have a nurse coming in to transcribe something, but often the nurse is busy, so then we quickly try and write something up. But our summary for the family is going to be some one line thing.*"

The patients reported that the NURI transcripts provided more detail than just the clinicians' notes.

> N.VM.P.708: "*As far as the discharge papers? It's sort of like the difference between a resume and a cover letter, you know what I mean? This is the cover letter that kind of gives all the detail portion of it, versus the resume that's just the bullet points. The chart notes cover both points, like you do A, you do B, you do C. But this is the whys*"

The patients and family caregivers reported that their medical conversations contained technical jargon that could be hard to grasp. Moreover, the patients felt hesitant to ask for detailed clarifications. Thus, by having control over the conversation (playing, pausing, reading, and searching for explanations), patients were able to spend the time they needed to understand any concepts they struggled with. For instance, N.SCH.P.02 felt like NURI helped them to revisit the details of their medical conversations without needing to ask their clinicians to repeat it.

> N.SCH.P.02 "*So I like the fact that I could look at this and go oh, yeah, we said that, we talked about that, he mentioned this, and I don't have to necessarily go grab him or have the nurses email him something. I can look at this. So I think that's cool.…Sometimes it's hard for the patient to understand exactly what's going on. If I can hear it a couple times, then I can figure it out.*"

The parent of P.SCH.01 stated that NURI helped them to assimilate information when things became overwhelming for them.

> P.SCH.P.01: "*Okay, the thing I like the most – I think just overall, all of it, being able to go back and find information when it can be very overwhelming.*"

Similarly, clinician N.VM.Dr.01 noted the value of NURI as a way to support patients in revisiting the important notes of medical conversations.

> N.VM.Dr.01: "*I guess from a doctor's perspective – I talk a lot to my patients. I spend probably too much time with them and talk a lot to them, so some patients who are detail oriented, they would want that. Both those patients are like in the room a lot of the times with notebooks, writing things down, so for those kind of patients I think it's helpful because they can go back and look at it.*"

5.4.3.4   Easy search

The participants greatly appreciated the highlights, topics, and questions NURI features as ways to pinpoint different pieces of information in the talk. Audio recordings are promising solutions to help patients remember the conversations they had with their clinicians. However, audio files are hard to skim—to find a piece of specific information, patients might need to listen to the entire audio file. This task becomes even more cumbersome when patients have multiple recordings with

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multiple parties. Speech-processing services turn these files into searchable notes that patients can skim without needing to listen to/read the entire conversation.

5.4.4   *Benefits of NURI*

In the previous section, I talked about the challenges that patients and caregivers face while conversing with clinicians. I then highlighted how patients perceived the value of using speech recognition to overcome these challenges. In this section, I discuss participants' reports of NURI's benefits: efficient and easier information-sharing, better collaboration, increased awareness, and better planning and acting capabilities.

5.4.4.1   Efficient and easier information-sharing

The patients and caregivers stated that NURI would help them to share medical information with other family caregivers in greater detail. One parent said that in the past, they had failed in sharing updates with the other parent in full details. They said that it is always stressful from them trying to remember every detail from medical conversations. Moreover, they stated that NURI would reduce his stress about trying to capture information and transmit it to his partner to keep them both informed, especially because his partner was the primary caregiver and the one managing their son's health.

> N.SCH.P.05: "*When you come into an ER, they ask what surgeries you've had and you try to remember them all. It's not in my partake. You go to ask my wife, she'll tell you. It's just a lot to remember, because my mind goes 100 miles an hour. I focus on – I got four kids, just trying to remember everything, remembering everybody's birthday. I can remember my two oldest ones and my middle son, I struggle with his at times.*"

The caregivers and patients reported that they would use NURI to share clinicians' instructions with third parties, like school nurses or dietitians. Caregiver SCH-P01 reported that one of the challenges of transferring information was remembering technical details the way the clinicians conveyed them. She stated that she could use NURI to replay snippets of audio to the school nurse to ensure an accurate transfer of information.

> N.SCH.P.01: "*…so having something that I can hand to them or even just say "hey, listen to this clip," and I could pull up this clip really easily of the doctor explaining to them how*

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this dietary issue affects them, just one little snippet of it. I would find that so helpful, working with all those other people…"

5.4.4.2 Better collaboration

The patients reported that NURI increased their perception and understanding of their conversations with their clinicians. They stated that they had better awareness of what was happening in their care. Moreover, they mentioned that they would use the NURI patient-facing notes to better communicate and collaborate with their care team. For instance, some participants said that they could use NURI to compare clinicians' instructions and discuss discrepancies in interpretations and recommendations with their care team.

> N.VM.P.1479: *"being able to look back at that exact section, some of the questions you ask, being able to listen back to their answers from your questions. Because that can help if you have the question again or forgot her answer, or want to ask it to a different person who had a different opinion. Some of the questions, like hey, are we going to be doing this medication or this medication, being able to ask multiple doctors. You can also just get their opinions, so I feel it could be really helpful."*

5.4.4.3 Better planning and acting capabilities.

The patients stated that NURI could help them better plan their care. They indicated that it could help them in perceiving and understanding their doctors' instructions, and thus, help them to follow instructions more accurately.

Further, the participants reported that they would use NURI to assign "to-dos" captured from the conversations to their caregivers. They could select specific tasks that they wanted to delegate to their caregivers and share these with them. Instead of having to explain things, they could just share the audio snippets of their clinicians explaining the procedures. N.VM.P.538 said they would ask their family caregivers to listen to recorded conversation so they could help the care plan.

> N.VM.P.538: *"…When they get it, they go ahead and handle it. I'm not into the computer that much, but that there, that's how I would let them hear the conversation. So I can get stuff taken care of. That's what I like about it."*

The caregiver of patient 1464 said that NURI could help them understand the conversation they missed and help play an active role in the patient's care.

N.VM.P.6414: "…… *I can read it at the same time and get a better understanding of what the conversations are with him about what's happening and what looks good and what needs work. So I thought it was an excellent*"

5.4.4.4   Acceptance of using NURI

In the previous sections, I highlighted patients' and caregivers' struggles in managing verbal communications in hospital settings. Then, I presented the benefits of having NURI, a speech-processing service to help patients record and annotate these conversations. Furthermore, I reported potential ways the patients could use NURI to play an active role in their care.

In this section, I report the participants' acceptance of NURI. Specifically, I detail any factors that could jeopardize their use of NURI. In my one-on-one interviews with patients, I asked participants if NURI impacted their wellbeing in any way, such as feeling uncomfortable or feeling worried about their privacy. The reason behind this analysis was to acknowledge any challenges that could prevent the implementation of NURI or lessen any of the benefits mentioned previously. New technologies such as NURI, while they provide needed support to users, they can also generate new challenges. For instance, electronic health systems offer great support for storing patients' information in a structured way; nevertheless, they have adversely affected clinicians and patients because clinicians' attention is split between the screen and their patients(Kazmi, 2013).

Thus, in this section, I feature the participants' thoughts and acceptance of using NURI. Specifically, from the patients' and caregivers' perspective, I report two main topics: the impact of NURI on privacy, and the impact of NURI on their relationship with their clinicians. As for the clinicians, I report their perceived potential NURI's impact on quality of care as well as the impact of NURI on their relationship with their patients.

5.4.5   *Acceptance of NURI from patients and family caregivers' perspectives*

In this section, I report the acceptance of using NURI from patients and caregivers' point of view. Particularly, I discuss patients' privacy and patients' relationships with their clinicians.

5.4.5.1   Patients' privacy

The patients and their family caregivers did not report any personal negative impact on their privacy, nor did they find NURI to be intrusive. They thought that NURI did not lead to any additional privacy concerns. They reported that the app should just follow the hospital's HIPAA

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requirements. Storing audio recordings of the clinician talking about their care did not seem to add any additional worries from the patients' and family caregivers' perspectives. Moreover, the patients did not report any negative consequences of using NURI on their side. On the contrary, the patients and their family caregivers reported feeling less stressed by not having the pressure of remembering every detail from the complex medical conversations.

> N.VM.P.20 *"I didn't really think about it being recorded at all when he was there and I was talking to him. VM 20."*

While in general, users worry about their privacy when using a smart assistant like Alexa, the participants did not report any privacy concerns. This may be because NURI was tested in a hospital setting. According to a PwC US protect.me survey[1], hospitals and banks are one of the most trusted institutions when it comes to user data privacy. Furthermore, the users had control over starting/stopping the recording of the conversation; this is in contrast with smart assistants that are actively listening for wake words such "Alexa" or "Hey Google." Nonetheless, the participants insisted that NURI should comply with the hospital standards in protecting their data.

5.4.5.2 Patients' relationships with their clinicians

Participants reported worries that NURI could impact their clinicians' truthfulness and their trust toward their care team.

5.4.5.2.1 *Truthfulness*

The patients and family caregivers worried that NURI could impact their clinicians' truthfulness. The patients and caregivers thought that the clinicians might behave differently if they remembered that they were being recorded; thus, they might be reluctant to say what they truly believe. To resolve this problem, one patient suggested offering clinicians protection from legal retaliation to help them feel more comfortable.

5.4.5.2.2 *Trust*

One patient, N.VM.P.0708, noted that clinicians' refusal to let them record their conversations could affect their trust. The patient stated that they did not see a reason for clinicians to refuse to be recorded, and felt that doing so was a red flag.

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[1] https://www.pwc.com/us/en/services/consulting/library/consumer-intelligence-series/cybersecurity-protect-me.html

N.VM.P.0708: "*... I get that this is about them giving their advice, but boy, if they're saying no, they don't want to be recorded? That would be more of a flag to me than them saying yes. Because why wouldn't you want to be recorded*"

In summary, the patients and their family caregivers did not identify any personal harm from using NURI. However, they worried that the technology could affect their relationship with their clinicians by leading them to behave differently because they were being recorded. In the next section, I present the clinicians' perception of the impact NURI had on them.

5.4.6   *Acceptance of NURI from the clinicians' perspective*

In this section, I present the clinicians' perception of the risk of using NURI. The clinicians noted two main reservations: NURI's impact on quality of care, and the impact of NURI on their relationship with their patients.

5.4.6.1   NURI's impact on quality of care

The clinicians worried that NURI could affect the quality of care delivery in two ways: showing inaccurate patient information and overwhelming patients with details. As for showing inaccurate information, clinicians stated that they could be stating inaccurate information during the process of talking to their patients. Therefore, some clinicians felt uncomfortable with the fact that NURI could record and highlight these inaccuracies. Clinicians explained these inaccuracies with several factors such as the change in the course of care. As a resident clinician participant at Virginia Mason N.VM.Dr.03 explains it,

N.VM.Dr.03: "*... one of the things I think about is that we try when we're talking to patients to not say things that are overly medicalized, but inevitably we slip. And so I worry that sometimes you're going to record a conversation and you'll say something that makes sense to us but doesn't get followed up under the course of that conversation and then later it just leads to more questions about what that means and whether or not that was like an accurate thing to say or an inaccurate thing to say. That to me I foresee as a potential source of confusing for the patient where it otherwise wouldn't be.*"

Another reason of sharing inaccurate information is observation that clinicians rely on their memories to share values and results at their patients' bedsides. By doing so, they avoid having a screen between them and their patients, allowing them to have genuine conversations. However, by relying on their memories, they might state false information and inaccurate values. For

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example, they might a patient's kidney function is healthy; however, they might not remember the exact creatinine value. Some clinicians felt the need of being more cautious with the fact that NURI could record and highlight these inaccuracies. As N.SCH.Dr.04 explains,

> N.SCH.Dr.04*: I guess just even like in the minutiae of – you have lots of patients so maybe whenever you're talking about one patient's creatinine and you say oh, your creatinine looks better, it was 1.1 today, but then you got them confused with another patient, and this patient's creatinine is actually 0.8, and then the family goes home and says, wait a second – we thought that our creatinine was X today, but then this documentation says it was Y. So some of the little minutiae like that, in some ways it would almost in my mind, if I could somehow as a provider looks back over the conversation – oh, did we actually say everything accurately? So in general I think it could be really helpful, but some of the little details make me a little bit more cautious.*

Regarding information overload, the clinicians worried that NURI provided too many details to their patients. The clinicians felt that a detailed reporting of their interaction could be overwhelming for their patients and their caregivers. To help patients capture the essence of the communication, some of the clinicians preferred that NURI only record the summary or the discharge plan. In addition to that, the clinicians worried about the emotional impact of NURI. They noted that patients could re-listen to the same negative information multiple times, which could lead to emotional distress. However, the patients did not agree. They thought that having every detail could help them to better understand their care. Furthermore, providing highlights could help to reduce information overload by allowing patients to skip to the parts they cared about the most instead of reading everything. N.SCH.Dr.01 explained their point of view regarding information overload by saying:

> N.SCH.Dr.01 Wow, this is everything, though. I don't know, to me, I don't know if it's – I just have kind of a personal philosophy. A lot of times it's like less is more, where what I think would be perfect from my perspective is something that gets all the key medical points and maybe the synthesis of the conversation, but doesn't have every single sentence.

5.4.6.2 NURI's potential impact on the patient–clinician relationship from the clinicians' perspectives

In this section, I highlight two to the clinicians' worries about using NURI in a hospital setting: litigation and communication truthfulness.

5.4.6.2.1 Litigation

One of the major worries that clinicians had regarding NURI is fear of litigation. The clinicians thought that the patients' access to an audio recording of their interactions could lead to more lawsuits. The reason behind this is that in general, the field of medicine has a lot of information uncertainties. For instance, clinicians can face uncertainties in determining a diagnosis. They make assumptions reflecting their best judgment based on the information they have available. With additional tests and further assessments, they might reach a better understanding of their patients' health problems. While finding the right problem to tackle, in their conversations with patients, they might state assumptions that end up being false. Then, they come back to re-discuss them later on when they have more clarity. Some of the clinicians thought that from the patients' perspective, this change in the narrative could be perceived as malpractice and would lead to lawsuits. As N.VM.Dr.1 explains,

> N.VM.Dr.1: *".....Because I want to have a very formal talk, I want to have qualifiers for everything so that, you know, "We think your kidney will improve fine, but – " And I feel like that might be less reassuring to families, that it would be harder to give firm answers if you're afraid if things don't go well, they could bring you to court and be like, "Look, he promised everything was fine and now it's not." So that might be one thing that will have to be figured out for widespread buy in."*

At the same time, Clinician N.VM.Dr.2 argued that NURI could also protect clinicians in some legal situations if they could use NURI recordings to prove that they communicated the right information to their patients,

> N.VM.Dr.2: *"I don't know. In some ways I suppose you could think that this may benefit the physician, because one of the issues that we have as physicians is very often the thought is if you haven't written it down, you haven't done it"*

5.4.6.2.2 Communication truthfulness

Some of the clinicians, like the patients and caregivers, reported concern about their willingness to be utterly truthful when interacting with their patients. The recording factor could lead to

discomfort; specifically, if recorded by NURI, the clinicians could behave differently. However, one clinician who had multiple recordings reported feeling more comfortable with NURI in the room on the second day. Thus, the effect of NURI on clinicians' truthfulness might diminish over time.

Some of the clinicians were worried that their patients would behave differently once they were being recorded. For instance, the patients could avoid speaking truthfully about topics such as drug use. As N.VM.Dr.01 states,

> N.SCH.Dr.01: *I had another patient who came with an epidural abscess and we didn't know why she was critically ill. I had to get her in neurosurgery, but later on, reading the chart, she admitted that she was injecting like Dilaudid. So would she have admitted that eventually to her doctor team if she'd been recorded every day? I don't know.*

In summary, the clinicians worried that NURI would disturb their interaction with their patients and this new change could lead to unexpected harm.

5.5 DISCUSSION

With this work, I contribute to a growing body of research studying the implementation of patient-facing AI agents in hospital settings. To my knowledge, this is the first research study to elicit the perspectives of hospitalized patients, their caregivers, and their clinicians on deploying AI agents to support patients' remembering and understanding of their medical conversions in hospital settings.

The patients' reaction to getting access to NURI exceeded my expectations. The patients praised this new access to verbally communicated information that had previously been lost to them. They valued the NURI features giving them access to information embedded in conversations through recordings, transcripts, topics, and questions. The clinicians expressed some reservations using NURI related to their workflow and to their relationship with their patients, such as litigation problems and lack of truthfulness.

Thus, in this section, I present the following design recommendations:

- Design functions to overcome clinicians' related communication challenges
- Design functions to improve the ways in which NURI is used for engagement
- Design functions to reduce NURI's associated risk

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5.5.1 *Design functions to overcome communication challenges*

The results echo previous research findings stating that patients face perception and processing challenges when they receive information in hospital settings. In addition to the cognitive and physical impairment, patients and family caregivers reported more communication challenges induced by their clinicians' communication style. For instance, during family-centered rounds, a highly recommended way of including patients in decision-making, patients reported it could be challenging to be part of the conversation. They noted that these rounds could be intimidating, as they featured the presence of large numbers of clinicians speaking quickly to one another in medical terms.

NURI represents a great opportunity to overcome these communication difficulties by recording conversations and by giving patients more time to process the details at a slower pace. In addition, caregivers who miss these rounds could have access to the conversation through the NURI app.

Another way NURI could help to improve clinicians' communication styles is to include features for providing them with feedback. NURI could provide training features for future clinicians by helping them to perceive the impact of their communication. For instance, it could report the trainee's speed of talk, number of interruptions in the conversation, use of technical terms without explanation, and more.

5.5.2 *Design feature to improve how NURI engages patients*

The patients reported that NURI supported them in playing an active role in their care in hospital settings. Thus, I propose design recommendations to streamline the use of NURI to support patients and their family caregivers in : better sharing, better awareness, and better collaboration with the care team.

Better sharing. The patients and family caregivers saw an opportunity to use NURI to share information with other caregivers, third parties such as school nurses and dietitians, and other clinicians such the primary caregiver outside of the hospital. Thus, adding features to facilitate sharing is essential. Future work could explore users' preferences for sharing their medical conversations with research questions such as "Which part of the conversation do patients want to share? Who do they want to share it with? For how long?"

Better awareness. As explained in Chapter 1, the hospital environment, including stress and emotional events, could cause attentional narrowing (Wessel et al., 2000). My results showed that NURI could help to overcome this challenge. Patients noted that NURI helped reduced the pressure of having to remember every detail and ease the tiring job of taking long notes. Furthermore, patients and family caregivers reported that NURI helped them to review their medical conversations at their own pace. From a design perspective, NURI could offer more ways of helping patients perceive and understand their medical conversations. One design example is the three types of information display as published by the Patient-as-Safeguards groups (Haldar, Khelifi, et al., 2020)

- Organizing information in categories to support patients' search for information
- Organizing information in a timeline display to support patients' perception of current and future care events
- Organizing information in a goal-oriented display to support patients in managing their care goals.

Better collaboration with the care team. The patients said they could use NURI to fix discrepancies. Specifically, if they heard contradicting information, they could use NURI to verify the contradictions and resolve them with their team. Thus, NURI could design a feature to highlight information that needed verification from the team. Patients could tag their clinicians in the information that needed their verification to help fix the discrepancies.

5.5.3 *Design functions to mitigate risks*

Some of the clinicians' participants reported worries around the impact of NURI on their workflow and on their relationship with their patients. Similar concerns were reported in the introduction of the OpenNotes study, a service that provides patients with access to their medical notes. In the OpenNotes study, the clinicians worried that errors or offending language in their notes could harm their relationship with their patients. Rather, after one year of using OpenNotes, both doctors and patients perceived relational benefits: 53% of clinicians believed patient satisfaction increased, and 51% thought patients trusted them more(Bell et al., 2017).

The preliminary results from testing NURI are highly promising: 14 out of 15 patients said that NURI made their communication better. Furthermore, the participants reported that NURI helped them to recall and understand their medical conversation. Thus, since NURI indicates a

positive impact on patients' communication experience, future work should conduct a longitudinal study to see if clinicians' skepticism would persist/change over time.

Furthermore, to avoid litigation problems, several research studies confirmed that a key factor in reducing malpractice lawsuits was to improve communication, which is a primary focus of NURI. In article by Huntington (2003), who reflects on previous research exploring the reasons why patients sue their doctors for malpractice, the author states that "Simply put, patients do not sue doctors they like and trust, even with considerable injury as a result of a medical mistake."(Huntington & Kuhn, 2003) Furthermore, The American Association of Orthopaedic Surgeons posit that good communication often reduces the incidence of malpractice lawsuits. Similarly, Bayer Institute recommends the "4E" communication approach: engage, empathize, educate, and enlist to improve communication and the clinician–patient relationship.

In my study, 80% of the participants stated that NURI made their communication with their clinicians better. Thus, NURI could improve the patient–clinician relationship and help to reduce lawsuits. Furthermore, one participant reported a situation where NURI helped her to address an incident she had with her team. The participant was upset about the lack of clarity regarding a medication prescription request. She reported that after reading her NURI patient-facing notes, she realized that her team had already addressed her issues and that she had simply just forgotten this.

Thus, I propose adding the 4E communication framework to further enhance NURI's positive impact on communication. NURI could highlight information that supports these 4E principles. Furthermore, with more advances in speech processing, it could support clinicians in correcting and clarifying any inaccuracies in their communications. Future studies should explore the factors that makes clinicians more comfortable with recordings, such as the seniority of the clinician, the information environment (medical versus surgical), and the sensitivity of the conversation.

5.6 CONCLUSION

In this chapter, I examined how patients and family caregivers used the AI agent NURI during their hospital stays. I found that the patients highly valued having such technology at their side to help them overcome their communication challenges. I also described the ways patients used

NURI to help them play an active role in their care by sharing information more effectively, collaborating more efficiently with their care team, and planning their care. Furthermore, I report the potential risks of having NURI at the bedside of hospitalized patients. While patients did not report any personal worries, clinicians worried that NURI could lead to malpractice lawsuits.

In conclusion, NURI delivered enormous support to help patients manage their hospital conversations with clinicians. Further work should be done to improve clinicians' acceptance of NURI.

Chapter 6. CONCLUSION

In this concluding chapter, I highlight how I fulfilled each of the dissertation aims that I introduced in Chapter 1. I then summarize my contributions and discuss the limitations of my work as well as opportunities for future research. Finally, I end with a concluding statement.

6.1 FULFILLMENT OF DISSERTATION AIMS

Fulfillment of Aim 1: Describe how technology and AI agents can best support patients during the hospital stays

To achieve the first aim, I created Muse cards, a new user-centered design method. I applied the method to 30 participants at Seattle Children's Hospital and Virginia Mason Hospital to help participants reimagine the design of their existing technologies to support the active role they play in hospital settings.

- I reported potential technological features that aligned with users' needs in hospital settings.
- I reported new AI opportunities to support hospitalized patients.
- I identified a framework to inspire future innovation in creating patient-facing technologies for emotional support, personalized communication, and informed patients.
- I used the results to create the NURI probe, an AI agent to support hospitalized patients by turning medical conversations into patient-facing notes.

Fulfillment of Aim 2: Determine which information is important in medical conversations from the patients', family caregivers', and clinicians' perspectives

I integrated the results from the Muse cards study to create the NURI prototype. Then, I conducted a probe study in which I recruited 22 patients and nine clinicians. Based on the qualitative analysis of the results of the probe study, I generated three groups of factors that defined which information was important in the conversation between patients and clinicians for patients' use from the patients', caregivers', and clinicians' point of view. The quality factors consisted of accuracy and validity, the patient-dependent factors consisted of emotional value and knowledge gaps, and the patient-independent factors comprised utility, criticality, and novelty. Using these factors, I created

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an annotation framework to help human annotators and machines annotate medical conversations to highlight important topics for patients. Moreover, I proposed design changes to the NURI prototype to utilize the annotated data in patient-facing prototypes. I reported patients' and clinicians' wishes for future AI and speech-processing use. Finally, I proposed design recommendations to implement these wishes at the patients' bedsides.

Fulfillment of Aim 3: Evaluate the impact of NURI on patients' hospital experience

I examined the design, use, and impact of NURI on patients', caregivers', and clinicians' experiences. I reported high satisfaction results from the survey analysis, in which 93% of participants said they would rather have NURI at their side in hospital settings than not. Through qualitative analysis of the interviews, I explained the reasons that patients and family caregivers gave for finding NURI to be a desirable technology. Specifically, they reported that NURI speech-processing services helped them to access notes promptly without having to wait for notes on patient portals. They valued the richness of the notes compared to other sources, such as clinicians' notes, which are curated for EHR purposes. The patients and their family caregivers praised the fact that NURI helped them to read, listen, and search verbal conversations at their own pace. I also highlighted participants' thoughts on how NURI could help them to play an active role and overcome the engagement gap in their own care (explained in Chapter I). The patients and family caregivers found NURI to be useful for sharing information with third parties, like other caregivers school nurses. Finally, the participants reported that NURI was helpful for collaboration and planning.

I conducted a risk analysis regarding implementing NURI in a hospital environment that focused on patients', caregivers', and clinicians' comfort. While patients did not report any personal reservations, they worried that NURI could influence their clinicians to act differently because they were being recorded. The clinicians worried about litigation. Lastly, I addressed the impact of NURI in my design recommendations, where I proposed design changes that would foster the benefits and mitigate the risks.

6.2 SUMMARY OF KEY CONTRIBUTION

In fulfilling the three dissertation aims above, I make several contributions to the following fields: human–computer interaction (HCI), personal health informatics, and AI agents for hospital settings.

6.2.1 *Contributions to human–computer interaction*

My contribution to HCI is the Muse cards method, which is a user-centered method that uses cards as design prompts to support users in reimagining the design of their technologies.

This method is unique by offering the following advantages:

- It limits participants' preconceptions of previous technologies that have failed to meet users' needs.
- Allows designers and researchers in promoting a creative design space that starts with features selection and allows users to expand with more futuristic and innovative features.
- Muse cards method uses two sets of cards. The first set consists of *feature cards*. The second set includes *creativity cards*. These cards are designed to help participants think about future innovative improvements. In Figure 35, I highlight the toolkit needed for creating the Muse cards.
- The analysis of the Muse cards promotes
  - A quantitative analysis that could guide researchers and designers in understanding the desirability of each feature from the user's perspective. The quantitative analysis pinpoints participants preferred technological features to overcome shortcomings in their current experience. This step
  - A qualitative analysis that identifies potential technological opportunities to benefit users.
  - Both analyses could help identify technological opportunities that are desirable and beneficial for users.
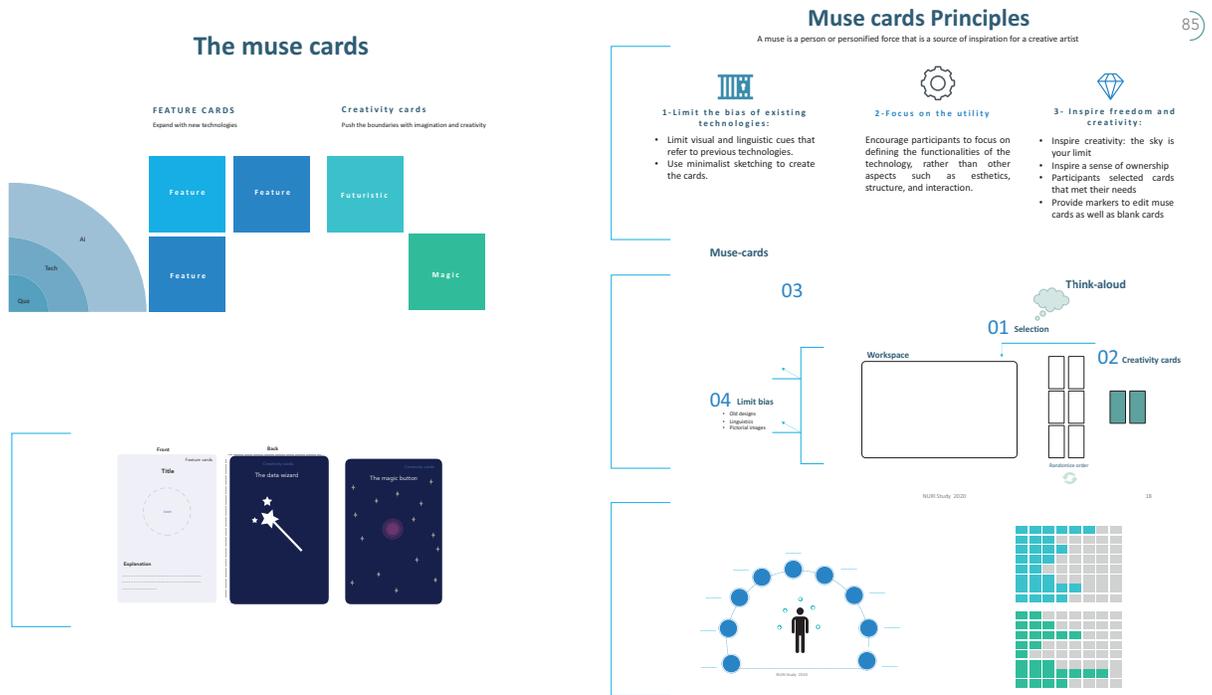
Figure 35. The Muse cards kit.

6.2.2 *Contributions to personal health informatics*

My contribution to personal health informatics is highlighting technological opportunities to support hospitalized patients overcome their engagement gap. First, I provide design recommendations to reimagine existing patient-facing technologies to better match users' needs in hospital settings. Second, I propose the NURI technological probe, an innovative technology to support patients remember and utilize their medical conversations.

- Design recommendations to reimagine existing patient-facing technologies:

In the muse cards study, I identified key technological features that would improve patients' hospital settings. I identified nine pillars of technological support in hospital settings: Supporting patients in evaluating their care, supporting recall, supporting safety, supporting access to information, including patients in teamwork, providing emotional support, supporting decision making, supporting personalized communication, and supporting accessibility.

These nine pillars help pinpointing the gaps in existing systems. Identifying these gaps is crucial, as it illuminates specific loopholes that can be mended. Second, it builds the path for innovation.

- The NURI probe study contribution

While previous research efforts focus on turning medical conversations into clinician-facing notes, the findings of the NURI study highlight how to turn medical conversations into patient-facing notes. To my knowledge, this is the first study to focus on processing conversations into useful notes for patients rather than clinical notes to fill the EHR.

- I offer a rich understanding of patients' information needs within medical conversations in hospital settings. I identified three groups of factors that defined what was important for patients in their medical information: quality factors (accuracy and validity), patient independent factors (novelty, criticality, and utility), and patient dependent factors (knowledge gaps and emotional value)

- Furthermore, I used these factors to create an *annotation framework* to turn medical conversations into patient-facing notes. Both human annotators and machines could use the framework to automate turning medical information into patient-facing notes.

6.2.3   *Contributions to application of AI agents for hospital settings*

My work contributes to research exploring AI agent use in hospital settings. Particularly, it advances the understanding of the implementation of AI agents as a part of the patient-clinician encounter.

- I identified the benefits of using AI agents in the context of medical conversations, such as prompt access to rich notes that patients can share, collaborate with their care team, and plan their care.

- I determined perceived acceptance of using such agents from the patients', caregivers' and clinicians' perspective. Moreover, I highlighted the clinicians' worries of litigation due to being audio recorded by the AI agent.

- I provided design guidelines that could be used to support the benefits of having AI at the bedside of hospitalized patients, such as creating features to help share information with third parties.

- I also shared design guidelines to mitigate risk, such as integrating the 4E model, a model the AAOS recommends to reduce malpractice suits though improving medical conversations.

6.3   Limitations and future work

While the methods and studies reported in this dissertation add new knowledge about the opportunities, needs, and impacts of using patient-facing technologies, particularly for AI agents, I acknowledge that the studies described here have several limitations. Due to the novelty of the technology, in the NURI study, I began recruitment by finding clinicians who would be willing to help us with the NURI probe. Then, we recruited their patients who were eligible for the study. This recruitment strategy, while convenient for a probe study, was limited in recruiting a diverse set of patients. Therefore, in future work, I would recruit a larger sample from different hospitals to achieve different demographics and more varied clinical situations.

In the NURI study, most of the participants recorded only one encounter with their clinicians. In future work, I could investigate the interaction with NURI throughout multiple visits, as this could provide a better understating of the longitudinal impact of using NURI, especially on clinical outcomes such as readmission rates and patients' adherence to medical instructions.

Despite these limitations, the findings presented in this dissertation describe an innovative use of technology to help patients become more engaged in their care by accessing their information from their medical conversations despite cognitive and physical impairments induced by pain, medication, and stress.

6.4   Conclusion

"Information is care[1]"(Tierney, Kanter, Fraser, & Bailey, 2010) This statement has shifted my understanding of and philosophy toward healthcare delivery. As a pharmacist trained in Tunisia, I used to believe in a paternalistic delivery of care. I thought clinical experts had better judgment in what was best for patients. However, after spending time in a hospital environment as my father's caregiver during an admission to the emergency room, I realized that without the right information patients are left in the dark, stressed, in pain, and unable to make informed decisions that could affect the quality of their lives.

Through this work, I invite clinicians, patients, and researchers to reflect on the use of technologies, primarily AI-powered artifacts, to help patients understand and utilize their medical

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[1] Donald Berwick, president of the Institute for Healthcare Improvement

information. Furthermore, I want to raise the awareness that without the right technologies, patients are left with an engagement gap, unable to manage a plethora of details.

Nouri is an Arabic name that means "my light." I hope that the NURI technology can be the light that guides patients through the darkness of disease, showing them a safe way to a better quality of life.

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APPENDIX A

Muse cards toolkit

Patients As (S)afeguards

Email:patientassafeguards@gmail.com

Our plan today: Design your own hospital app

1   Pick the features you like   2   Design your own app

A1
A2

Features' library

A1
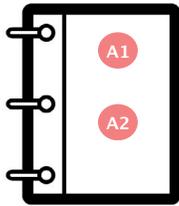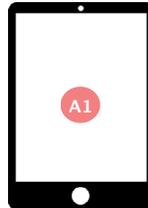
Your design

3 Pick your personal assistant in the hospital and give it the super power you need

Nap Time
Do Not Disturb

Set D : Learning more about my health

D1 What does my result mean?

Xray

What does the doctor say :

Ask Question

D2 Doctor's drawing

Explanation

More information

Ask Question

D3 Why am I taking this medicine?

Medicine

More information

Source   Ask Question

D4 Educational video

Notes :

Ask Question

D5 What does my doctor say ?

Record 06-06-2016

Dr. Nadine

Play

Notes :

Ask Question

D6 How does my equipment work ?

Equipment

More information

source   Ask Question

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

G2 Doctor's feelings about my health

G3 Lab results over time
Blood Test Results

G4 My health problems
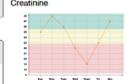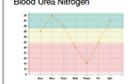
Bowel Movement: Creatinine   Dr's notes
Kidney Function:
Abdominal Pain:

Blood Urea Nitrogen

G5 Search for anything

G5 Ask Jesse Penguin

Ask me anything!

e.g What time is my next blood draw?

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

Type here

Send

I4 Chat with another patient

I5 Read other patient's stories

I6 Filter Patients By:
- ☑ Age
- ☑ Same health issue
- ☐ In the hospital now
- ☐ ? _____

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
- ☐ ....

save

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
⊕ add new symptom

E1 Learn more about my medicine

Medicine

What is this medicine?

Amount

What should I look out for?

Why am I taking this?

This medicine may not be right for you if:
- You have an allergy to Penicillin
- 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

Report a problem   Write a question

Set E: More info and safety

E2 FAQ by patients like me

Frequently asked questions:
Question 1 ?
Question 2 ?
Question 3 ?

E4 Personalize my safety checklist

Safety Checklist

Recommended for you:
- Provider's hygiene
- Medicine checklist
- Hazards

Save

Medicine checklist : SR's
- ☐ I'm taking the right medicine   ⓘ
- ☐ I'm taking the right amount   ⓘ
- ☐ I'm taking my medicine the right time   ⓘ
- ☐ I'm taking my medicine the right way   ⓘ

Report a problem   Save

E3 Learn more about my medical tests

Glucose tolerance test

What is this test?

Why am I taking this test?

What should I look out for ?

Report a problem   Write a question

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
- 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

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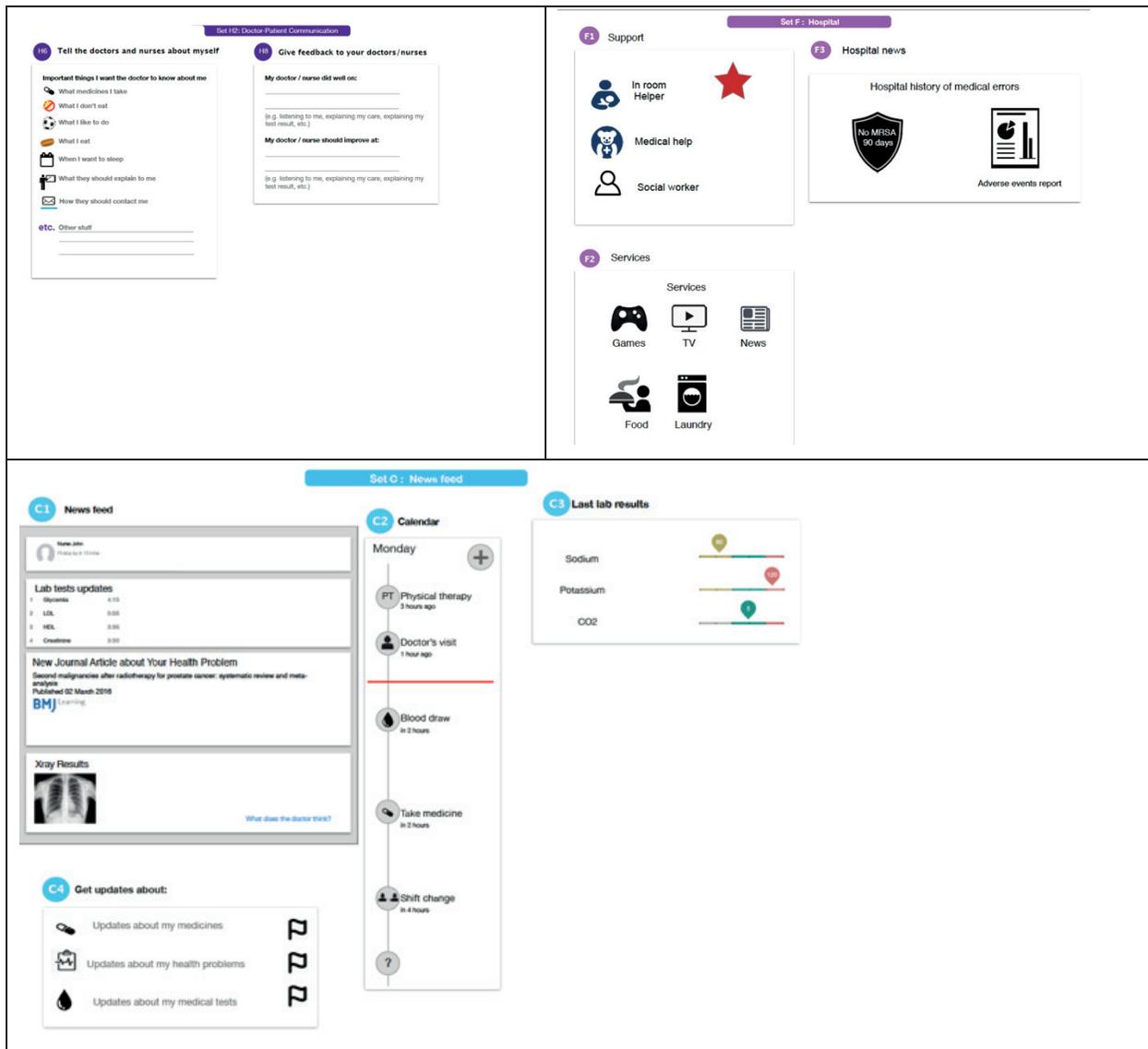
APPENDIX B

Report for NURI _ Patient_ Evaluation Survey

Response Statistics	1.Are you here as
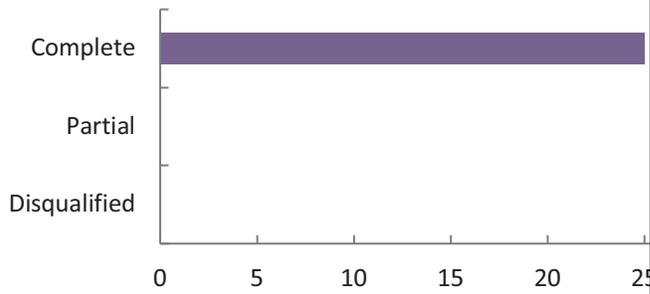
	Count	Percent
Complete	25	100
Partial	0	0
Disqualified	0	0
Totals	25	
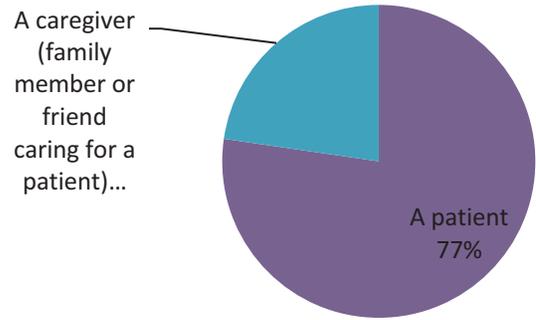
Value	Percent	Count
A patient	77.3%	17
A caregiver (family member or friend caring for a patient)	22.7%	5
	Totals	22

2.Hospital
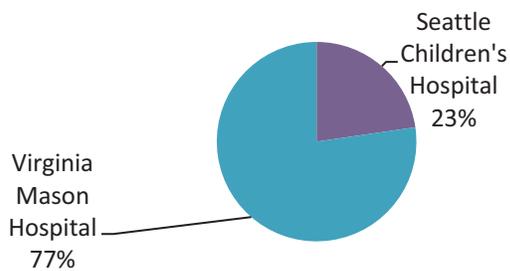
Value	Percent	Count
Seattle Children's Hospital	22.7%	5
Virginia Mason Hospital	77.3%	17

3.Adult Patient's age

Value	Percent	Count
25 to 34	11.8%	2
35 to 44	17.6%	3
55 to 64	35.3%	6

149
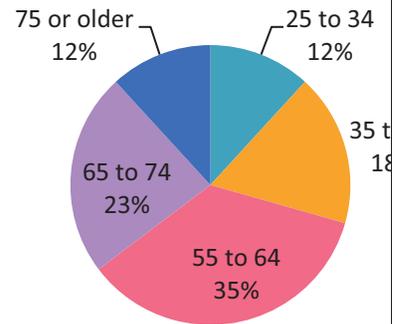
	Totals	22		

65 to 74	23.5%	4
75 or older	11.8%	2
	Totals	17

4.Caregiver's age
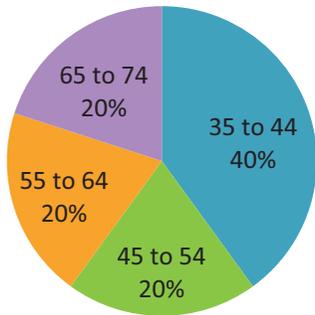
Value	Percent	Count
35 to 44	40.0%	2
45 to 54	20.0%	1
55 to 64	20.0%	1
65 to 74	20.0%	1
	Totals	5

5.children patients' Age
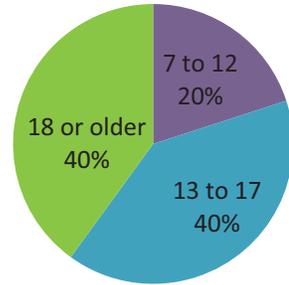
Value	Percent	Count
7 to 12	20.0%	1
13 to 17	40.0%	2
18 or older	40.0%	2
	Totals	5

6.I'm very comfortable using technologies
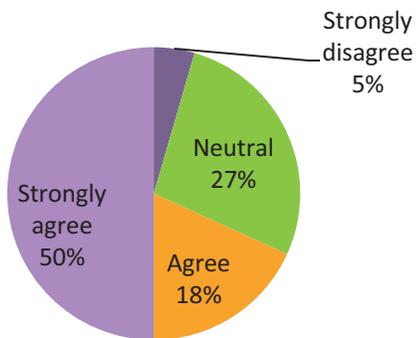
Value	Percent	Count

7.Have you ever used an intelligent assistant such as Alexa and Siri ?

150
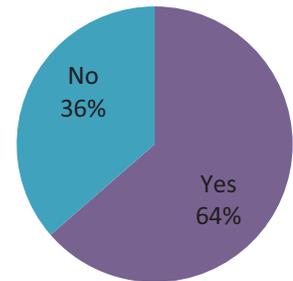
Strongly disagree	4.5%	1
Neutral	27.3%	6
Agree	18.2%	4
Strongly agree	50.0%	11
	Totals	22

Value	Percent	Count
Yes	63.6%	14
No	36.4%	8
	Totals	22

8.How easy is it for you to understand what is happening in your care?
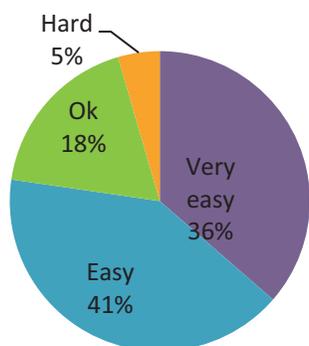
Value	Percent	Count
Very easy	36.4%	8
Easy	40.9%	9
Ok	18.2%	4
Hard	4.5%	1
	Totals	22

9.Have you ever recorded a medical conversation?
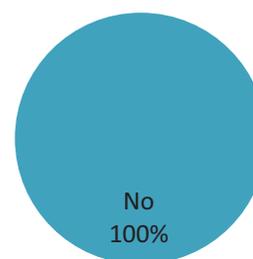
Value	Percent	Count
No	100.0%	22
	Totals	22

10.Education

151
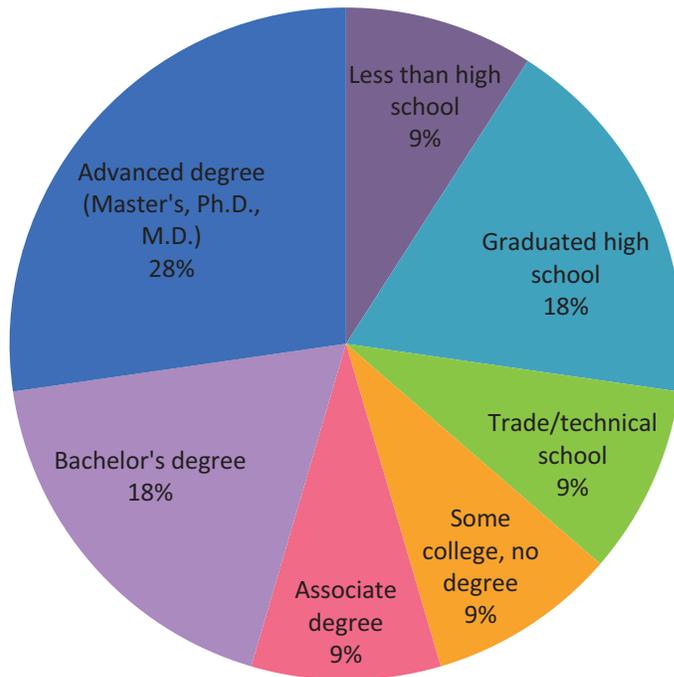
Value	Percent	Count
Less than high school	9.1%	2
Graduated high school	18.2%	4
Trade/technical school	9.1%	2
Some college, no degree	9.1%	2
Associate degree	9.1%	2
Bachelor's degree	18.2%	4
Advanced degree (Master's, Ph.D., M.D.)	27.3%	6
	Totals	22

11. Race/Ethnicity / Heritage
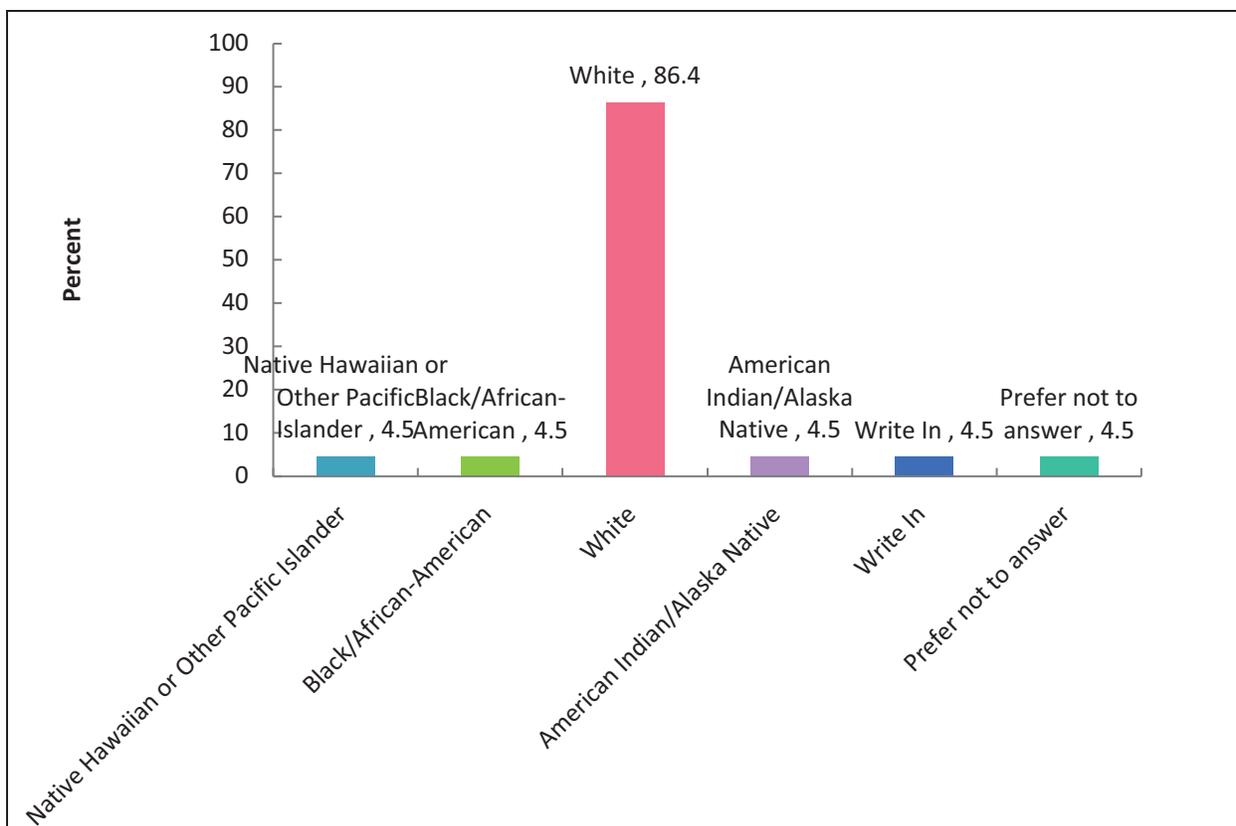
Value	Percent	Count
Native Hawaiian or Other Pacific Islander	4.5%	1
Black/African-American	4.5%	1
White	86.4%	19
American Indian/Alaska Native	4.5%	1
Write In	4.5%	1
Prefer not to answer	4.5%	1

12.What is your gender?	13.Which topics do you care about the most in your discussion with your care team? (1 is the most important, 7 is the least important)

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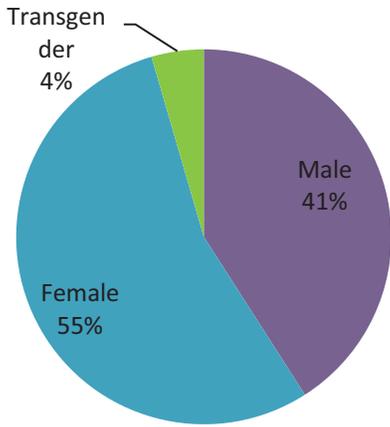
Value	Percent	Count
Male	40.9%	9
Female	54.5%	12
Transgender	4.5%	1
	Totals	22

Item	Over all Rank	Score	Total Respondents
Diagnosis	1	116	22
My test results	2	103	22
What my care team is doing for my care	3	100	22
What I need to do for my care	4	88	22
Progress of my care	5	85	22
My medications	6	82	22
Lifestyle and diet recommendations	7	42	22

15. How certain are you that you are able to remember all that your doctor told you?
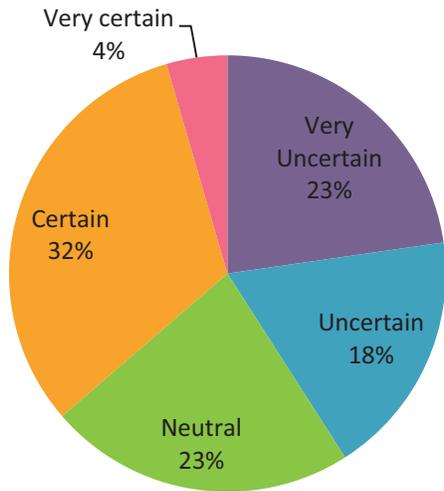
Value	Percent	Count
Very Uncertain	22.7%	5
Uncertain	18.2%	4
Neutral	22.7%	5
Certain	31.8%	7
Very certain	4.5%	1
	Totals	22

16.How certain are you that you are able to understand all of what your doctor told you?
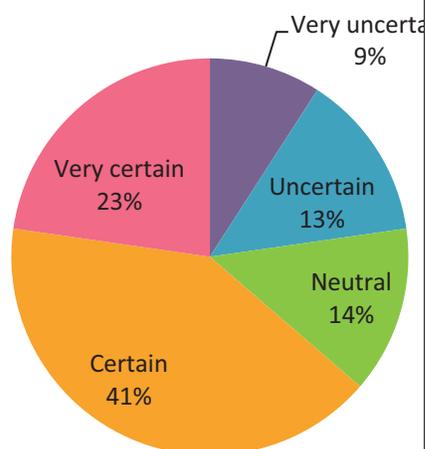
Value	Percent	Count
Very uncertain	9.1%	2
Uncertain	13.6%	3
Neutral	13.6%	3
Certain	40.9%	9
Very certain	22.7%	5

17.How certain are you that you are able to successfully plan your care after talking with your doctor?
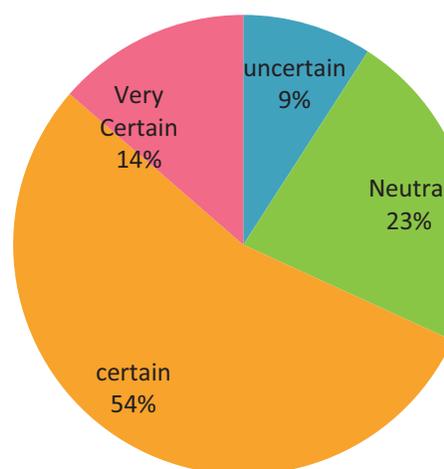
Value	Percent	Count
uncertain	9.1%	2
Neutral	22.7%	5
certain	54.5%	12
Very Certain	13.6%	3

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	Totals	22

	Totals	22

18.How certain are you that you are able to successfully follow your doctor recommendations from the conversation?

Value	Percent	Count
Uncertain	13.6%	3
Certain	54.5%	12
Very certain	31.8%	7
	Totals	22

19.How certain are you that you are able to successfully share all the news your doctor told you with your caregivers (family and friends)?

Value	Percent	Count
Uncertain	13.6%	3
Neutral	13.6%	3
Certain	45.5%	10
Very certain	27.3%	6
	Totals	22

20. How certain are you that you are able to successfully re-explain what your doctor/nurse told you to your family caregivers

21.Are there any questions that you wish you have asked during the conversation we recorded with your doctor?

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Value	Percent	Count
Very uncertain	9.1%	2
Uncertain	27.3%	6
Neutral	27.3%	6
Certain	22.7%	5
Very certain	13.6%	3
	Totals	22
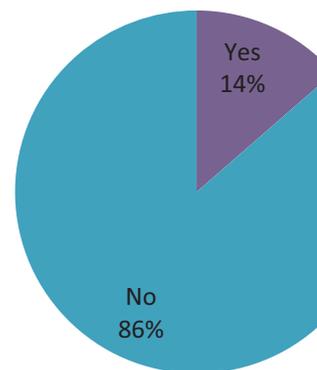
| Value	Percent	Count
Yes	13.6%	3
No	86.4%	19
	Totals	22

24. From the NURI generated transcript/audio, which topics do you care about the most? (1 is the most important, 7 is the least important)

Item	Overall Rank	Score	Total Respondents
My test results	1	80	15
Diagnosis	2	79	15

26. How well did NURI meet your needs in revisiting the conversations you recorded with your doctors and nurses?

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What my care team is doing for my care	3	70	15
Progress of my care	4	58	15
What I need to do for my care	5	57	15
My medications	6	51	15
Lifestyle and diet recommendations	7	25	15
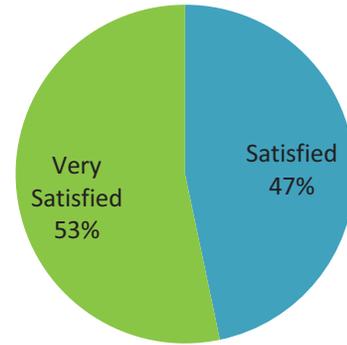
Value	Percent	Count
Satisfied	46.7%	7
Very Satisfied	53.3%	8
	Totals	15

27. What do you think about the features? (1 star for the least, 5 start for the most)

		Usefulness	Design
Play audio recording	Count	15	14
Read transcripts	Count	15	15
Replay highlights	Count	15	15
Check questions I asked	Count	15	15
Links to educational materials	Count	15	15

## 29. With the help of NURI, How certain are you that you are able to understand all of what your doctor would tell you?
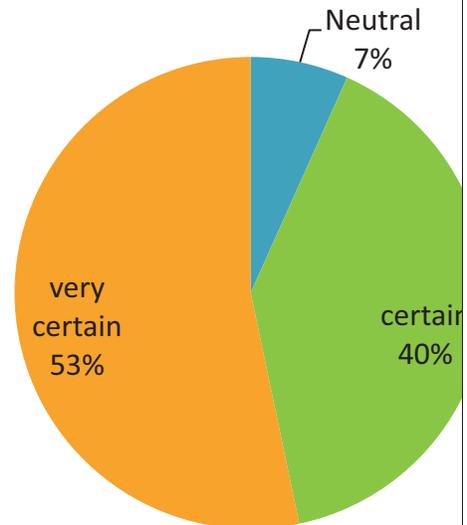
Value	Percent	Count

158

	Neutral	6.7%	1
	certain	40.0%	6
	very certain	53.3%	8
		Totals	15

30.With the help of NURI, How certain are you that you are able to successfully plan your care after talking with your doctor?

Neutral
7%

very certain
53%
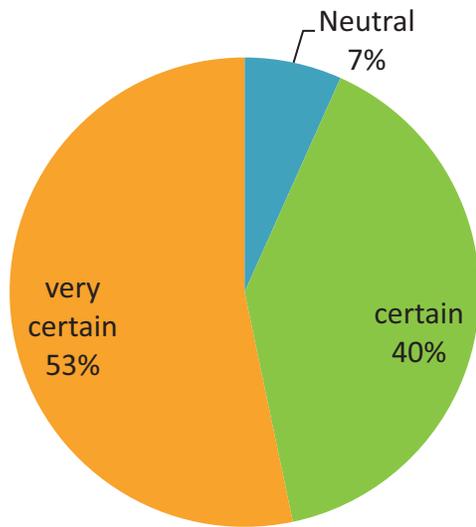
certain
40%

Value	Percent	Count
Neutral	6.7%	1
certain	40.0%	6
very certain	53.3%	8
	Totals	15

31. With the help of NURI, how certain are you that you are able to successfully follow your doctor recommendations from the conversation?


Neutral
7%

very certain
60%
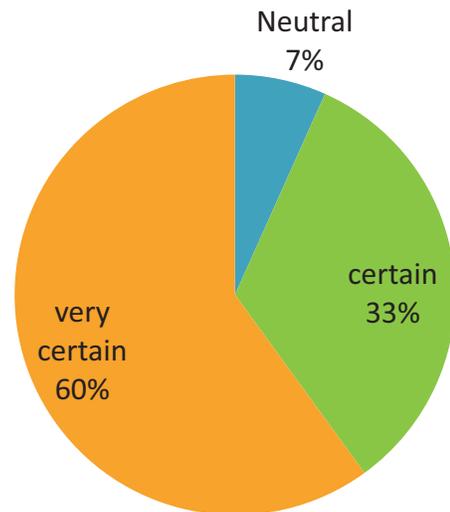
certain
33%

| Value	Percent	Count
Neutral	6.7%	1
certain	33.3%	5
very certain	60.0%	9
	Totals	15

32.With the help of NURI, how certain are you that you are able to share all the news

33.With the help of NUIRI, how certain are you that you are able to

your doctor/nurse told you with your caregivers (family and friends)
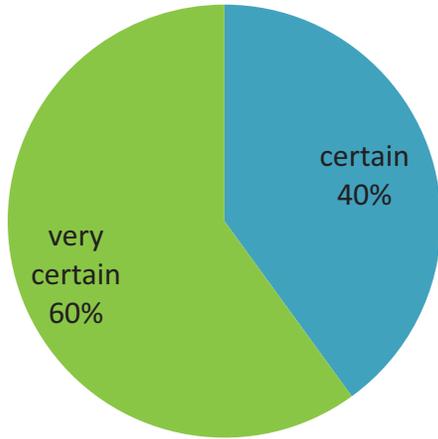
Value	Percent	Count
certain	40.0%	6
very certain	60.0%	9
	Totals	15

successfully re-explain what your doctor/nurse told you to your family caregivers
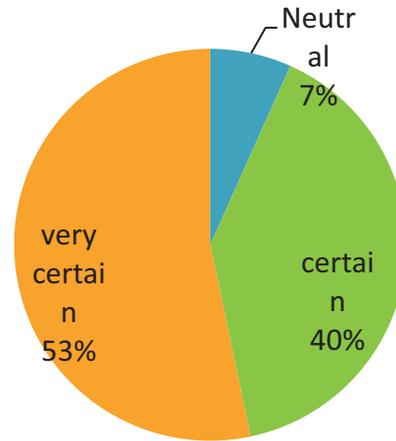
| Value	Percent	Count
Neutral	6.7%	1
certain	40.0%	6
very certain	53.3%	8
	Totals	15

34.Based on your experience using this system, please indicate whether you agree or disagree with the following statements:

	Strongly disagree		Disagree		Neutral		Agree		Strongly agree		Responses
	Count	Row %	Count	Row %	Count	Row %	Count	Row %	Count	Row %	Count

I would like to use this system frequently.	0	%	0	%	2	13.3%	7	46.7%	6	40.0%	15
the system is simple.	0	%	1	6.7%	2	13.3%	7	46.7%	5	33.3%	15
the system is easy to use.	0	%	0	%	3	20.0%	8	53.3%	4	26.7%	15
I think that I could use the system without the support of a technical person.	0	%	2	13.3%	1	6.7%	9	60.0%	3	20.0%	15
the various functions in the system were well integrated.	0	%	1	6.7%	0	%	11	73.3%	3	20.0%	15

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The system was consistent	0	%	0	%	2	13.3 %	8	53.3 %	5	33.3 %	15
I would imagine that most people would learn to use the system very quickly.	0	%	0	%	3	20.0 %	7	46.7 %	5	33.3 %	15
I found the system very intuitive.	0	%	0	%	2	13.3 %	10	66.7 %	3	20.0 %	15
I felt very confidence using the system.	0	%	0	%	2	13.3 %	8	53.3 %	5	33.3 %	15
I could use the system without having to learn anything new.	0	%	0	%	2	13.3 %	9	60.0 %	4	26.7 %	15

35.SUS score
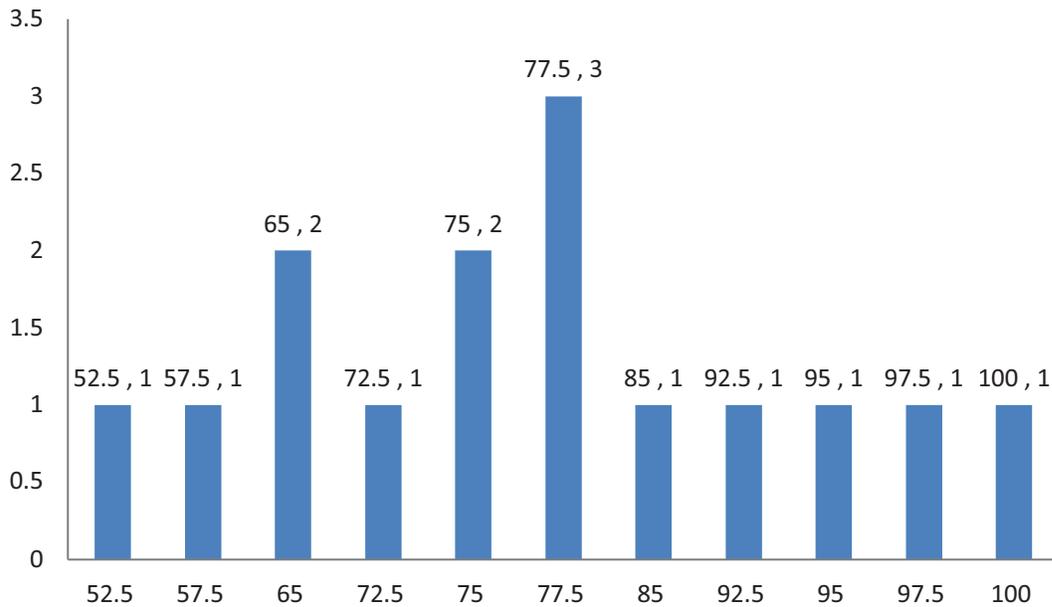
## 36.Would you rather
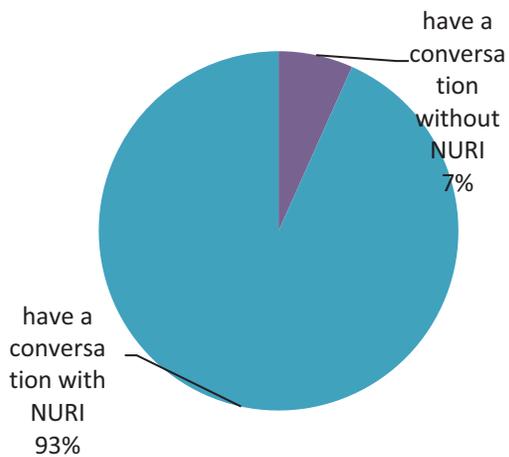
Value	Percent	Count
have a conversation without NURI	6.7%	1
have a conversation with NURI	93.3%	14

37.Having NURI made communication with my doctors and nurses:
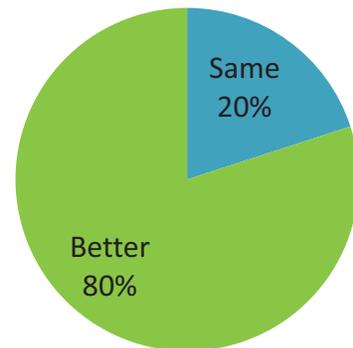
Value	Percent	Count
Worst	0	0
Same	20.0%	3
Better	80.0%	12

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	Totals	15			Totals	15

38.NURI helped me remember the conversations I recorded
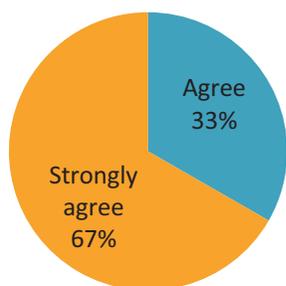
Value	Percent	Count
Agree	33.3%	5
Strongly agree	66.7%	10
	Totals	15

39.NURI helped me understand the conversations I recorded
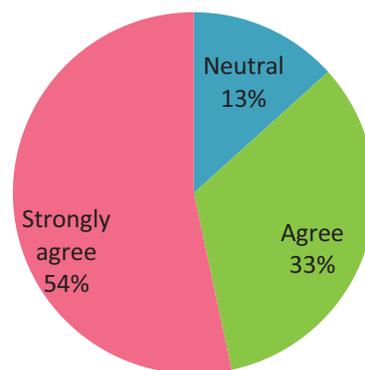
Value	Percent	Count
Neutral	13.3%	2
Agree	33.3%	5
Strongly agree	53.3%	8
	Totals	15

40.Rank your preferences for followups after medical conversation

Item	Overall Rank	Score	Total Respondents
NURI	1	57	15
paper summary	2	37	14
Audio Recording	3	36	14
Nothing	4	9	9

APPENDIX C

NURI interviews

NURI patient Interview

Metadata
Patient _____
Used NURI by themselves (Yes /No)____Number of recordings_____
Length_____

Thanks a lot for helping us test Nuri – the app on the iPad. We are looking forward to getting your feedback about it. We want to ask you some questions about NURI. And, we want to learn more about your preferences for summarizing and simplifying the medical conversations you have with your doctors and nurses.

INTERACTION WITH NURI?

Perceived value:
1. So, how did the rest of your hospital stay go since I last saw you?
2. Did you get the chance to use NURI by yourself? How did that go?
3. In what ways did you find Nuri helpful? Do you have any examples of that?
4. In what ways did you find Nuri not helpful/harmful? Do you have any examples of that?

Impact on patient-doctor relationship:
1. In what ways did Nuri help you **notice /understand** what your doctors and nurses has told you
2. Is there anything that you learned that you wouldn't have noticed otherwise? If yes, could tell me more about it
3. How comfortable were you using NURI?
4. How comfortable do you think your doctors and nurses were with you using NURI?
5. What could it be changed to get everyone more comfortable with using NURI?

Optional:
1. In what ways did Nuri make it harder to **notice /understand** what your doctors and nurses has told you
2. In what ways did Nuri make it harder to **notice /understand** what your doctors and nurses has told you

How to summarize and simplify

- Ideally, Nuri will be able to summarize the conversation for you so you don't have to read or listen to the whole conversation.
- #go through of the transcripts
- Are there any questions that you wish you asked your doctors? Is there any questions you want to ask now?
- So, we will go through one of your transcripts. And, imagine you are teaching Nuri how to summarize future conversations for you by telling it which part important, which part is not, and why.

The second thing we want to do is to make this tool explain things for you.

Since we identified these important concepts. Let's see how to explain them better and make them simpler.

- For this part, what resources do you think will be helpful understand things better: Doctors, nurses, websites, peer patients
- **Format:** What format would be better?
  Text, audio, video, AR/VR

Let's summarize

1. For your future conversations, would rather have Doctor and nurses + prototype VS Just Doctor/nurses? Why?
2. What concerns do you have about using this prototype?
3. What would you change?
4. Is there anything else you want to tell me about using NURI

- What did you like the most about using Nuri?
- What did you dislike the most about using Nuri?
- Is there anything else you want to add?

NURI clinician Interview

Thanks a lot for helping us test Nuri. We are looking forward to getting your feedback about it.

INTERACTION WITH NURI?

Perceived value:
1. In what ways did you find Nuri helpful? Do you have any examples of that?
2. In what ways did you find Nuri not helpful/harmful? Do you have any examples of that?
3. What concerns do you have about using Nuri?

Impact on patient-doctor relationship:
1. In what ways did Nuri help your communication with your patients
2. In what ways did Nuri harm your communication with your patients
3. How comfortable were you with your patients using NURI?
4. How comfortable do you think your patients were using NURI?
5. What you rather interact with your patient with NURI or without NURI? could it be changed to get everyone more comfortable with using NURI?
6. What would you change?
7. What else did you think about Nuri

How to summarize and simplify

- Ideally, Nuri will be able to summarize the conversation you had with your patients so they don't have to read or listen to the whole conversation.
- So, in this exercise, imagine you are teaching NURI how to summarize future conversations for your patients by telling it which part is important, which part is not, and why
- **Resources:** Is there any resources you want NURI to use to explain these concepts
  - Doctors, nurses, websites, peer patients
- **Format:** What format would be better?
  - Text, audio, video, AR/VR