User Interfaces for Patient-Centered Communication of Health Status and Care Progress

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The recent trend toward patients participating in their own healthcare has opened up numerous opportunities for computing research. This dissertation focuses on how technology can foster this participation, through user interfaces to effectively communicate personal health status and care progress to hospital patients.

I first characterize the design space for electronic information communication to patients through field studies conducted in multiple hospital settings. These studies utilize a combination of survey instruments, and low- and high-fidelity prototypes, including a document-editing prototype through which users can view and manage clinical data to automatically associate it with progress notes. The prototype, activeNotes, includes the first known techniques supporting clinical information requests directly within a document editor. A usage study with
ICU physicians at New York-Presbyterian Hospital (NYP) substantiated our design and revealed how electronic information related to patient status and care progress is derived from a typical Electronic Health Record system.

Insights gained from this study informed following studies to understand how to design abstracted, plain-language views suitable for patients. We gauged both patient and physician responses to information display prototypes deployed in patient rooms for a formative study exploring their design. Following my reports on this study, I discuss the design, development and pilot evaluations of a prototype Personal Health Record application providing live, abstracted clinical information for patients at NYP. The portal, evaluated by cardiothoracic surgery patients, is the first of its kind to allow patients to capture and monitor live data related to their care.

Patient use of the portal influenced the subsequent design of tools to support users in making sense of online medication information. These tools, designed with nurses and pharmacists and evaluated by cardiothoracic surgery patients at NYP, were developed using topic modeling approaches and text analysis techniques. Embodied in a prototype called Remedy, they enable rapid filtering and comparison of medication-related search results, based on a number of website features and content topics. I conclude by discussing how findings from this series of studies can help shape the ongoing design and development of patient-centered technology.
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DEDICATION

To my husband, Richard Patterson
CHAPTER 1
INTRODUCTION

Making improvements to health care in the United States is a major focus for health care organizations, medical practitioners, corporations, consumers, patient advocates, and politicians. Often, health information technology (HIT) is invoked as a broad solution to a wide variety of problems in health care, promising improvements in efficiency, patient safety, accountability, billing, and more. But experts in both HIT and medicine agree that the widespread shift from a paper-based system to an electronic one begets a rich set of challenges and opportunities for the application of computer science and Human–Computer Interaction (HCI).

As computing technology is rapidly integrated into care settings, data in HIT systems continues to grow in size and complexity. Thus far, this complexity has limited access to these systems, and their data, to expert users such as care administrators, clinicians, and biomedical researchers. While many organizations call for advancements in data analytics, feature extraction, organization, and visualization to make meaningful use of clinical data, efforts to advance the state of the art have focused thus far on serving expert users. Consequently, laypeople, such as patients and their family members, cannot benefit from the rich data—and
resulting knowledge—that resides within the clinical information systems used to manage their care. These limitations disenfranchise patients from the inherently collaborative nature of patient care. Opportunities are lost for patients to resolve discrepancies in their data, add to the data when it is incomplete, and use it to inform timely, collaborative decisions.

As these information systems evolve to manage the complex information landscape in healthcare settings, it becomes increasingly imperative to provide patients with tools to access and contribute to their clinical information, in patient-centered ways. Our current lack of such tools impacts clinicians’ responsibilities while potentially leading to other serious consequences. As I discuss in more detail in Chapter 2, numerous studies describe patients’ poor ability to retain verbal information received during care, as well as negative patient outcomes tied to lack of access to information during care.

Creating such tools for patients requires efforts to address the complexity of technical terms and organization of their data, support for patient exploration and research of unfamiliar terms and concepts, and an increased understanding of temporal considerations for making views of the data available (viewing emotionally-charged diagnostic test results, prior to a discussion about it, could have serious consequences for both patients and the care organizations on which they rely).

In fact, HIT will need to be broadened to support patient understanding of clinical and health-related data, according to patient preferences, capabilities, and healthcare goals. It will need to support the review and management of patient data shared among multiple care team members, as well as allow task management, event outcomes, and care plans to be tied to that data. As a recent Computing Research Association innovation workshop described, “Empowering people—providers and consumers—improves healthcare quality. Healthcare
requires effective actions by both consumers and providers; thus, transformational influences of information technology on healthcare will come via enabling both providers and consumers to achieve more, both independently and together” (Graham et al., 2011).

This dissertation comprises a series of studies to design, build, and evaluate simplified presentations of health information to allow hospital patients to more readily understand health status and medical treatment information. It follows an iterative, user-centered design paradigm, incorporating design studies followed by the development of prototype systems that provide novel information presentation and interaction techniques to communicate patient status and care progress information. The design studies include fieldwork and ethnography conducted with clinicians and patients to understand patients’ electronic information needs during specific types of hospital care, and to organize clinical information effectively for real-time presentations of patient data during that care. The prototype systems include algorithmic approaches to creating graphical and textual patient-friendly explanations of inpatient medication events, medication-related web pages describing medication therapies, and inpatient communication tools.

In designing for hospital patients, these studies address an important challenge faced by those in already-challenging circumstances: hospital patients frequently lack information about various aspects of their care, including their current health status, and their expected clinical course.

THESIS STATEMENT

In summary, this thesis addresses how HIT can promote patient engagement in hospital care through novel computational applications that enable 1) situational awareness, 2) learning about
treatments and therapies, and 3) patient articulation of experiences and concerns. Promoting such engagement can positively impact health outcomes by improving patient satisfaction and knowledge, reducing patient anxiety related to lacking or forgetting clinical information, and providing needed mechanisms to capture patient-reported data to supplement existing data in clinical information systems.

I outline principles for applications that promote patient engagement in care settings. These principles were distilled through findings of a series of studies conducted in multiple care contexts with patients and clinicians. I discuss how these principles are underscored by data derived from field observations, interviews and surveys, as well as findings related to the design and deployment of three technology applications. I then describe the impacts of augmenting HIT, including Clinical Information Systems (CIS), through approaches to designing technology for patient use, arguing that designing such technology according to the principles outlined promotes patient engagement in their care. In particular, I highlight opportunities for patient-centered technology to improve patient satisfaction, help patients understand and participate in decision-making about treatments, and offer opportunities to clarify and correct electronic data in the medical record. While measuring the direct effect of patient engagement on health outcomes is beyond the scope of this dissertation, I offer evidence of the potential for novel computational applications to impact patient engagement in measurable ways.

To frame the empirical basis for these claims, I draw on evidence from six studies. Each study builds upon findings from the previous study or studies within this dissertation. Each of the six studies focuses on a particular facet of enabling electronic communication of patient status and care progress. The first of these addresses the information needs of physicians, while the remaining five studies address patient needs. After summarizing related work in Chapter 2, I
describe my studies and contributions in Chapters 3–8, concluding with discussion in Chapter 9.

In Chapter 3, I explore how data in a typical Electronic Health Record (EHR) system informs physicians’ working representations of patient status and care progress. I first describe fieldwork including observations and both semi-structured and structured-interviews in two ICUs. I then describe the development of a novel note-taking application, with which ICU physicians created and managed sample progress notes.

Next, in Chapter 4, I describe two studies addressing the discrepancy between the structure and terminology used in the EHR and the abstracted, plain-language views that are useful to patients, by gauging both patient and physician responses to a patient-centered information display prototype. This prototype, a large-format display placed in patient rooms, included abstractions of selected clinical information based on the patient’s medical record.

In Chapter 5, I describe a field study designed to offer a detailed assessment of electronic medication information needs of patients during inpatient cardiac care. Chapter 6 outlines the design and development of a custom PHR portal to communicate information about the patient’s inpatient medications, home medications, allergies, and care team, and to provide a mechanism for capturing patient feedback on pain levels and aspects of care. I also describe a refined design for medication information in the custom PHR portal. Through interactive browsing of organized views of this data, patients can learn more about them by accessing relevant, personalized content from sources such as the National Library of Medicine consumer web site, MedlinePlus (Miller et al., 2000).

After validating our techniques through heuristic and content analyses, we conducted a larger study with cardiology step-down patients to understand whether and how they used the software. This study collected a combination of data from survey instruments, semi-structured
interviews and logged usage data for the purposes of data triangulation (Farmer et al., 2006). Triangulation was used to confirm, refute, or clarify findings by reporting and comparing data gathered describing the same study events, through different methods. Before concluding Chapter 6, I discuss techniques, guided by established EHR usability and information design guidelines (Armijo et al., 2009; Powers, 1988; Tang and Newcomb, 1998) to present inpatient medication information. These techniques were refined through iterative review by pharmacists, from which additional guidelines for their design emerged.

In the refined medication information views presented in Chapter 6, each medication entry is augmented with a short explanation of the medication’s uses. In Chapter 7, I discuss a study with physicians and lay people assessing the feasibility of using online sources to select short, plain-language explanations to include in patient-centered views of clinical data. I follow this chapter with an exploration of approaches to identify topic-based explanations of medication-related information from consumer-facing webpages. Finally, in Chapter 8, I introduce novel search tools in a user interface for medication-related web searches. These search tools include topic-based explanations and other topic-based browsing tools, identified previously from consumer-facing webpage content.

In Table 1.1, I introduce each study by summarizing its purpose and/or research aims and corresponding measures used. In Table 1.2, I provide details of specific study settings, participants, methods, instruments, and analysis, for each study. Finally, in Table 1.3, I tie the study measures and the study design details outlined in the previous two tables, to the evidence yielded from each study—I draw on this evidence to derive the principles of patient engagement that are central to my thesis statement. Each study is further described in detail in the chapters that follow. Together, these chapters describe a course of experimentation to explore presentation
and interaction techniques that make salient patient status and care information available in ways that support patient engagement in care.
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<td>• What are the temporal and relational features of the data retrieved during documentation of patient status and care?</td>
<td>• How are these features expressed in documentation about patient status and care?</td>
<td>3</td>
</tr>
<tr>
<td>1a</td>
<td>Observe and analyze patient responses to large-format displays of abstractions of clinical information. Arrive at a large-format design for presenting this information during care. Uncover steps needed for automated abstraction.</td>
<td>• What information in the patient record is useful for &quot;live&quot; patient review during care?</td>
<td>• How should this information be abstracted for display in a patient-friendly manner?</td>
<td>3</td>
</tr>
</tbody>
</table>

STUDIES AND ASSOCIATED RESEARCH AIMS
<table>
<thead>
<tr>
<th>Study</th>
<th>Description/Aim(s)</th>
<th>Research Question(s)</th>
<th>Measure(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>4b</td>
<td>Understand physician attitudes about sharing EHR data directly with patients.</td>
<td>- Are physicians willing to allow direct, automatic information sharing with patients during clinical visits? - What types of information are physicians concerned about sharing on an information display with patients during visits, and why? - Patient use of portable electronic notepad applications over 24-48 hours</td>
<td>Patient use of portal and electronic notepad applications over 24-48 hours</td>
</tr>
<tr>
<td>4a</td>
<td>Assess which portions of the electronic health record are sensitive for direct patient view during care and why.</td>
<td>- What are the user interface functional requirements, based on the findings from the previous three studies, for the design of a patient-centered inpatient portal? - What information types and aspects of presentation are needed to support viewing of detailed information on inpatient medications?</td>
<td>Patient responses to Satisfaction and Engagement Survey</td>
</tr>
<tr>
<td>3</td>
<td>Determine patient information needs related to electronic information on inpatient medications.</td>
<td>- Given knowledge of general of information types and aspects of presentation are known, what interactions are needed to support viewing of detailed information on inpatient medications?</td>
<td>Nurse-reported information needs</td>
</tr>
<tr>
<td>2b</td>
<td>Understand physician attitudes about sharing EHR data directly with patients.</td>
<td>- Assess which portions of the electronic health record are sensitive for direct patient view during care and why.</td>
<td>Physician participant survey responses</td>
</tr>
<tr>
<td>Study Aim(s)</td>
<td>Research Question(s)</td>
<td>Measured(s)</td>
<td>Chapter</td>
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<tr>
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</tr>
<tr>
<td>Search tools</td>
<td>High-quality Web content allows patients to better locate relevant information.</td>
<td>Expert use session</td>
<td>6a</td>
</tr>
<tr>
<td>Search tools</td>
<td>Can search tools based on page- and site-based features help patients to locate relevant online medication information?</td>
<td>Patient and family member responses to search tools</td>
<td>6b</td>
</tr>
<tr>
<td>Described explanations: ranked of Web-based</td>
<td>What are the similarities and differences between how doctors and patients view &quot;good&quot; explanations?</td>
<td>Expert evaluation of tools</td>
<td>7</td>
</tr>
<tr>
<td>Study participant responses to search tools</td>
<td>How can we characterize properties of &quot;good&quot; explanations?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Setting</td>
<td>Participants</td>
<td>Instrument(s)</td>
</tr>
<tr>
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</tr>
<tr>
<td>1a</td>
<td>Cardiothoracic ICU, Surgical ICU</td>
<td>Attending Physicians and Residents (n=12)</td>
<td>• ICU Data Monitoring and Use Survey (n=8) • Field observations</td>
</tr>
<tr>
<td>2a</td>
<td>Emergency Department (ED)</td>
<td>ED Patients (n=18)</td>
<td>• Large-format paper prototypes, Wizard-of-Oz field study</td>
</tr>
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<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4a</td>
<td>Cardiothoracic ICU, Surgical ICU</td>
<td>Step-Down Patients (n=20)</td>
<td>• Custom PHR Portal</td>
</tr>
<tr>
<td>4b</td>
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<td></td>
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**Study:**

1. **Cardiothoracic ICU, Surgical ICU**
   - Setting: Cardiothoracic ICU, Surgical ICU
   - Participants: Attending Physicians and Residents (n=12)
   - Instrument(s): ICU Data Monitoring and Use Survey (n=8)
   - Methods: Field observations
   - Analysis: Hybrid thematic analysis

2. **Emergency Department (ED)**
   - Setting: ED
   - Participants: ED Patients (n=18)
   - Instrument(s): Large-format paper prototypes, Wizard-of-Oz field study
   - Methods: Hybrid thematic analysis, inductive coding
   - Analysis: Hybrid thematic analysis

3. **Cardiac Step-Down**
   - Setting: Cardiac Step-Down
   - Participants: Step-Down Nurses (n=6), Step-Down Patients (n=11)
   - Instrument(s): Medication Information Needs Interview Guide
   - Methods: Semi-structured survey
   - Analysis: Hybrid thematic analysis, inductive coding

4. **Cardiac Step-Down**
   - Setting: Cardiac Step-Down
   - Participants: Step-Down Patients (n=20)
   - Instrument(s): Custom PHR Portal
   - Methods: Semi-structured interview
   - Analysis: Comparative inductive coding, descriptive statistics

**Study:**

1. **Cardiothoracic ICU, Surgical ICU**
   - Setting: Cardiothoracic ICU, Surgical ICU
   - Participants: Attending Physicians and Residents (n=12)
   - Instrument(s): ICU Data Monitoring and Use Survey (n=8)
   - Methods: Field observations
   - Analysis: Hybrid thematic analysis

2. **Emergency Department (ED)**
   - Setting: ED
   - Participants: ED Patients (n=18)
   - Instrument(s): Large-format paper prototypes
   - Methods: Field observations
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3. **Cardiac Step-Down**
   - Setting: Cardiac Step-Down
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   - Methods: Semi-structured survey
   - Analysis: Hybrid thematic analysis, inductive coding

4. **Cardiac Step-Down**
   - Setting: Cardiac Step-Down
   - Participants: Step-Down Patients (n=20)
   - Instrument(s): Custom PHR Portal
   - Methods: Semi-structured interview
   - Analysis: Comparative inductive coding, descriptive statistics
### Study Setting

<table>
<thead>
<tr>
<th>1a</th>
<th>Cardiac Step-Down Patients (n=12)</th>
<th>• Remedy search prototype</th>
<th>• Treatment of patients to reduce symptoms and improve outcomes</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Non-specific Clinical Domain Experts (n=8)</td>
<td>• Web-based survey</td>
<td>• Assessment of knowledge and skills in managing Cardiac Step-Down patients</td>
</tr>
<tr>
<td>1b</td>
<td>Cardiac Step-Down Patients</td>
<td>• Remedy search prototype</td>
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</tr>
</tbody>
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### Participants

<table>
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<tr>
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<th>Participants</th>
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<tr>
<td>1a</td>
<td>Cardiac Step-Down Patients</td>
<td>Physicians actively practicing in U.S. hospitals (emergency medicine, neurology, cardiology, pediatrics, surgery, and internal medicine)</td>
</tr>
<tr>
<td>1b</td>
<td>Cardiac Step-Down Patients</td>
<td>Physicians actively practicing in U.S. hospitals (emergency medicine, neurology, cardiology, pediatrics, surgery, and internal medicine)</td>
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### Methods

<table>
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<tr>
<th>Study</th>
<th>Measure(s)</th>
<th>Evidence</th>
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<tr>
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<td>Engaged in Cardiac Step-Down Patients</td>
</tr>
<tr>
<td>1b</td>
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### Analysis

<table>
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<tr>
<th>Study</th>
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<th>Evidence</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
<tr>
<td>1b</td>
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### Table 1.2 Summary of designs of dissertation studies.

<table>
<thead>
<tr>
<th>Study</th>
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<th>Evidence</th>
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<tr>
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<td>N/A</td>
<td>Engaged in Cardiac Step-Down Patients</td>
</tr>
<tr>
<td>1b</td>
<td>N/A</td>
<td>Engaged in Cardiac Step-Down Patients</td>
</tr>
<tr>
<td>Engagement Principle</td>
<td>Evidence</td>
<td>Study Measure(s)</td>
</tr>
<tr>
<td>----------------------</td>
<td>----------</td>
<td>-----------------</td>
</tr>
<tr>
<td>• Analysis of differences in patient and nurse-reported patient information needs</td>
<td>• Patient preference for intervention</td>
<td>• Medication search task correctness</td>
</tr>
<tr>
<td>• Patient use of electronic notepad</td>
<td>• Expert preference for intervention</td>
<td>• Medication search task completion</td>
</tr>
<tr>
<td>• Patient use of portal application over 24-48 hours</td>
<td>• Adoption of custom PHR portal, recorded use of portal applications</td>
<td>• Patient use of electronic notepad over 24-48 hours</td>
</tr>
<tr>
<td>• Situational awareness, learning about treatments and experiences and articulation of preferences</td>
<td>• Agreement in ratings of high-quality explanations</td>
<td>• Study participant ratings of Web-derived micro-explanations</td>
</tr>
</tbody>
</table>

Table 1. Evidence for thesis claims based on study measures.
CONTRIBUTIONS

The specific contributions of this dissertation, including the novel computational applications referred to in the thesis statement, include:

1. *Design of interaction techniques implemented within a novel document-editing prototype, to explore how electronic information related to patient status and care progress is derived from the EHR.* This prototype, activeNotes explores clinician retrieval, review and documentation of patient status information, including laboratory results, and previous progress notes. It introduces interaction artifacts called activeTags, which allow the user to flexibly specify information-update criteria and manage progress note content. ActiveTags are annotations that are attached to a content fragment and associated with data actions (retrieval, updates, and alerts) that act upon that content.

   The activeNotes prototype is the first clinical document editor to embody information retrieval (IR) techniques that support free text information requests directly within the document editor. Using activeTags in a qualitative study with ICU physicians, I learned about features of and relationships between clinical data types that are often reviewed when assessing health status and care progress.

2. *Characterization and analysis of the design space for electronic information delivery to hospital patients.* This characterization considers situational factors unique to the care environment and the electronic information within it, to provide the means to organize a novel research agenda focused on the challenges and opportunities that exist in leveraging the EHR and automating information extraction and abstracted presentation. It includes analyses of the usefulness of a variety of clinical information types to patients, assessment of
the detailed electronic information needs of patients at the point of care (Wilcox et al., 2012), and examinations of the ways in which electronic access to information affects patients’ and clinicians’ experiences (Wilcox et al., 2010).

3. **Design and pilot evaluations of a deployed prototype PHR portal application providing real-time, inpatient-centric clinical information to hospital patients.** This contribution represents the endpoint of an iterative process involving designers, medical informaticists, and both patients and providers in two care settings. This design process allows us to determine how information in an inpatient-centric application can be structured, organized and presented to patients effectively to allow them to both review and comment on information during care.

4. **Characterization of quality of short explanations of medical events and demonstrated feasibility of extraction.** This contribution identifies features of suitable consumer-facing web content from which fragments can be extracted to serve as explanations of medical events (Wilcox et al., 2011). These fragments, called “micro-explanations” were explored in a study soliciting perspectives of physicians and laypeople in determining explanation quality. After this study, I applied automated approaches to topic modeling, and text analysis to extract candidate “micro-explanation” content. After validating the usability and effectiveness of our approach through heuristic evaluations with the research team and content validation sessions with domain experts, I integrated these topic-based micro-explanations into a patient-centric web search application for further study with cardiology inpatients (Chapter 8).

5. **Design, implementation, and evaluation of tools to support users searching for medication information.** This contribution includes a medication information search prototype embodying tools to support rapid filtering and comparison of medication information search results, based on a number of website features and content topics. The tools were designed to
assist patients in locating relevant, high-quality web content. A field study with cardiothoracic surgery patients and their visiting family members during the post-operative hospital stay explored the utility of our prototype in comparison with an existing general-purpose search engine, validating the design of our tools. A follow-up study with domain experts offers further design insights.

TECHNOLOGY INFRASTRUCTURES

Two types of systems are augmented in the studies that follow: an Electronic Health Record (EHR) system, and a Personal Health Record (PHR) system, or PHR portal. EHRs are collections of digital patient medical records and other clinical information relevant to patient care. Their design and implementation was intended for doctors and hospital administrators, and they are generally owned by healthcare institutions. PHRs are secure, online health repositories, intended for patients. Patients can use PHRs to input information, see information from the patient record (once it has been exported from the EHR to the PHR or tethered) and access, manage, and share that information.

METHODS

I applied a combination of research methods to accommodate the specific research questions of each study. Some studies employ quantitative approaches, while others apply qualitative analyses. The use of multiple methods enabled me to gather rich data to conduct formative evaluations. The scientific roles of formative approaches have nuanced differences across different domains, yet echo a similar purpose: they offer preliminary findings serving as the foundation upon which specific phenomena of interest can be identified for further investigation. They serve to inform the design of subsequent research interventions (Rossi et al., 2004) and the
development process of technological artifacts (Carroll, 2003) and information systems (Kaplan and Maxwell, 2005). These evaluations are particularly useful for field studies (the studies described here were primarily conducted in clinical settings—a strength of formative evaluation includes its ability to “enable researchers to explicitly study the complexity of implementation projects and suggest ways to answer questions about context, adaptations, and response to change” (Stetler et al., 2006).

In this dissertation research, many of the formative studies conducted occurred “in the field” and thus utilized qualitative approaches. While they enable exploration, the qualitative studies I describe take a systematic approach to uncovering phenomena using techniques to collect and review data through multiple phases of analysis (Patton, 1987). While the end goal is not the translation of data to a numeric value, the methods are applied following a comparative degree of rigor to those of quantitative methods.

These qualitative methods consist mostly of thematic analysis. In thematic analysis, the goal is to identify a number of themes that adequately capture and describe textual data. Research has explored the flexibility of thematic analysis (Braun and Clarke, 2006), noting that it can be conducted in different ways in accordance with various methodological approaches. In this dissertation, I conducted thematic analysis in two primary ways:

1) An inductive, data-driven, iterative approach, referred to in the dissertation as *comparative inductive coding*. This approach borrows heavily from Grounded Theory (Charmaz, 2006), in that multiple members of the research team independently read through the transcripts and coded interview responses inductively. Researchers used an in-vivo style (as in open-coding) in which small “chunks” of transcribed textual data were assigned labels that were not pre-defined (i.e., not necessarily based on the
These low-level codes were then compared in an iterative fashion across research members to refine them (similar to axial coding). The team met to compare and contrast the themes, which were then refined (merged or split to more appropriately represent coherent groupings). The team iteratively determined higher-level themes represented by the groupings.

2) A hybrid, constructivist approach combining deductive and inductive strategies (Fereday and Muir-Cochrane, 2008), referred to in the dissertation as *hybrid thematic analysis*. In this approach, a researcher assigned codes that were strongly tied to the transcribed responses, as above. Members of the research team (typically two to three) reviewed these codes. In parallel, deductive approaches were used to organize the codes in terms of the researchers’ theoretical interest in the area or topic. The groupings were refined iteratively to consider both data-driven themes and themes representing theoretical interests. In reporting these data, I state which themes were specifically pursued in the interview questioning.

**RESEARCH ASSUMPTIONS**

This dissertation makes six main research assumptions. The first concerns the patient participants in these studies. Patients are viewed as non-experts (i.e., laypeople) in medicine—I consider health-related educational and explanatory materials designed for laypeople to be patient-directed materials. While data related to patients’ prior experience with personal health information management were collected, it impacted neither the design of studies nor the design of technologies created. No participating patients had medical degrees.
The second assumption concerns study methodologies used in the studies with hospital patient participants (described in Chapters 4, 5 and 6), in which it is assumed that by engaging patients during their hospital care, these patients can verbalize authentic and accurate information needs associated with a particular care context (e.g., needs related to Emergency Department (ED) care, post-cardiac-surgical care).

Next, it is assumed that computerized tools designed for inpatients, of the kind detailed in this research, would not replace verbal or written information—patients would not be required to rely solely on these systems to receive health status and care information. The assumption that, in addition to verbal communication, using a computerized tool would be a suitable method for communicating clinical information to patients is based on the Institute of Medicine (IOM) support of the use of information technology as a tool to increase safety and quality in health care (IOM, 2001).

It is assumed that explanatory materials designed for readers with lower health literacy also benefit those with higher levels of health literacy. This assumption is based on literature in the public health domain investigating information interventions written at levels accommodating varying health literacy skills (Powers, 1988).

Next, I assume that the prototypes I describe could be implemented within larger information ecosystems. Such implementation efforts might take several years. However, the past decade has seen increases in PHR technologies that make tethered data from the EHR available to patients through encrypted web services (Vawdrey et al., 2011b). These technologies are currently available at the health system, institution or EHR vendor level. For each of the prototype systems, I provide block diagrams that depict how they would interact with components in an existing information system. However, some of the functionality demonstrated
by the prototypes would currently require manual configuration, input and review. For example, patient-facing views of data might require that clinicians vet or even directly input certain information before it is provided to the patient. In the chapters describing the prototypes, I distinguish between manual input and functionality and automated approaches. For much of the manual functionality that was needed to conduct the studies, I discuss how automated techniques might be approached.

Finally, the analyses of studies described in Chapters 7 and 8 include hypothesis testing. In both, non-parametric tests are chosen, as normality cannot be assumed in the samples. In both, I use $\alpha=0.05$ as a threshold for significance. Test-specific calculations that are used to determine significance are reported with the results of each test.
CHAPTER 2

REVIEW OF THE LITERATURE

INTRODUCTION

This chapter summarizes the key socio-technical phenomena in medicine, medical informatics, public health, and other health-related domains that influence my research questions. It summarizes the literature supporting the significance of my thesis claims and contributions—comprising the humanistic “why” of the thesis. In subsequent chapters, I draw specific connections to technologies, studies and other work as they relate to the particular facet of research I discuss.

Here, I present four socio-technical foundations of the thesis: 1) The patient record as an artifact mediating healthcare coordination; 2) Clinical information transparency and its effects; 3) Patient-technology interactions in the hospital, with a focus on communication and information needs; and 4) Patient use of online resources to clarify aspects of treatment and aid in decision-making.
In healthcare practice, the electronic patient record largely mediates healthcare work (Fitzpatrick and Ellingsen, 2012). EHR systems serve as the primary repository for patient data—determining how it is stored, accessed, and consequently acted upon. These systems facilitate access by clinicians to patients’ medical histories, diagnostic tests, therapies and follow-up plans. They also serve as the primary means by which patient documentation is created, stored, and viewed. The prevailing paradigm of patient record utilization includes access and use of the system by clinicians during and outside of consultations. Patient access to this information is limited—occurring either in discussion with their clinicians (e.g., particular data in the patient record is referred to), through formal patient-initiated directives for a paper copy (typically requiring several weeks) or via PHR portals. PHR portals, when available, present views of portions of the patient record, delivered online but populated after the visit.

While EHR systems are now widely deployed in inpatient and ambulatory settings, early research identified the long-term agenda needed to better design these systems and organizational practices to support care processes (Shortliffe, 1999). In response to reports highlighting current health care system failures and inadequacies, the Joint Commission together with the IOM set forth patient safety priorities focused on enhancing the effectiveness of clinical communication (IOM, 2001; The Joint Commission, 2008). A number of negative health outcomes (increased length of stay, patient harm, and poor compliance) as well as inefficient use of resources have been tied to inadequate communication about patient care (Fagin, 1992; Larson, 1999; Sexton et al., 2000; Zwarenstein and Reeves, 2002).

Research on how the EHR and related technologies impact communication, including how the electronic record is used to prepare for and facilitate patient consultations, is critical to
improving clinical communication. Early research on the impact of these systems on communication calls for the need to better design them to consider practices in which the record is written, read and used in patient–clinician consultations (Heath and Luff, 1996). In line with this call, the Joint Commission prioritized the development of informatics solutions to improve communication in the clinical setting as a key patient safety goal (Joint Commission, 2002).

Patient care processes are heavily influenced by the form of communication (e.g., face-to-face versus electronic mail) (O’Connor et al., 2009); furthermore, communication between physician and patient is one of the few factors strong enough to be predictive of patient compliance with therapies (Becker and Maiman, 1975; Clever et al., 2008; Davis, 1971; Fuertes et al., 2007; Haynes et al., 1987; Ley, 1982) Thus, research focused on understanding how informatics solutions can best support the presentation, reasoning about, and sharing of clinical health record data—to support patient–clinician communication—is critical for effective care and positive long-term health outcomes.

CLINICAL INFORMATION TRANSPARENCY

In the interest of improving communication and information retention, interest has been growing in extending traditional hospital information systems to directly share information with patients. Patient-facing views into EHR systems can provide patients with information on their health, on the expected flow of clinical activities, and on the identity of their care teams during a hospital stay. Such sharing of information can provide unprecedented opportunities to educate patients, and, more generally, to better allow patients and their family members to participate in care planning and health-related decision-making (Greenfield et al., 1988; Kaplan et al., 1995; Maly et al., 1999). It is through this participation that patients can experience decreased
decisional conflict, and greater engagement and patient satisfaction: outcomes that have been shown to strongly relate to better long-term health outcomes (Bird and Walji, 1986; Larson et al., 1996; Longtin et al., 2010; Pratt et al., 2006).

The benefits of *direct, automated* information sharing come at a cost, however: providers are potentially removed as information filters between patients and their medical data (Bickmore et al., 2009; Wiljer et al., 2008). Concerns arise around patient comprehension of information, liability, and the altered role of physicians and nurses.

One trend in the vein of health information transparency focuses on the impact of direct sharing of physician-composed progress notes. In a large, recent trial, patients who opened notes about themselves reported feeling more in control of their care, and the majority of patient participants taking medications reported increased medication adherence. Notably, the volume of electronic messages from participating patients to their clinicians did not change (Delbanco et al., 2012).

Another, early facet of the literature focusing on clinical information transparency examines patient and physician responses to sharing *paper* charts with patients in various ambulatory and inpatient settings. Ross and Lin reviewed and aggregated earlier studies (2003), finding a modest benefit to such information sharing. Patient “access” to their medical record requires both the institutional infrastructure to make it available, and the ability for patients to utilize the information in it. Winkelman and Leonard identified structural characteristics influencing patient utilization of medical records and proposed an evaluation framework for patient-centered health record structure (2004).

The dominant trend in increasing patient access to clinical information includes the use of PHR systems to increase patient information access to diagnostic test results, medication orders,
and other clinical information, after visits. These systems are now offered by many healthcare organizations and provide features and services that include secure messaging with providers; laboratory test results, medication lists, problem lists, and health summaries; prescription refills; and appointment scheduling (Kaelber et al., 2008; Reti et al., 2010). Some examples of PHRs includes Columbia University Medical Center’s Patient Clinical Information System (PatCIS), which allowed patients to review and actually contribute information to their electronic records via the web (Cimino et al., 2002), and more recently, myNYP.org, released in 2009 to allow adult patients of NewYork-Presbyterian hospital to access their visit information, with additional educational resources for cardiovascular patients (http://www.myNYP.org).

There are many important areas for future research on PHR systems: health-services research is needed as well as technical research and development (Tang, et al. 2006). A recent review of published evidence on the impact of PHRs on care outcomes discussed a patient portal intervention leading to a quicker decrease in office visit rates and slower increase in telephone contacts, increase in number of messages sent, changes of the medication regimen, and better adherence to treatment (Ammenwerth et al., 2012). However, only a few controlled studies are available for analysis—the authors call for further work as concrete evidence that such interventions improve the quality of care is lacking.

In addition to health services research, computing research focused on PHRs is also needed. Such research includes usability, scalability, privacy and security policies and software architectures (Brennan et al., 2010; Tang et al., 2006). Still, recent work focusing specifically on the potential for PHRs to aid patient–clinician communication has identified several benefits of their use (Sun et al., 2013). Insights drawn from these studies of PHR access and use (CHCF,
2010; Halamka et al., 2008; Kaelber et al., 2008; Tang et al., 2006) have implications for inpatient technology design.

While turning to studies of PHR design and use can inform aspects of the design of inpatient technology, it is important to note the ways in which PHR technology does not directly translate to inpatient settings. A comprehensive understanding of the inpatient experience is required in order to successfully extend the current paradigm of patient information access to this context: hospitalized patients are often involved in critical decisions about the course of their care requiring that they review information about their current condition and therapeutic options. This requires that information be made available in ways that are suited to the care environment, and patients who are getting acclimated to a new physical reality within that environment—a reality that often includes pain, limited time to make decisions, and emotional strain and stress (Skeels and Tan, 2010). As noted in the above section, conversations and shared decisions made with providers during care can potentially dictate the fate of one’s life—at a minimum, they impact the patient experience: a predictor of longitudinal patient compliance and therapeutic adherence (Clever et al., 2008; Fuertes et al., 2007; Haynes et al., 1987; Robinson et al., 2008; Trachtenberg et al., 2005; Vermeire et al., 2001).

The Institute of Medicine takes the view that “patients should have unfettered access to their own medical information” noting that such access can increase the quality of care and reduce medical errors (IOM, 2001). In an inpatient context, such access means that patients can review the completeness and correctness of key information in their record—serving as an added level of safety. They can also play a role as data reviewers and even contributors: directly reporting side effects and pain levels electronically to aid in data collection and assessment of therapies. Technology can also provide tools to answer patients’ questions in the context of care,
when patients can resolve concerns with physicians managing their health and treatment plans—before opportunities to do so are lost (AHRQ, 2011).

PATIENT-TECHNOLOGY INTERACTIONS IN THE HOSPITAL: FOCUS ON COMMUNICATION AND INFORMATION NEEDS

In this thesis, my interest lies primarily in computational approaches to promoting patient engagement in care. A key starting point includes a review of research on patient-technology interactions and patient needs during care. Led by Prey, my colleagues and I reviewed research on technology to support patient engagement in inpatient settings, identifying two high-level aims of current papers to-date (Prey et al., 2013). The first aim assesses design requirements for the inpatient setting; the second aim includes interventions that have been evaluated for their impact on patient engagement. These interventions have thus far focused on delivering health information (generic as well as patient-specific), or providing personalized decision support, advanced communication tools, or entertainment. While our paper contains a comprehensive review of the related work in inpatient engagement, I supply a summary here, concentrating on literature that is particularly relevant to this thesis: literature addressing patient interactions with information technology and information and communication needs.

Design Requirements

Information Needs

While there is evidence suggesting that the provision of better information to patients leads to improved health outcomes, the information needs of patients are often not met, especially within the hospital setting (Hibbard, 2003; Larson et al., 1996). In Cumbler et al.’s recent survey of hospital patients, 90% of respondents wanted to review their hospital medication list for
accuracy, while only 28% had been given the opportunity to do so (2009). But information related to particular treatments is not the only gap in patients’ knowledge: O’Leary and colleagues found that only 32% of hospital patients they surveyed could correctly name even one of the hospital physicians caring for them (2010). Access to adequate information about care has been studied in an ED setting, where it was shown to positively impact patient satisfaction (Björvell and Stieg, 1991). Patient satisfaction, in turn, has been shown to impact treatment adherence and compliance (Larson et al., 1996). In an ambulatory setting, a randomized controlled trial of patients dealing with chronic conditions showed that patients who received an information intervention, including access to their charts, experienced improved physical functioning, patient satisfaction, and patient-reported health status (Maly et al., 1999).

**Supporting Patient-Centered Interactions with Health Information Technology**

Patients receiving hospital care face physical discomfort and limitations, while they struggle to keep track of changes in care staff, dynamic schedules for diagnostic tests and other procedures, added and discontinued medications, and frequent staff changes. While they must often complete forms related to their care, read educational materials, and review consent forms and research related to treatments, clinical settings are not currently conducive to patients’ information work (Unruh et al., 2010). Not only do clinical environments, by their current design, constrain patients in conducting information work, but patients experience constraints in mobility imposed by treatments and procedures. Morris & Karlson, in a recent position paper, introduce the view that hospital patients are “situationally-impaired” users, whose impairments vary during the stay with changes in side effects, levels of stress, fatigue and stages of physical rehabilitation (2011). They echo an important phenomenon that has been identified in early literature—one that I discuss in more detail in Chapters 4–6: patients’ memory for medical information is poor.
(Kessels, 2003; Ley, 1979; McGuire, 1996; Schlenk et al., 2008). Technology that supplements verbal communication can give patients opportunities to fill important gaps in memory. Noting that access to information is key to promoting positive health outcomes, aiming to support patients’ information retention is also critical for realizing these outcomes.

Patient-centric technology should also consider other communicative needs of inpatients, including the practical and mechanical aspects of user interfaces to facilitate communication. Skeels & Tan (2010) conducted interviews with bariatric surgery patients to explore how technology can be used to improve the inpatient experience, identifying opportunities primarily relating to supporting communication through clinical information sharing, data-supplemented patient-clinician exchanges, and additional input modalities including voice to enter commands or log data. Patients in their study desired the ability to send more information with the call button signal so nurses could prioritize their calls. They also discussed the need for electronic tools to assist them in visualizing their care progress steps and expected daily events (e.g., to help them prepare for a visit by their doctor). Their findings, which complement results that I present in Chapters 4–6, show that study participants wanted to track medications, pain scale data, and billing information, at a detailed level, and requested tools to search for information about their conditions, therapies and approaches to a healthy lifestyle (Skeels and Tan, 2010).

**Interventions**

*Patient-specific information delivery*

Bickmore and colleagues developed a virtual nurse to assist patients in reviewing their visit and discharge information. The nurse is an animated conversational agent that reads and refers to portions of the discharge packet to patients, using pointing gestures along with questions to keep
patients engaged in the experience (2009). A study with 19 patients at Boston Medical Center found that patients were comfortable receiving information from a computer, appreciating that they could take as much time as they needed with the nurse to review information and ask questions. While these early results are promising, the technology does not directly facilitate patient–clinician communication to allow patients to clarify information with their physicians, nor does it directly support the review of real-time diagnostic or therapeutic orders or results, which can allow patients to monitor their progress and status at a fine-grain level. Furthermore, as presented, the technology utilizes a workstation-size computer monitor, requiring the use of a cart to place the technology at the bedside.

With the rapid increase in mobile phone and tablet computer use, new approaches to presenting health information on portable devices have been proposed. Much work in medical informatics and applied computing has focused on designing systems to extend clinical information availability for mobile contexts (Chen et al., 2004) and for rich content types (Ebadollahi et al., 2006; Johnson et al., 2008). These systems, designed initially for clinician end-users, could also be leveraged to allow access to information by patients. Varduloukais et al. developed a mobile phone application that provided patients with a manually-updated “interactive report on their progress, care plan, and care team throughout their emergency department stay” (2012). Consistent with results of studies I outline in Chapters 4 and 6, patients reported benefits of being kept aware of care events and reported that the information helped to reduce anxiety as well as allow them to “regain some semblance of participation in their own care.”

Earlier this year Dykes et al. reported on an iterative, participatory process to design an electronic bedside communication center (2013). They used a tablet device to show patients
tailored patient information including names and images of their care team members, expected daily schedule, labs and medication information, and educational content. Through usability testing with eight hospitalized patients and three family members on general medical units, they found that their design allowed user discovery of most of the important features in the tool, and patients speculated that the tool would be useful to them if made available throughout their stay. I further elaborate on this tool and patient responses to it in Chapter 6, noting how the technology, and its associated study approaches and results, compare to our design, implementation, and analysis of a custom inpatient portal.

*Remote Participation in Care*

In addition to within-clinic communication of patient information, recent technologies have also been proposed to allow remote communication and data access, to “real-time” or synchronous care information. Baby CareLink, introduced a decade ago by Safran, was a web-based application used by parents to remotely follow the hospital care of their premature infants (Safran, 2003). The system allowed parents to track clinical documents, see messages from care team members, read educational resources, and see infant growth data and images over the course of neonatal care, leading to what the authors claim to be a 75% reduction in quality-of-care problems.

Video conferencing is another means by which clinicians, patients, and family members have communicated during care. A project at Lehigh Valley Hospital introduced collaborative rounds in the intensive care unit where family members could join through virtual meetings between family members and an off-site Intensivist (Anthony et al., 2005). These virtual meetings made heavy use of multimedia sources to review patient conditions, results, and plans of care including digital radiology films and vital sign trends, and were found by clinician users
to improve patient safety and staff response times.

PATIENT USE OF ONLINE RESOURCES

Many studies have examined the quality of online health information (Berland et al., 2001; Jadad and Gagliardi, 1998; Kitchens et al.; LaRue, 2008; Wang et al., 2012) and guidelines and instruments have been developed to assist end users in assessing information quality (Marcus, 2010; NLM, 2012a). Indeed, improving the quality of online health information is a crucial public health objective. However, relatively few researchers have studied the role of web search user interfaces in mediating consumer access to health resources (Slater and Zimmerman, 2003).

Web information quality guidelines are a valuable consumer tool, but their use is limited to those who know how to access and apply them and have the time to do so (LaRue, 2008).

Wang and colleagues (2012) discuss a lack of studies of usability and effectiveness of popular general-purpose search engines for health-related information. In their comparative study of Ask.com, Yahoo!, Bing, and Google, they found that the page rankings of the search engines corresponded in varying ways to both expert rankings of quality and volunteer rankings of usability. Some search engines returned general consumer-oriented content in their top results, yet covered fewer non-profit organization and government agency websites in these results. Others emphasized non-profit organization websites, but also included sites with excessive advertisements. Another recent study focused on the quality of information returned by popular search engines, given a range of health terms. The study found that levels of information quality varied across different health terms: top results for preventative and social health were considered by experts and lay users to be of lower quality than those for diagnostic and treatment information for physical injuries and diseases (Kitchens et al., 2012).
Previous work on patient use of online medication information focuses primarily on understanding information needs and exploring why and how people use the Internet to meet those needs. A recent Pew poll found that patients rely on the web for medication information when preparing for visits with their physicians, to learn from peers’ experiences with medications, and to aid in making decisions—in collaboration with their care providers—about dosage changes or alternative medication therapies (Fox, 2011). Supporting such activities can directly increase patients’ engagement in their own healthcare. Moreover, patients who utilize online medication information have reported increased autonomy, improved knowledge, and better adjustment to aspects of life that are affected by medical treatment (Pohjanoksa-Mäntylä et al., 2009; Xie, 2009).

Martin and colleagues studied older adults taking over-the-counter medications to understand how to effectively communicate information about medications and assist them in selecting them. Based on the challenges expressed by participants in their study, they call for research on technology to address the current limitations of drug labeling, such as better supporting the recognition of keywords when trying to locate information, and access to simplified explanations (2013). Inspired by this call, our work focuses on the use of tools in the search user interface to permit recognition of concepts discussed in the online literature, and enable selective viewing and comparison of explanatory content from these sources.

A key issue identified in research on health-related web search and navigation is the danger of self-diagnosis and escalation of medical concerns (White and Horvitz, 2009). Although consumers typically utilize online medication information to supplement, not replace, the advice of healthcare professionals (Fox and Duggan, 2013; Pohjanoksa-Mäntylä et al., 2009; Xie, 2009), the quality and accessibility of online materials are highly variable. As I discuss further in
Chapter 8, this variability motivates our work on developing tools to support consumer assessment of medication information search results.
CHAPTER 3
ACTIVENOTES

This study is documented in the following papers:


INTRODUCTION

To design information systems that effectively communicate patient status and care progress in patient-centered ways, I begin by exploring the lifecycle of electronic information related to these communication goals: how EHR systems capture patient status and progress information and make it available in user interfaces, and how the information is used in discussion and documentation about patient status and care progress. In most hospital settings, a particular artifact captures this lifecycle: the patient “progress note”. A patient progress note is a
clinical document, written by a hospital physician, describing a patient’s status and the physician’s assessments and care plan for the patient. An attending physician, who has primary responsibility for the patient’s care, composes a daily note for each of their patients. These notes are referred to by other clinicians as care is transferred or shared, and are included in the official medical record for legal and billing purposes.

Analyzing clinical information to inform mental models of patient status and care progress often involves retrieving, comparing, and contrasting information to make retrospective sense of data from multiple sources. These sources include information artifacts, observations, and discussions, which together guide the meaningful conceptualization of a patient’s current health and medical needs. This cognition-intensive process is described by the term “sensemaking” (Paul and Reddy, 2010).

Guided by research in this domain, I set about to develop an understanding of how EHR data is accessed and used in formulating the progress notes that these physicians create everyday—including how the information retrieved from the EHR relates to sensemaking about patient health status and care progress. I did this through a collaborative research project, in which I had an opportunity to study the role of the patient progress note in two ICU settings, and work with colleagues at IBM Research to create novel note-taking technology to better understand how physicians draw on information in the record when reasoning about and reflecting on patient status and care progress.

Creating a progress note requires a physician to gather, review, and comment on previous and current patient data such as lab results, information from medical rounds, medications, procedures, and tests to determine patient health, as well as select relevant information to put into the current note. Current EHR systems include facilities for creating and managing progress
notes (Tang, 2003); however, we studied Intensive Care Unit (ICU) physicians who found the documentation features of these systems did not support their reasoning about patient health status and care progress. They gather patient data through oral briefings by residents, fellows, nurses and data queries on EMR systems, but then use other tools, such as generic document processing systems, to note patient status and care progress. They also use at least one additional documentation aid (paper, self-developed software, or self-designed macros), to assist them in tracking and noting progress.

I engaged these physicians in a multi-phase design exploration to understand more about how they compose and use progress notes. First, I conducted fieldwork in two ICUs at New York Presbyterian Hospital (NYP). The fieldwork revealed that the clinical information retrieval (IR) capabilities of the EHR systems in use allow access to comprehensive clinical information, but do not adequately allow physicians to automate and customize data retrieval and note management preferences to support their sensemaking and reasoning processes.

Based on this fieldwork, I developed a study prototype, activeNotes, to use as a tool to gain insight into the note creation process. ActiveNotes introduces activeTags to support user control of updates to patient information inserted into a note. I also explored the specification of user-customized alerts associated with these updates.

ActiveNotes is an integrated environment that offers physicians two side-by-side views (Figure 3.1): an editable note view and a patient information view in which the system displays results from data queries. As a note is edited, activeNotes dynamically interprets new content created by the physician in the context of the existing note to detect potential information requests. If requested via a hot-key, the system automatically formulates queries for retrieving information from multiple data sources. The physician can review and insert the retrieved data in
real-time, as well as associate with note content an *activeTag* that will control subsequent updates to that data. Each *activeTag* links the tagged content with the automatically-generated queries and data actions for retrieval, updates, and alerts. The physician can configure the actions of an *activeTag* to obtain the updated values at specified times, and have these updates automatically reflected in the note, as well as evaluated against user-specified alert mechanisms.

In the following sections, I first describe related work. I then present insights about physicians’ workflows and current processes for note creation gained from observations, semi-structured interviews, and a survey conducted in two ICUs at NYP. Next, I describe the *activeNotes* prototype and how it incorporates physician customization of patient information retrieval into the note creation process using interaction artifacts I call *activeTags*, to manage progress note content. I then present findings and feedback from a qualitative study of the prototype conducted at NYP with 15 physicians. I describe how physicians applied *activeTags* and suggested desired uses of tags when used in conjunction with IR: to manage note content, specify IR preferences, communicate with other clinicians, and organize aspects of patient care.

The observations, interviews, prototype, and feedback sessions I describe are components in a single design exploration. The use of these study components together form the first dissertation contribution: *design of interaction techniques implemented within a novel document-editing prototype, to explore how electronic information related to patient status and care progress is derived from the EHR*. Using the prototype allowed me to study user behavior such as clinical data tagging and IR mixed with the construction of free-text explanations in progress notes.
Figure 3.1. activeNotes screen, showing data for a fictitious patient. See Figures 3.2 and 3.4 for details.
BACKGROUND

Mønsted and colleagues examined the role of the patient record in follow-up consultations at local hospitals. They found that the record enables the formation of narratives and collaborative work with patients to further resolve uncertainties and details in those narratives. In their view, these narratives serve as a workable medium to capture and organize practical experience and provide time- and context-dependent knowledge (2011). Such narratives, when they are able to be explained and externalized, could serve as powerful tools for patients who must make decisions about their care.

We planned our fieldwork based on previous approaches to studying clinician interactions with information artifacts in hospitals (Pope, 2005; Tang and Carpendale, 2007; Zhou et al., 2009). Literature on modeling workflows and information processes in clinical settings (Ash et al., 2001; Ho et al., 2008) helped us understand how progress note creation and use fits into the complex workflow of the physicians I studied, and where the best opportunities to design interventions lie. Studies of personal note-taking (Kleek et al., 2009) were also helpful in understanding physicians’ use of short, informal personal notes.

The design of activeNotes is motivated by previous work on ICU practice (Malhotra et al., 2007), which explores the importance of patient progress notes and the need for computer-assisted support for their creation. Our work is also informed by studies of research prototypes and systems (Haas et al., 2005; Hripcsak et al., 1999) and commercially-available systems (e.g., Amalga; eCareManager; Eclipsys), all of which currently use form- or template-based user interfaces for note creation, configurable at the administration level rather than the user level. Users of these systems cannot view data in the context of the note they are creating without
switching views, unless they use a form-based UI, and cannot automate IR tasks. One commercial system (PracticePartner) is an exception and supports free-text entry and user-defined templates, but does not allow physicians to customize updates to note content, and forces entry of certain note content in the process of free-text note editing. One research prototype, eNote (Haas et al., 2005), assists physicians in automating IR for managing note content, but does not retrieve lab values and vitals, or allow the user to review several related data items before selecting data for insertion.

Research focusing on specific considerations for supporting patient progress note input (Rosenbloom et al., 2004; Weir et al., 2003) motivates the need for computer-assisted support for patient information retrieval, integrated into the note creation process, as well as interaction techniques to support updates to notes.

Much work in medical informatics and applied computing has focused on designing systems to accommodate rich content types (Ebadollahi et al., 2006; Johnson et al., 2008). Recent HCI work has also focused on rich presentation and interaction techniques for viewing and browsing patient data (Gresh et al., 2002; Plaisant et al., 1998; Wang et al., 2008), and novel interactive visualization techniques have been designed to assist ICU physicians in viewing multi-dimensional clinical data (Bade et al., 2004). However, there is little research on how to design tools that enable physicians to flexibly retrieve clinical patient data in the context of describing patient status and progress.

A related application that supports note-taking and sensemaking of medical information is Entity Workspace (Billman and Bier, 2007). It allows users to discover high-level information from structured content (e.g., question answering) and to search, read, and create notes in a single environment. It provides automatic highlighting of terms, techniques for importing text
from documents into a note, and support for annotating and organizing information in a note. While we also create an integrated environment for searching documents and creating content, we focus primarily on supporting specific queries to retrieve relevant information from dynamic data sources and previous patient notes.

Recent HCI research has also focused on rich presentation and interaction techniques for viewing and browsing patient data. A survey of the literature related to the review of patient status and progress primarily includes visualization techniques for displaying clinical patient data over time. In addition to visual characteristics that show data attributes such as “in normal range” or “outside of normal range” through changes in color, shifted position, or the use of different styled fonts, three primary approaches to visualizing clinical data over time have been identified in the literature.

First, techniques have been proposed to allow browsing of clinical data at several levels of detail, in order to support an overview or visual summary of the data (often a visual trend) while supporting navigation to comprehensive information (Chen et al., 2004; Lam et al., 2006; Pieczkiewicz et al., 2007; Plaisant et al., 1998; Wang et al., 2008). For example, Plaisant, Wang and colleagues demonstrated such techniques in an application called LifeLines, which uses facets arranged in a chronological timeline to show “silhouettes” representing data in a patient's medical history (i.e., compacted lines with no labels, but color and thickness to indicate duration of applicability). The silhouettes are useful to estimate the volume and type of information available and to identify co-occurring medical events, problems, and treatments. When a lab test facet is closed, the presence and location of labs are depicted as red dots along the timeline. Selecting the dot reveals its label and loads a window with related, detailed data next to it.
Other techniques proposed by Powsner and Tufte depict clinical quantitative data as an abstraction of the data over time. To create visual summaries, individual data points are “plotted” according to five qualitative groups, spaced further apart for recent data and more closely together for data collected in the past (1994).

Finally, techniques to show relationships between data types over time have been proposed by Bade as well as several others (Bade et al., 2004; Pieczkiewicz et al., 2007; Plaisant et al., 1998; Wang et al., 2008). Wang and colleagues introduced techniques to align clinical events according to end-user–specified criteria to spot co-occurring, precursor, and subsequent events.

Our design prototype, activeNotes, offers activeTags for viewing and managing updated data. The term “tag” is often applied to annotations attached by a user to an item (Ames and Naaman, 2007). While we are inspired by and support these types of tags in our prototype, we further extend the idea to dynamic data entries. ActiveTags for these entries serve as identifiers of the data and as placeholders (Hughes and Carr, 2002; Rhodes and Starner, 1996) that reflect the ultimate values of the data, and are associated with a set of rules to control how the data entries are reflected in a document. Extending a number of ideas explored in the hypertext literature (Frisse et al., 1991; Golovchinsky, 1997), we provide users with mechanisms to manage how dynamic source content is reflected in the new document. However, activeTags go several steps further: they contain source content that is determined by interpreting a user’s information request automatically, based on an analysis of note content, as well as queries for searching for patient data from multiple sources, also determined automatically.

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1 I carried out all fieldwork, led the design work and conducted the development of the activeNotes prototype and activeTag interaction techniques. The design involved an iterative process in which all collaborating researchers had input. The prototype connects to technology created by Jie Lu and colleagues at IBM Research (cited in the Data Retrieval section below).
Previous tag facilities include Smart Tags (in Microsoft Office), which can automatically recognize common entity types such as a person’s name or address, and support type-specific actions to perform common tasks (e.g., add a name to an Outlook address book) (Hughes and Carr, 2002). A Smart Tag can also be preconfigured to link to content (e.g., a legal clause) in a content management system, such that changes to text in document content will be dynamically populated via the linked content tag. ActiveTags differ from Smart Tags in three ways. First, upon creation of an activeTag, our system interprets its associated content in the context of other text in the document to formulate queries on source content. For example, if the query needs identifying patient data, it will obtain it automatically from other sections of the note. Second, activeTags allows users to determine what to tag and offers control of update and alert mechanisms for managing the tagged content. Third, rather than linking to a specific single source, activeTags are associated with one or more queries, such that the content linked to by an activeTag is not a document, single entry in a database, or action, but a set of queries that may be used to retrieve results according to user-specified, data-aware, rules.

The use of activeTags to assist note creation is also inspired by the work of Hsieh et al. (Hsieh et al., 2008). They introduce tags in instant messaging (IM) that alter the behavior of the tagged items (messages) to facilitate near-synchronous communication in IM clients. Senders can tag their IM messages to trigger different types of support on the receiver’s side for different types of tasks (e.g., tasks that do not require immediate attention, or tasks that have deadlines).

SETTING AND PARTICIPANTS

For the first phase of this study, I observed the workflow, environment and note creation strategies of six physicians (two attending physicians and four residents) over an elapsed time
period of six months in the Cardiothoracic Intensive Care Unit (CTICU) and the Surgical ICU (SICU) between October 2007 and April 2008. To clarify information about their strategies for documenting patient status and care progress, I conducted a written survey of eight attending physicians in the CTICU and SICU, including the two attending physicians observed earlier (for a total of 12 observed and/or surveyed. I also conducted semi-structured interviews with all 12 physicians.

Following the creation of activeNotes (described below), I conducted a qualitative study with 15 (11 male, 4 female) physicians who used the tool. The physicians were practicing in the CTICU or SICU, and were between 29–55 years old; 11 are attending physicians, and four are residents with one to four months of experience in an ICU. The study was approved by Columbia University’s Institutional Review Board.

FIELD STUDY

The note creation process includes the formulation of assessments and care plans for the patient. Physicians gather factual information from multiple sources such as the EMR systems, the patient database, printed lab reports, prior patient notes, and oral presentations or written records of residents and fellows. Some templates used to document various aspects of patient status and care progress are shown in Appendix A.3. Much of the note creation process in the ICU occurred in the context of collaborative group discussion and question answering, often during a process called ‘medical rounds.’ As previous work on information seeking in ICUs suggests (Reddy and Dourish, 2002; Reddy et al., 2002) during these collaborative discussions, physicians asked several types of questions to determine a patient’s status and plan their care.

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1 Drs. Feiner and Lai guided field study approaches.
2 I conducted the evaluation of activeNotes and the analysis of resulting data. Dr. Desmond Jordan, the clinician member of the research team, assisted in developing instruments for the qualitative evaluation.
Some answers can be found in clinical data sources, but many include experiential or organizational information, gained through discussion with other clinicians and their own observations.

Physicians logged these comments and observations as they arose in the context of group conversation and patient care, at the patient’s bedside, and preferred to create their own note structure and type freely during this process. While they also document clinical patient data found in the EMR system, they do not want to be hindered by structure or additional task-switching during rounds, so they perform data lookups separately, noting placeholders for information during the composition process. Gaps in resident reports, as well as the lack of data availability on the devices used during rounds, account for most of these placeholders. Physicians estimated that, typically, 25–50% of the information they requested from residents during rounds is not known or noted by a resident, even if it is in the database, requiring that this information be looked up after rounds and documented.

I further studied clinical information needs during note creation, and found that they are dynamic and context-sensitive, as they depend on patient status and content that has already been entered in the patient note. For example, below the heading “Abdomen” in a note section entitled “24 Hour Events”, physicians may need lab results for the past 24 hours related to the patient’s liver function. In contrast, below the same heading “Abdomen” in the “Physical Exam” section of a different note, physicians may need information about whether bowel sounds were present for the patient during the most recent physical exam. An anatomy of the primary Attending Critical Care Note (the daily patient progress note) is included in Appendix A.2.
**Attending Physician Survey**

I conducted a survey to learn more about the current note creation process, including individual mechanical processes for composing notes, challenges involved in creating and updating note content related to the information systems and applications currently in use, and the frequency with which notes are updated and referred to throughout the day. Physicians answered questions about their experiences composing the Attending Critical Care Note (the progress note that is submitted to the medical record). The full survey and set of responses are detailed in Appendix A.1.

Among the eight attending physicians surveyed, four have worked in an ICU for less than three years, one for five years, and three for more than 20 years. They estimated that their typical day in an ICU lasts around 9–12 hours, during which they reported spending 2.5–8 (mean = 5) hours on medical rounds for patient care. Each physician estimates writing 10–18 (mean = 16) notes per day. Six create 80–90% of note content during medical rounds, while two create their notes after rounds, relying on their memory.

Five of the six attending physicians who compose patient notes during medical rounds at the patients’ bedsides use a laptop computer and a document processing application such as Microsoft Word. One physician handwrites patient notes during rounds and types them into a computer later. All physicians surveyed consider the task of collecting relevant and correct patient data the greatest challenge in composing an Attending Critical Care Note. They admitted spending considerable time navigating through previous notes to locate relevant patient information, especially notes written by other physicians. Most of this time is spent visually searching through documents to find pieces of information relevant to their current information need.
A patient note is usually not inserted into the patient record immediately after it is created. The physicians estimated that up to eight hours could elapse between the point at which the note is created and the time it is submitted to the record, during which they continue monitoring patient status. Throughout the day, the physicians keep track of patient information, such as lab results, vital signs, and ventilator settings, to analyze a trend of measurements, detect abnormalities, and adjust assessments and plans for patient care accordingly. While the attending physicians all agree that patient notes should be updated to reflect the above changes, they have different opinions on when the updates should be performed. Two physicians think notes should be updated immediately when new information becomes available; two would like to update notes periodically, and four consider it sufficient to perform updates once before notes are submitted to the patients’ medical records.

When asked how convenient it is to make updates to an Attending Critical Care Note directly using current systems, six of the eight physicians said that it was either somewhat inconvenient or very inconvenient. Follow-up by residents is the primary source of the updated information, updates are typically delivered verbally, and the physicians have to manually edit each note once they obtain these updates. The surveys also revealed that physicians have rejected rigid template or form-based UIs for creating notes that impose a strict document structure, because the structure often conflicts with their mental model of the patient’s current status. As one physician stated, “I am hostile to rigid templates. They impede my ability to think about the patient. I make many connections and they don’t represent how I think.”
Figure 3.2. activeNotes user performs a data query and inserts the query result, then tags the query with an activeTag. Data are for a fictitious patient.
They have also rejected systems that require heavy task switching between IR and text editing. Other key problems related to keeping note content up-to-date and complete were identified:

1. Physicians often rely on their own memory, or a jotted reminder, to update the note with any missing data that becomes available after the note is created. Such a list varies from patient to patient.

2. If new data becomes available, updates to the note require that a physician repeat the manual data retrieval and insertion process described earlier.

3. It is time consuming to locate in the patient note related content pieces that require updating and to replace them one by one with the updated values.

4. Tools to enable monitoring preferences for specific information and define criteria for physician notification about data availability are limited in the current EHR systems.

**Physician-Designed Interventions**

Each physician surveyed keeps an informal, shared, note, accessible on the hospital intranet, to log observations and patient information. This informal note is entered and accessed via a secure web form, consisting of four large text boxes, without labels, designed by the physician member of our research team. Physicians use this unstructured form (shown in Figure 3.4) as an easy way to communicate information among care team members, separating information to match a care situation, a process that does not always conform to structured headings. They refer to this form as the “cheat sheet” because it allows them to write their thoughts along with patient data that is relevant to patient care throughout the day, in a manner that does not require adherence to a specific structure. Physicians create their own structure for the patient using the free-text areas, and this varies from patient to patient.
Some physicians also frequently print their own note templates to informally log data and aspects related to care delivery on paper, writing on the paper throughout the day. They sort through the information and choose items to insert into the Attending Critical Care Note, from the paper, at the end of their workday. One also programmed a macro in Microsoft Word to help him with auto-completion of his most frequently used terms in a note.

ACTIVENOTES DOCUMENTATION PROTOTYPE

ActiveNotes is a study prototype that queries data from a composite, anonymized, patient profile created from the hospital database. Our goal in designing this study prototype was to adopt a realistic data schema, with comprehensive patient data for a sample patient to provide as much authenticity as possible on which to base responses, while maintaining the design flexibility required to conduct a formative study. We note that further research is needed to extend our design to comply with relevant standards, requirements for hospital billing, and thorough provisions for patient safety. We implemented activeNotes using a combination of Adobe Flash with Adobe Flex 3 for the UI and Java for the back-end.

Design Process

Following our initial fieldwork, we analyzed findings from our observations, our interviews with physicians, the data types in the EMR systems, and approximately fifty previous printed progress notes.
Figure 3.3. An expurgated view of a "cheat sheet" used to informally organize notes on patient status and care progress.
Based on this work, we formulated the following design goals:

- Allow free-text note entry with context-sensitive support for IR via information requests, initiated in the editor.
- Allow the user to specify a data request for all labs related to a particular organ system or function through high-level terms (e.g., all lab work related to heart function with a request for “cardiac” or “chest”).
- Allow data displayed in result sets to be inserted in the note with minimal keystrokes or mouse clicks.
• Provide annotations of automatically inserted data items and data review capabilities for verifying note content before note submission.

• Provide customizable support for managing note content, according to user-defined settings. For example, allow users to group note entries under a category of their choosing, and perform subsequent data look-ups for all items in a category.

• Provide support for reviewing updates to data included in a note and viewing the history of noted data.

• Display the progress note for the patient from the previous day, and highlight items in the previous note that are relevant to an information request to facilitate analysis of changes.

I iterated through sketches of proposed note editing UIs with two collaborating physicians, who helped me to identify clinical vocabulary requirements, and usage examples for our design prototype. Further research is needed to extend our design to comply with relevant standards, requirements for hospital billing, and patient safety. Our goal at this stage was to build an exploratory research tool.

The activeNotes UI includes two main interaction areas: the Note Area on the left, entitled “Attending Critical Care Note” (Figures 3.1, 3.2a,c,d,f) and the Results Area on the right entitled “Patient Information” (Figures 3.1, 3.2b). The note area is an augmented rich text editor. A user can type a note as she normally would, and at any time during note editing, can signal the system (by pressing Ctrl-Space) to retrieve the needed patient information based on the content inserted into the note thus far.

Data Retrieval

Data retrieval in activeNotes is supported by the recognition of text in the context of the note entered in the note view (Figure 3.2a). When requested, the system looks at text that the user has
just typed, highlights the last term that it recognizes as an information request, and automatically formulates queries to retrieve information relevant to the request from appropriate data sources. The system adopts an existing natural language input processing algorithm (Lu and Zhou, 2009; Zhou et al., 2006) to analyze existing note text to build appropriate queries. For example, a physician wanting to check on lab results related to the patient’s renal function (in this context, how well the kidneys are filtering blood) can type “renal” in the note and press Ctrl-Space to request relevant data (Figure 3.2a). The system detects the information request and formulates database queries to retrieve the values of relevant data items such as the patient’s Blood Urea Nitrogen, or BUN level (how much broken-down protein still exists in the kidneys to indicate how well they are filtering this protein) and Creatinine level (small molecules of creatine waste, also filtered by the kidneys) (Figure 3.2b). The IR architecture we build upon is shown in Appendix A.4. Occurrences of this information in the previous day’s patient note are also highlighted to speed reference to relevant content in that note. A user can click a data point in a chart or in a row of a result table to indicate her wish to have the corresponding result automatically inserted into the current note.

Each information request is interpreted in the context of the existing note so that relevant information (e.g., patient identity, date, time, or organ system under review) can be embedded by activeNotes in the automatically-generated queries. Users can request a single piece of information (e.g., heart rate), or multiple pieces of related information at once (e.g., ventilator settings, or information at the organ system level such as renal).

Retrieved information is placed in the patient information view and can be automatically inserted into the note (Figure 3.2c). In this way, note-driven retrieval allows users to dynamically
gather data while entering free-text and without leaving the current UI or losing control over content, format, or structure.

*ActiveTags*

An activeTag is an annotation that is attached to a content fragment and associated with data actions (retrieval, updates, and alerts) that act upon that content. Users can attach activeTags to data-related note content to indicate their wishes to obtain live updates, or to receive alerts when the automatically updated content meets certain criteria (e.g., exceeds a threshold). Users can also use activeTags to request automated updates for patient data that was not available when initially requested. This way, users can avoid forgetting to revisit a patient note to fill in missing data.

To associate an activeTag with some content in the note, a user can click anywhere within the word to have it selected and highlighted, and right-click to bring up the context-sensitive tag menu (Figure 3.2d). Users can configure an activeTag by choosing among different options for when and how to perform updates. For example, a user can request that an update be run immediately, at a specific time, or on a specified schedule (Figure 3.2e). Users can specify through preference options whether or not the originally inserted value should be automatically replaced with the updated value (Figure 3.4a–b).
In addition to update options, users can request that an alert be generated if user-specified criteria are met. Users can choose to receive alerts (by email or SMS message) when the updated value goes above or below a threshold value, and/or when the updated value increases or decreases by a specified amount relative to the original value.

Physicians can also use activeTags to create labels that are meaningful to them, to organize content across patient notes, without setting data retrieval preferences. At any time, a user can choose to view and manage all the activeTags organized by labels, or based on user-
specified update or alert options (e.g., times or frequencies of updates, and types of alerts). Users can also use activeTags to track the value of a data item over time.

The numeric data items retrieved from the database are presented in interactive charts or tables whose format is determined by the amount of data retrieved and user-set preferences. The previous patient note is also displayed with the matched keywords highlighted. The user can click on the data she deems relevant to the note, causing it to be inserted into the note automatically at the position where she issued the information request. In developing the study prototype, I implemented support for note updates using activeTags; however, I did not actually deliver alerts that were specified using the activeTag menu, since I performed the study for a fictional patient.

I presented activeTags to physicians as a tool to assist in managing note content by attaching annotations to note content, and specifying automatic update and alert criteria with patient information retrieval. These tools were designed based on physicians’ use of personal notes to assist them in recalling note updates. However, my motivation in introducing these tags was also to understand how physicians appropriated and desired to use the tagging functionality in the context of editing progress notes.

**Automation**

An important design choice in creating our prototype included the decision to enable automatic updates to note data. Indeed, values that are populated or updated automatically should be reviewed for accuracy, and consistency of values with written statements on progress should be reviewed. However, the requirement that updates be edited manually is burdensome in both cognition and time, and the current preferred documentation method relies heavily on manual entry due to the flexibility it affords for commenting in free-text, introducing several hazards
As Embi et al. point out (Embi et al., 2004), different approaches to reviewing and inserting note content will result in different cognitive behaviors, potential hazards, and impact on workflow. To address this in our design, all tagged values are annotated in the note (Figure 3.2f) and updated values are also annotated in the note and complemented with a history of the updated value shown in the right-hand pane (Figure 3.3b). Users can view updates without automatically updating note content.

**ACTIVENOTES STUDY**

**Methods**

Working within the realities of a hospital ICU posed challenges for the design of our study. Physicians were often on call, and a request for even 30 minutes of their time is a lot. Thus, we planned a training session, task, and survey that could be completed in at most 30 minutes. Since we were at risk of interruptions from cell phones and pagers, we opted for qualitative feedback during and after use of the system.

Both the training and study task were performed using a laptop computer we provided with a mouse that could optionally be used instead of the built-in trackpad or trackpoint. The task involved first reading a scenario setting the background information on our fictional patient

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**PROBLEM LIST**

Systolic Heart Failure, Renal Insufficiency, Hyperkalemia, Metabolic Acidosis

**24 HOUR EVENTS**

Patient is in critical condition, **Temp:** F 98.2, **Heart Rate:** 110

**Chest:** Vent Settings FiO2 40%, **Resp Rate:** 21, **TV:** 605ml

...
(shown in Appendix A.5), and two Attending Critical Care Notes for this patient from the previous day (shown in Appendix A.6). Of the two Attending Critical Care Notes provided for training purposes, one resembled a standard note in a patient medical record, with no additional annotations. The other was annotated to include underlined and bolded terms. These annotated terms denoted words the system had recognized and used to retrieve patient data results (Figure 3.6). After a participant read the patient scenario, the study coordinator introduced activeNotes, comparing and contrasting it with word processing applications familiar to the participant, and described the features with examples.

Training included using three sample terms for which the system formulated queries and provided results. Results were presented in the right hand panel of the application, with highlighted occurrences of the keyword in the previous patient note, and other data query results. Thus, the participant could also use the information request utility to navigate the previous Attending Critical Care Note, as well as view results from the patient database.

In the examples, the study coordinator demonstrated the difference between an information request to the system on a specific item like “BUN” included as one item in a “Basic Metabolic Panel (BMP)” and a higher-level request, such as “BMP”. With the latter, the system returned multiple lab results for the patient, including BUN. The third example was an information request for the less specific term, “Renal”. Results here included tables of data items that would be noted when evaluating the patient’s renal function, such as BUN, Creatinine, CO₂, Albumin, and amounts of urine expelled. In all cases, the previous day’s note was displayed with the corresponding terms highlighted. The physicians were shown how to insert data by clicking on the results, and how to tag note content to set automatic updates and create personalized data
alerts. Participants then practiced a few data look-ups and note insertions. The study script is included in Appendix A.7.

After practicing, we asked them to continue completing the progress note for this patient, allowing them to use the system without intervention. Three sections of the note were pre-filled-in to provide some context. Physicians were asked to focus on one of the following empty sections: “24 Hour Events” or “Vitals, Vent Mode, Labs and Medications”. We asked each participant to use a “think-aloud” protocol and comment on their experience obtaining, inserting, and managing data related to their information needs.

Since we had sample data for labs, vital signs, blood gases and ventilator settings, we instructed them to assume that any information they could not look up was unchanged from the previous day (noted in the background information we provided). They were allowed to refer to the annotated note for examples, as well as enter any terms for information they wished to request, even if those terms were not listed as examples on their reference sheet. After they completed a note section, we asked each participant qualitative questions to structure their feedback, including “What is the greatest benefit of the system?”, “What is a major drawback of the system?”, and “In your opinion, would physicians use this? If so, why? If not, why not?” All questions included in this interview can be found in Appendix A.8.

RESULTS AND DISCUSSION

One goal in studying physician use of our prototype was to understand how ICU physicians might manage progress note content given techniques to perform context-sensitive retrieval of patient data during note editing. A second goal was to understand how ICU physicians might use tagging in conjunction with IR. Comments from physicians describing their experiences are
outlined below, grouped according to the thematic analysis of usage comments and interview responses using the hybrid approach described in Chapter 1.

**Use of activeTags**

During the study, physicians applied activeTags and suggested desired uses of these tags for progress documentation management. Below I describe how these uses yielded insights into the role of the EHR in reasoning about patient status and care progress in this setting.

**Temporal context**

Keeping track of length of days and amounts, counter functions to help update the note:

One mentioned, “I’d like something that helps me keep track, in the note, how many days a patient has been on a certain medication”. P7 mentioned, “It’d be nice to be able to configure how trends are shown upfront, and be able to design graphs from the things you request (e.g., WBC against platelet count, within the interface, temp changes against BP) basically customize the trends.”

Almost all mentioned that they would like the data presentation to include additional statistics about the baseline values for the patient and minimum and maximum values for the past 24 hours. They also requested summaries for fluids in and out. One mentioned that even if writing something about labs in a 24 Hour Events section, “I’d prefer to see 72-hour results for context”.

**Grouping related items for data retrieval**

Several physicians wanted to tag a number of patient data items using a single heading, then specify update and alert criteria for all data items associated with the tag. For example, P13 said, “I want to tag a few different things that I look at, like the blood cell count and the platelet
count, with the same tag. Then set up updates for that tag name to see both things get updated together.”

Making “to dos” and “follow up” items clear

Physicians mentioned their desire to share tagged data with other care team members, through alerts to those team members, and annotations to the “next person who has to read this”. P5 said, “Alerts would be really great if I could not only set one up for myself, but for the resident, as a way to remind them to follow up on this thing.”

Assisting in recalling items related to care delivery

Many physicians commented that they would like to use the tags to note tasks that are related to care delivery. P15 said, “Take cultures, for example. I might only tag culture results for an alert. But this is something I would definitely use. Cultures take three days and it could be easy to forget by then that they need to check for them. But these are absolutely crucial to the diagnosis of infectious diseases.” P1 said, “I’d probably tag everything, because I like to stay on top of things in whatever way I can”. Other uses in this category include ‘tracking’ things that specifically need to be communicated verbally to other care team members, not to share the note content directly, but as P11 stated, “to note to myself to ask someone about this thing”.

Making relationships to medical history explicit

P2 mentioned, “I would like to pull from other types of notes for the patient directly, not just the previous note. The residents write a complete admission summary for the patient. This has a lot about their history that I might want to pull from directly. Any documents like that, I might pull from when I write a note. It’d be great if these could be included in the interface and [they were] interactive.”
Metrics for ranking data

When introduced to the automated IR capability and activeTags, half of the attending physicians studied expressed a desire to use our system to create their own templates, by using tags to “rank items in terms of importance” and “separate informal notes” from formal note content during note editing. P4 commented, “Note completion is not a learning task about the patient's condition—it’s figuring out what needs to be said about this patient based on what is going on with him or her, and this would help me to better identify that.”

When pushed to elaborate on this preference, these physicians mentioned that they would create sample notes with information requests as “placeholders”. The information requests would be applied to specific problems, or problem combinations--based on problems that the patient was experiencing, in order of criticality, and then visit each information request, setting up updates to reuse the note the next day with the most up-to-date values already inserted. P1 described how tags could help him reuse his own format: “I want to be able to do things smoothly, and decide when I put in values that I think are important, not be told what to put in and in what order.” P14 mentioned a similar use, "Patients have different profiles. For a problem, I’d probably set up a data profile, then set updates according to how important it is to monitor each, for a certain problem."

In addition to ranking by criticality to life support, ranking by collaborative task management also emerged as a strategy. P12 said, “I’d use tagging to help prioritize what order to transfer items in. Sometimes I have to hand over a paper with patient data I’ve collected on it, because you get called to do something else. In the morning when I come in, there’s a lot to do and there’s [a] bottleneck in transferring information. If I have things I’d like to keep track of for a patient, I’d use this system to set that up and keep updates. It’d also be easier to keep
someone else updated on the things I’ve been tracking for a patient [if they are tagged], if I need them to take over.” Finally, P6, a resident, mentioned yet another strategy for their ranking data, stating that, “Residents get burned by not knowing most up-to-date information.” While another mentioned, “I’d like to list the information needs that I want, and click to get all of these at once. Then [have the option] to filter the results on just the most recent, to bring all of these in”.

Health Information Technology research focused on standards and protocols to facilitate the exchange of information between systems (both within and between institutions) is needed to fully realize this goal. However, recent efforts in improving interoperability of disparate systems, shows evidence of progress toward this interoperability (Furukawa et al., 2013).

CONCLUSIONS AND FUTURE WORK

In this chapter, I described a design exploration focused on techniques to support data input and management of electronic progress note content. Our design exploration included observations, structured and semi-structured interviews, design and implementation of the activeNotes prototype, and feedback gathered in a qualitative study with 15 ICU physicians to understand the role of tagging and IR when used with progress note documentation.

In designing activeNotes, we focused on the integration of automated, context-sensitive patient data retrieval into a note-editing environment. The system automatically recognizes information requests specified in free-text in a patient progress note, interprets new note input in the context of the existing note, formulates corresponding queries, and retrieves relevant information. We introduced activeTags to explore user specification of automated updates and alerts for patient data in a note.
Feedback from a qualitative study suggests that the IR and tagging techniques were well-received. Throughout the study, physicians proposed several uses of tags in conjunction with IR, and three techniques for ranking note data emerged from physician usage of activeNotes: ranking based on criticality to life support, temporal availability (the most recent data available), and ranking for collaborative task management (data needed by collaborators to whom patient care will be “handed over” or shared).

In the next chapter, I discuss how knowledge gained from this study helped to guide us in selecting and presenting data from the EHR of a large, urban Emergency Department, for display on a large-format prototype designed for patients and their family members.
CHAPTER 4
CHARACTERIZING THE DESIGN SPACE FOR INFORMATION DELIVERY TO HOSPITAL PATIENTS

Studies in this chapter are documented in the following papers:


INTRODUCTION

In Chapter 2, I discussed research focused on PHRs, noting attempts by researchers to address questions of sharing and security (Cimino et al., 2002; Halamka et al., 2008; Kaelber et al., 2008; Tang et al., 2006) and work demonstrating that PHRs can bridge critical gaps in continuity of care (Halamka et al., 2008). However, there has been limited research exploring the sharing of health information with patients during hospital visits. The Virtual Nurse project

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uses an intelligent agent to present discharge information (Bickmore et al., 2009), and Jones assesses the value of educational kiosks at the point of care (Jones, 2009). Other work, described at length in Chapter 2, examined patient and physician responses to sharing paper charts with patients in various ambulatory and inpatient settings.

In this chapter, I explore the design of in-room, patient-centric information displays, based on iterative design with physicians. Using this preliminary design as the central object in two studies, I explored presentation techniques and candidate information types—primarily sourced from a deployed clinical EHR system—to include in an in-room, patient-facing information display. In this collaborative research, I worked with colleagues at Microsoft Research and MedStar Health to investigate responses to information, abstracted from the EHR and provided on large display prototypes, to determine if and how these displays are useful to patients and their family members and the ways in which the displays affected patients’ experiences in a dynamic care environment.

The direct delivery of information from clinical database to patient represents a fundamental change to the traditional flow of clinical information, however. We therefore explore two sides of increased information transparency through in-room electronic displays: patient attitudes toward the displays and physician attitudes.

We find that both patients and physicians generally support direct delivery of electronic information to patients, and uncover important considerations for the design of patient-facing information displays.

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1 I created the IRB proposal and managed the consent process. I also led all fieldwork. I created the prototype design and produced the artifacts. The design involved an iterative process in which all collaborating researchers (Dr. Dan Morris, Dr. Desney Tan and Dr. Justin Gatewood) had input. Drs. Morris and Tan managed portions of the patient and family member consent process, and worked with me to conduct patient interviews, transcribe data, contribute thematic coding and analysis, and report on results.
information systems. Below, we report on these findings, and discuss the feasibility of a fully-automatic implementation of our design. In particular, this chapter describes:

1. A preliminary design for an in-room patient information display, representing the endpoint of an iterative process involving patients, providers, and designers.
2. Findings from a study detailing patient and family member responses to information provided on such a display: how it is useful to patients and their family members despite certain concerns, and the ways in which it affected patients’ experiences in the ED.
3. Findings from a survey study exploring attending physician attitudes about electronic patient-facing information displays in the ED.
4. Identification of challenges and opportunities that exist in leveraging the EMR and automating the information extraction and construction process used in our study.

The study findings described here, together with results of a study described in the next chapter, form the basis of my second dissertation contribution: *characterization of the design space for electronic information delivery to hospital patients.*

**OVERVIEW OF STUDIES**

**Patient Responses to Displays**

First, we explored how a patient-centered information display can deliver useful information to a patient during the course of an ED visit. We conducted a Wizard-of-Oz (WOZ) study in which we manually compiled information extracted from the patient medical record and constructed posters that mimicked a potential digital display (Figures 4.1 and 4.5–4.7). We placed these posters in patient rooms and updated them as frequently as appropriate. We interviewed patients and family members, as well as physicians and nurses, to garner feedback
about our design. 18 patients were presented with real-time information displays based on their medical records. To elicit guidelines regarding specific information types, privacy, use cases, and information presentation techniques, we conducted semi-structured interviews with patients, family members, and hospital staff.

**Physician Responses to Displays**

In this study, we explore attending physician attitudes about the ongoing sharing of information drawn from the hospital EHR during visits to an ED. We report results of a study of patients and family members use of large-format, patient-facing displays. We follow this study with a survey completed by 22 physicians, following the trial deployment of the patient-facing displays. The survey was designed to explore the following research questions:

1. Are physicians willing to allow direct, automatic information sharing with patients during clinical visits?
2. What types of information are physicians concerned about sharing on an information display with patients during visits, and why?

**SETTING AND PARTICIPANTS**

We conducted our study in the ED of a large urban hospital in the Washington, D.C. area. The hospital is a tertiary care facility and a major teaching hospital. The 40-bed ED primarily sees an urban and underserved population, and sees approximately 77,000 visitors per year. This research was approved by the appropriate human subjects internal review board.

**Emergency Department Patients**

Eighteen patients (11 female) and eleven visitors (8 female) volunteered to participate in the study over the course of approximately two weeks. Patients ranged from 29 to 84 years of age,
with a mean age of 54. In a demographic survey we conducted while constructing the poster, 69% of patients reported that they regularly used a cell phone, but only 31% reported that they regularly used a computer. 13% of patients had college degrees, 47% had associate’s degrees or started college, 27% completed high school but no college, and 13% had not completed high school.

We briefed physicians and nurses in the department about the goals of the project and the study procedure, and asked them to identify eligible patients. Screening criteria required patients to be able to converse with researchers, to be medically stable, and to be able to read text on our posters. Other criteria were applied for both patient and researcher safety; patients considered by the staff to be potentially dangerous or highly contagious were not approached for consent. If an approached patient was willing, we collected informed consent from the patient and any visitors who were present and who wanted to participate.

**Emergency Physicians**

Attending physicians present at departmental staff meetings (n=31) were given the option to participate in a six-page written survey. 24 physicians agreed to participate, and 22 physicians (71%) completed the survey. Participants included twelve male and ten female physicians. Eight participants were under 34 years of age, eleven between 35 and 44, and three between 45 and 54. Participants had a wide range of clinical experience, from three to 27 years of practice. In addition to having been approved by the IRB, the survey was reviewed by two non-participating experts for content validity.

**WOZ STUDY: PATIENT RESPONSES TO IN-ROOM DISPLAYS**

Our display prototypes were designed to support an exploratory study around in-room
information presentation; we sought to reduce pragmatic constraints and maximize flexibility in our approach to creating and using them. We chose paper prototypes as they present few restrictions on form factor, permit familiar interaction (i.e., patients and caregivers could write on them), and minimize space and IT support footprint. This allowed us to deploy our prototypes in a variety of spaces. An additional goal, of course, was to begin with information display design prototypes that we thought would be most useful to patients.

To do this, we began with an iterative design process involving our design team and collaborating physicians. In the early phases of this project, Dr. Gatewood, an Attending Physician in the ED and a member of the core research team, synthesized comments and observations from 24 colleagues, comprised of attending physicians, residents, and nurses in the ED. We asked them to articulate candidate information types to include on our display by considering factors such as frequent patient information requests, important events related to the delivery of care, and information frequently conveyed to patients during consultations.

We also considered important methodological constraints around information types. In particular, we analyzed the information available in the medical record system deployed at the hospital in which we conducted our research and determined items we could reasonably extract. We also iterated with our panel of care team members in order to learn more about the kinds of information they would be willing and able to provide during our field study, particularly when such information was needed to clarify data in the EMR or to fill in information gaps.

Finally, we iterated through proposed categorization schemes and designs, continually providing design prototypes to collaborating care providers, who helped us refine terminology, organize content, and consider practical situational factors such as text size for readability and display placement within rooms.
Our final design included several headings that could be dynamically included or excluded from the poster as appropriate. These headings were (verbatim to what was seen on the poster): Reason for Your Visit, Your Health Profile, Your Vitals, What’s Next, We’ve Completed, Medications, and Your Care Team. To create structure on the display and to provide some make information groupings clear, we divided the poster into three basic panes labeled Your Profile, Your Visit, and Your Care Team (Figures 4.1 and 4.3–4.6).

After obtaining informed consent and conducting the demographic interview, the researchers prepared a prototype display for each patient based on data from their medical record. Thirteen of these prototype displays were prepared as large-format posters (approximately 3’ wide by 4’ high) placed at the patient’s bedside (Figures 4.2 and 4.4–4.6), and 5 were prepared as letter-sized handouts (Figure 4.3), as a preliminary exploration into
alternative form factors. Layout and content were identical across our two form factors. Preparing a prototype display typically took around 30 minutes. While much of the information was collected from the EMR and from the patient’s medical chart, all information presented on the prototype was screened by the patient’s attending or resident physician before deployment, to avoid misinformation. These discussions also provided a valuable opportunity to collect targeted feedback from providers about presentation techniques, and to inform the process of building reports automatically. These exchanges will be discussed in more detail in the Results section.

After deploying each prototype, we conducted semi-structured interviews with patients. Interviews included general questions about the ED visit but were primarily focused on patients’ subjective and objective responses to the prototypes. Questions were designed to elicit specific responses without directing patients’ attention to specific aspects of the poster. For example, we asked patients “Which section of the poster do you find the most helpful and why?”, “Which section of the poster do you find the least helpful and why?”, and “Is there anything on the poster that surprises you?” After the initial interview, we monitored a patient’s medical records and updated the display accordingly. For example, when tests were ordered, we added new content to
the “What’s Next” section of the poster, and when medication was administered, we added it to the appropriate list on the prototype. For letter-sized handouts, updates were implemented by replacing the entire handout.

As with the initial deployment, physicians were consulted before presenting any updated information to a patient. With each update, patients were given time to read and respond to the update. A session was complete when the patient left the ED or when the patient entered a state, as determined by the patients’ physician(s), where no further updates would occur. In either case, a final interview was conducted, and poster-format prototypes were removed from the room. Patients who received handout-format prototypes were allowed to keep them, and patients who requested printed photos of their poster-format prototypes were accommodated.
Figure 4.3. Patient information display provided to a participating patient as a handout.
Figure 4.4. Patient information display for a participating patient, presented as a large-format poster.
Figure 4.5. Patient information display for another participating patient, presented as a large-format poster.
WOZ STUDY RESULTS: PATIENT RESPONSES TO IN-ROOM DISPLAYS

The field notes and interview transcripts were analyzed by the researchers for themes related to communication and information needs in the context of patient information needs.

Patient Responses to Information

Perhaps the most important research question we sought to answer was whether patients would find an in-room information display useful, and, if so, what specific types of information patients would find most useful.

Subjective response was consistently very positive.

In general, patients’ subjective responses to our prototypes were profoundly positive. For example, P0 called her poster an “innovative idea, glad doctors here are doing this with you. This makes you feel you’re in your own loop. And that’s awesome.” P3 stated, “[The prototype] is perfect.”

Only one of 18 patients (P9) was somewhat ambivalent about the prototype, describing it as “all right”. This patient’s ED visit was relatively minor, and it was established early that she would be discharged with no major treatment, leading (anecdotally) to what appeared to be a reduced interest in the details of her care relative to other patients.

The high subjective satisfaction we observed in 17 out of our 18 patient participants cannot necessarily be generalized to all patients in the ED; our filtering criteria and the need to obtain informed consent eliminated, among other populations, primarily-unconscious patients and hostile/aggressive patients. Exploring the subjective response of these populations to an information display is methodologically beyond the scope of this work.
Interestingly, we consistently observed that overall subjective response to our prototypes was positive even when patients already felt well-informed during their visit. For example, when asked whether he had been kept sufficiently informed about his father’s care, P8’s son answered “[Yes], they’ve been keeping us abreast of what’s going on”. But his response to the poster was still overwhelmingly positive: “This is very helpful…this is right…”. Asked the same question, P12 said, “[Yes], they’ve been very good at keeping us up to date”, but still said “This is good, good. I’m going to write all that down in my book” and praised the prototype as highly useful. In both of these cases, patients saw an archival and summarization value in the information display, even though the staff had already provided them with much of the same information. Similarly, P15 states, “Yeah…they come in and update me but…I mean I can’t keep track of it all. That’s why I like this [poster].” She indicated that she was sufficiently informed, but the poster allowed her to process the overwhelming amount of information at her own pace.

P13 indicated a similarly high level of satisfaction with her updates, but still indicated that the poster prototype was useful to her because “I see that they’ve paid attention to what I said.” In other words, the information display confirmed that information had been accurately transferred to the system, which was a subjective benefit to her.

Patients reported that our prototypes had a calming effect

Several patients volunteered comments on the posters that suggested that information in the poster had a calming effect, improving their overall subjective state. P0 discussed wanting to know what her vital signs were when she arrived, but was frustrated when she was unable to quickly access that information. “Even if not in real time,” she reported, “at least you know, and it would calm me down.” P4 reported being calmed by just seeing the “What’s Next” section,
and having a sense of what her care plan was. P17 indicated that having some questions answered immediately, “took away a lot of fear”.

P11 offered an interesting insight regarding the calming effect of the poster, suggesting that even when a patient is not sufficiently coherent to be directly interested in additional information, the calming effect of an in-room information display on visitors and family members provides a tremendous benefit to patients: “…it would keep her calm. Other people panicking around you will stress you out.”

Responses to specific information types

One of our core research questions asked which types of information would be most interesting to patients, and how patients would react to specific information types. This section addresses those questions.

1. “What’s Next”

When asked what section of the poster was most useful, patients most frequently referred to the “What’s Next” section. This was consistent with our initial hypothesis that the most significant value of an in-room information display would be in keeping patients informed about their care plan. Reasons cited often included resolving uncertainty about a patient’s hospital course. Illustrative comments include those by P13, “It’s always the next question…what’s next…” and P4, “What’s Next—it tides you over, lets you know what’s going on.” Other reasons cited for focusing on this part of the prototype included surprising or new information (P3, for example, learned the specific destination of her pending transfer) and an expectation that it would be the most dynamic section (P13: “It will probably change the most often.”)

Interestingly and contrary to our hypothesis, a small number of patients indicated that this was not a useful section, in some cases that it was the least useful section. P12’s wife, when
asked what section she would remove if required to remove a section, replied “What’s next… because the nurses have been telling you what’s next.” In this case, the patient and his wife were paying close attention to verbal updates, so they were more concerned about record-keeping and long-term memory. They maintained an extensive archival medical record and saw the main value of the poster in information assembly, although they were strongly positive on the poster overall.

2. “We’ve Completed”

The “We’ve Completed” section was also frequently cited as the most useful component of the poster. As discussed above, this was frequently the case when patients were well-informed about their care plan but saw an archival and information-confirming value in the prototype. P8’s family shared care responsibilities, and kept detailed records of his care to support that process; his son found the “We’ve Completed” section to be the most useful aspect of the poster, stating that “[it provides] details about what happened throughout the day, so we can go back later, can ask our dialysis doctor about this potassium issue.” Interestingly, this visitor (P8’s son) had not been present throughout the visit, and therefore also benefited from a comprehensive list of what had occurred earlier in the day.

Other patients found the “We’ve Completed” section to be the most useful component of the prototype because it put them in a better position to answer questions from providers about their own care (providers frequently ask questions in environments, like the ED, where care is frequently transferred). P15 cited the “We’ve Completed” section as the most useful, explaining, “I like to have a list…so I can keep track of what’s actually been done, so I know where things are the next time someone comes in.”
Reasons for being less interested in the “We’ve Completed” section than other sections fell into two general categories. Some patients were acutely aware of what had happened throughout the day, particularly the set of patients who had received no pain medication. This was the case with P7 and her husband: “We know where we’ve been and what was done.” Another category of patients had low self-assessed health literacy and were not interested in the details of labs or other tests, only wanting to know what the prognosis and next steps were. When asked about lab results, P10 stated, “I wouldn’t know how to read [them] anyway.”

3. “Your Medications”

We were somewhat surprised at how frequently the “Your Medications” section (describing medicines administered during the hospital visit) was cited as the most useful aspect of the prototype. Patients and their caregivers generally demonstrated a high level of concern about medications, and having a detailed record of medications administered alleviated those concerns to some degree. P12’s wife, for example, indicated that this was the most useful component of the poster, stating “I need to know what went into his system, in case anything happens.” P11 expressed a similar sentiment: “If I go in again and it worked, how do I know how to ask for anything again?” P11 and his wife spent time matching the medications listed on the display to their memories of how those medications had been administered, which demonstrates the general level of concern around medications, and also highlights one of the important suggestions that arose for presenting medication information: patients tend to remember medications by form of administration (e.g., pill, IV, injection, patch), not just by name or even purpose.
Because pain medication was a significant component of most patients’ treatment in the ED, patients also responded positively to knowing when pain medication had been administered. P3 explained “My pain was coming back and I was wondering why, now I see how long it’s been since my last dose of medicine and I know why.” This was consistent with reports from providers that patients frequently request information about availability of pain medication.

4. “Your Vitals”

Even though we were not able to continuously update vital sign information (we labeled them as “vitals when you arrived”), and even though most patients had vitals monitors in their rooms, patients generally responded positively to having vital sign information present on their posters. Vital sign monitors are critical for care and are thus generally positioned to be accessible to staff,
not necessarily to patients (P0’s husband stated, “I wish it were easier to see vitals. I check the monitor here, but it’s behind us.”). Not surprisingly, patients who were well-informed about the interpretation of their vital signs responded positively to having them accessible. P6 stated “Didn’t know my pressure was so high, it’s 156/100”, and P10 stated “I have high blood pressure, so I track that”. Interestingly, patients who were not necessarily looking for specific information in vital signs were still aware of their importance and appreciated having vital signs accessible. P7’s husband cited this as the most interesting aspect of the poster, stating “I was with her when they ran the lab work, so I know that they were taking blood tests, but I didn’t see the vital signs.” This highlights another important aspect of this component: vital signs are often collected early in a patient’s visit and not specifically discussed numerically later on; visitors who were not present at the beginning of the visit—or patients who were not cognizant at the beginning of the visit—benefit from a persistent vital signs display.

However, no patient participants reported vital signs as the most interesting component, possibly because most patients already had an in-room vitals monitor (though visibility varied among rooms). One participant—P8’s son—cited vital signs as the least interesting component, explaining that “we take his vitals at home.”

5. “Your Care Team”

P7’s husband expressed a common sentiment, motivating the inclusion of names and pictures of each patient’s care team: “I’ve been focused on [my wife], even when they introduce themselves. But I want to know their names.” P8’s son, who was closely involved with long-term care for his father, expressed a deep attachment to knowing the names of his father’s care providers: “I particularly like the names of people who’ve been monitoring my father.” P11 highlights that even though a patient may want to know their care team members’ names, a patient’s own
periods of irritability can get in the way of this process: “I want to be tended, but I also want to be left alone, so I tell them to leave me alone sometimes.”

Despite desire to know names, only three participants remembered any of their providers by name, when asked before we deployed our prototypes. P12’s wife summarizes the almost-ubiquitous response patients provided when asked about their care team: “Yes, they [introduced themselves]. But when you’re stressed in here it’s hard to remember names.” Patients and their family members frequently mentioned stress, pain, and medication as possible hindrances to their ability to recall new names and faces.

Only one participant (P14) indicated that this section was not useful, but interestingly this patient responded in a definitively positive manner to the aesthetic impact of this section. This highlights another important aspect of the “Care Team” display: a personal aspect to the design that offers value beyond the information it presents.

6. Health Profile / Allergies

The “Health Profile” section of the display typically housed information about medications that patients were taking at home and medications to which they were allergic. No patients specifically indicated that these were the most useful components of the poster, but response was positive to this information, particularly allergies. This is interesting, because allergies are generally self-reported, but P0 highlights a common sentiment around this topic: patients wanted confirmation that their self-reported allergies had propagated properly to their current care team. P0 states “[I was] afraid the doctor would forget, and if they were right there, they could just look up and see.” In fact, this patient and her visitor later referenced the poster when double-checking that a medication did not contain iodine, to which the patient was allergic. P9 expressed
similar sentiments (“They see that I’m allergic to Percocet, so they won’t give that to me”) and P12’s wife (“[Listing allergies is useful] to make sure they know.”)

P13 described another interesting aspect of listing allergy information, particularly in contrast to information about medications taken at home: “I forget [my allergy information] sometimes. My meds I take every day, it’s hard to forget them. Allergies I only deal with when I’m here.”

**Privacy and Data Sensitivity**

While interesting privacy caveats and guidelines did emerge, one of the major surprises in our interviews was that privacy was not a major concern around the types of information we were presenting. Even with our large-format poster prototypes (4’×3’), and despite rooms being shared with another patient and separated from the ED floor only by curtains, patients generally felt that the benefits of an in-room information display outweighed any privacy concerns. This section highlights patient responses around privacy, including exceptions to this trend.

We did not include patient names on large-format displays, as this was expected to provide little benefit at a high risk to confidentiality. Nearly all patients underscore this privacy constraint; when asked whether they would be comfortable having their names on the poster, all patients indicated they would not, even those who had no other privacy concerns.

We also highlight that privacy concerns around the large size of the poster prototypes were not a reason for patients to decline consent, since patients were offered the letter-sized prototype as an alternative. Only one patient (P6) declined the large-format prototype and elected to receive a letter-sized handout. In other words, it does not appear (anecdotally) that any patients declined to participate on the basis of privacy concerns associated with the prototype size, which would cloud our analysis of privacy concerns.
P1 summarized the general trend toward being comfortable with the included information: “Nothing that’s so personal that it bothers me.” This was particularly interesting since this patient was very privacy-conscious and asked numerous questions about the specific data to which researchers would have access. This patient indicated specifically that he would be comfortable having everything relevant to this visit on a large display in his room, but would not be comfortable including his complete medical history.

When asked whether she would have concerns with visitors seeing the information on the prototype P13 responding emphatically, “No, not at all. My family would love to see this.” P16 was asked whether the size of the poster was a concern, and specifically responded that the size of the poster was a direct benefit: “I like that I don’t have to strain my eyes to see it. On a computer monitor, information like this can start to run together. I like this.”

With that said, patients did provide some insightful guidelines with respect to data privacy, in addition to exclusion of names. P6, who declined the large-format prototype, reiterated P1’s concerns about previous medical history. P6 similarly appreciated that we listed only a number of medications that she was taking outside of the hospital, not the specific medications, which would reveal information about medical conditions from which she suffered. This case was particularly interesting, because P6 willingly shared her handout with visitors and even with her roommate, whom she had only met during this visit. In other words, she drew a very strong line between information relevant to the present visit (which raised no privacy concerns whatsoever) and information about existing conditions or previous treatment (which raised strong privacy concerns).
**Information Display Use Cases**

The previous sections examined patient responses to the information display prototypes. This section focuses on the proposed use cases for in-room information displays that emerged during discussion with patients, and any poster-centric actions specifically observed during our visits.

**Patient Displays Facilitate Within-Visit Information Sharing**

In several cases, our prototypes provided an artifact to focus discussion with visitors and family members. For example, P0 reported using the poster as a focal point for discussion with her sister and her husband, who were present at the hospital. P7 used the prototype to update her husband on what had happened before he arrived, and P7’s husband in turn used the poster as a guide when summarizing the present visit by phone to remote family members: “Yes, I used it to tell [family members] her vitals, and who was on her care team, and what went down and the reason. I was able to use the poster when I talked to them, so I told them a lot of what was on it.” P11’s wife similarly used the “Care Team” section of the poster to ask the patient about each provider who had visited while she was out, and P15 reported referring to the poster extensively in a phone conversation with her two cousins.

Prototypes were also used in several cases to facilitate discussion between providers and patients. For example, P0 used the poster as a starting point to present her medical condition to a consulting physician, and P16 used the poster as a reminder about topics she intended to discuss with her physician: “A lot of times, you talk to the doctor, and don’t remember what they said. Now you can pick out the stuff that you want to ask about, or words that you don’t know like ‘electrolytes’.” P11’s wife and P7’s husband both used the poster to discuss care status with their
attending physicians, and in P7’s case, the attending physician was reminded by the poster to double-check on reported allergies, which had become relevant to the patient’s care plan.

Patient Displays Facilitate Post-Visit Information Sharing

While our methodology did not permit us to assess whether our prototypes influenced patient or provider behavior outside the hospital, patient responses strongly suggested potential value for sharing information with others post-visit. Very frequently, participants expected to use the information presented on our prototypes when visiting other doctors, particularly when it was in letter format or, by request, in printed photograph format. P3, P7’s husband, and P12’s wife all indicated they would bring their reports (or printed photographs of their posters, which P7 and P12 requested) to their primary care physicians. P12 and his wife even specifically suggested adding the current date to the design, because the use case of providing information during a subsequent visit was important to them, and “Every time you come back to the hospital, they ask you what dates, you can never remember what dates things happened.”

In addition to sharing information with subsequent providers, most patients reported wanting to share the information on our prototype with family members who were not present during the hospital course. For example, P4 wanted to share it with her mother, reporting that the poster would allow her to “tell someone basically verbatim what happened to me in the hospital.”

Patient Displays Facilitate Post-Visit Information Archiving

Although our prototype was primarily designed to address within-visit concerns, many participants, particularly older patients with chronic conditions (or family members caring for such patients), reported maintaining extensive medical records at home, and quickly saw the
value of a condensed visit summary for archival purposes. This was particularly evident with participants who received letter-sized prototypes; all of these participants put the prototypes away for archive. P12’s wife requested a printed photograph of the poster and inserted it into a medical notebook that she maintained for her husband and brought to all of his hospital visits. P16 maintained a similar archive, and we observed her taking extensive notes from the poster, to produce a “physical reminder of what happened, since it’s so hard to remember otherwise.” This consistent response suggests that many of the guidelines presented in this paper will apply equally well to patient-centric discharge reports, though further work is required to validate this hypothesis.

An interesting exception to this trend was P15, who specifically suggested that she would not want to take a paper version home, and implied that she preferred not to remember the visit at all. This is an interesting tension in both post-visit and within-visit information reports: many patients desire additional information, but also may benefit emotionally from some detachment from medical details.

*Patient Displays Provide Needed Memory Aids in the ED*

Particularly in an ED, patient consciousness and awareness go through tremendous variation as pain, exhaustion, and sedation set in and fade. This has a profound impact on a patient’s ability to remember critical treatment information. P3, for example, had an excellent memory and remembered every detail of the researchers’ interactions with her (including names) over the course of a couple hours, but reported not remembering any names that were presented to her in the morning because at the time she was “in too much pain to remember anything.”

P11 summarized this benefit nicely: “Sometimes when you come in you’re in pain, or you get some meds, and when your mind clears up, it’s useful to see what’s been happening.” While
physicians and nurses strive to answer patients’ questions, even providers with a strong commitment to keeping patients informed may not always see patients during periods of lucidity.

**Care Provider Feedback and Observations**

Initially, we were unsure whether providers would be supportive of an information display that reported information to patients, bypassing the traditional information flow through providers to patients. We were also unsure whether providers would support the specific structure of our prototypes, which – while designed in conjunction with physicians—were tailored to a patient information model. Thus, another goal of our study was to assess provider response to in-room patient information displays *during their deployment*, and particularly to our prototype designs.

This section explores the initial responses of providers (doctors and nurses) to our prototypes during our WOZ study. Comments in this section were offered by physicians working with us to construct our prototypes, but did not result from in-depth interviews focusing on the display design. Later in this chapter, I describe a survey study designed to capture detailed sharing preferences: examining specific information types, temporal aspects of presentation of information during care, and language and data simplification preferences.

Overall, providers’ subjective responses to our prototypes were markedly positive, and all were supportive of our research efforts. There was no direct incentive for providers to participate in our study, and in fact we required some amount of time—a valuable commodity in the ED—from each doctor to confirm that information was appropriate and to fill in gaps in the EMR (often to populate the “What’s Next” section of each poster). It’s thus a strong statement of support that all 16 physicians whose patients we interviewed were willing to work with us, recognizing the value of an in-room display and the potential long-term benefit and time-savings associated with in-room patient displays.
Provider Response to Specific Information Types

1. “What’s Next”
Multiple providers cited “What’s Next” as the category they expected would be most useful to patients. One physician offered the powerful suggestion that he would be willing to have the EMR field he typically uses to take notes about pending steps automatically pushed to a patient display, recognizing the potential impact on patient experience. This is encouraging, as this category is difficult to automate, and leveraging physician notes would greatly facilitate the inclusion of this information in a fully-automatic system. This is also a surprising sentiment, as we expected physicians to uniformly object to automatically pushing notes to patients. Other physicians were also positive on automatic pushing of “What’s Next” information, but raised concerns over presenting specific steps in the care process. One physician suggested that patients often have a hard time understanding the role of the physician in the diagnostic process, and that patients would expect an immediate diagnosis or discharge if they saw a discrete series of planned tests.

2. “We’ve Completed”
Though physicians supported the availability of the care record provided in the “We’ve Completed” section, concerns were raised over certain information types, particularly lab results. Even patients with high health literacy are often unqualified to interpret results, which are frequently meaningless in isolation. Almost all physicians with whom we spoke highlighted the danger of reporting individual lab results as “normal” or “abnormal”, stating that normality and relevance can only be assessed holistically, in the context of a patient’s care profile. Lab results, often collected in complex batteries, are particularly problematic: one physician stated that, “Almost all of these grouped results will have an abnormal in them—typically meaningless.”
With that said, simplified language like “normal” and “abnormal” did not raise objections and was supported by most physicians as appropriate terminology for the posters. The extraction of “normality” from raw results was the objectionable step, highlighting an important challenge for future work: the application of machine learning techniques to synthesize “normal” and “abnormal” assignments that physicians are comfortable with presenting to patients. This is a highly simplified form of the much larger problem of automated diagnosis, but a problem that we feel deserves significant attention from both the HCI and AI communities.

3. “Your Vitals”

Some providers raised similar concerns over the potential for misinterpretation of information in the “Your Vitals” section of the poster. One nurse suggested that the availability of vital signs information would lead to constant requests to hospital staff for interpretation, and one physician suggested specifically that, “sometimes [a] blood pressure [reading] escalates concern”.

4. “Medications”

Providers uniformly viewed the “medications” section of the prototype as a positive feature. Information about medications administered is objective and readily available in the EMR, and providers indicated that they received numerous questions about medications administered and would appreciate having this information automatically and persistently delivered. One nurse went even further, suggesting that, “everyone has a right to know what’s going into their body”, and one physician highlighted a practical aspect of this section: allowing for potential correction of misinformation regarding home medications and allergies.

5. “Your Care Team”

We were concerned that providers would object to putting their pictures on the poster prototypes (in the “Your Care Team” section), but with few exceptions all providers were remarkably
positive about the inclusion of their photos. One physician expressed concern around photos, stating that she often cares for emotionally unstable patients, and that it is not uncommon for a patient to be upset; in these cases, she prefers a degree of anonymity. She also raised concerns about patients blogging about their ED experiences and using her photo if it were made readily available.

Other interesting concerns arose around the inclusion of “non-core” members of the care team, such as technicians. Typically, staff other than doctors and nurses “float” among larger portions of the hospital and are unlikely to be seen again by individual patients, raising frequent concerns about confusing patients with superfluous names and faces. Another interesting set of responses arose around the inclusion of providers outside the ED who had been contacted regarding a patient’s care. We did not include these providers in the “Your Care Team” section of the prototype, but did refer to them in other sections when sufficient information was available (e.g. “We’ve contacted your oncologist, Dr. A, to discuss your care”, or “You will be admitted under the care of Dr. B.”) This was seen as a very valuable component of our prototypes; one physician even suggested a dedicated “We’ve Contacted” section. Providers and patients both recognized the potential for laying a foundation for continuity of care across clinics.

Information Simplification

Discussions with patients and physicians elicited several guidelines for presenting information in patient-accessible language. This section focuses primarily on the presentation of tests and test results, which elicited significantly more discussion than other sections of the poster with respect to presentation techniques and terminology.

In many cases, we elicited physicians’ opinions by proposing a relatively literal description of a test that had been ordered, for inclusion in the “What’s Next” category. Fluid
labs were generally listed in the EMR with formal names like “CHEM8” or “PTT/ProTime”. These terms were not particularly patient-accessible, which challenged physicians to develop simplified explanations. Interesting strategies and relevant factors emerged in this process.

Frequently the description that a physician determined to be most appropriate was an indicator of the function a test served for a particular patient. For example, P4’s attending distilled a complex series of test batteries, each comprised of 10 or more individual tests, to “infection screening”, since the goal in this case was to rule out infection.

In other cases, simplification of a test name or result was a straightforward translation process. For example, the test described in the EMR as “PTT/ProTime” is consistently used to evaluate blood thickness, and physicians were comfortable listing this test on patient’s posters as “PTT/ProTime—To see how thin your blood is”.

In still other cases, physicians determined that there was not a straightforward simplification of a test or result, but still recognized the value in keeping the patient informed. P14’s attending preferred not to simplify the result “Elevated Creatinine and BUN”, but in order to encourage the patient to ask questions about this result, suggested that we list this result as “Elevated Creatinine and BUN: Your care team will discuss your results with you”. This had precisely the desired effect: P14 specifically noticed this result and verbally requested a definition.

In addition to suggestions on translation and simplification, providers suggested other mechanisms for improving patient understanding of individual tests and results. Several providers suggested reporting labs not only by name and function, but by specimen type (blood, urine, image, etc.), since this would be more consistent with patients’ memory of the relevant
events. This paralleled P11’s suggestion to present *medications* by form of administration (pill, IV, etc.), a suggestion also reiterated by providers.

A high-level guideline reiterated by providers was to link tests ordered, results, and medications specifically to the patient’s complaint, since patients—particularly those in pain—are tightly focused on their immediate concerns. For example, P6’s attending physician suggested listing pending labs as: “Bloodwork ordered, to determine whether your chest pain is related to your heart or lungs.”

**Study Limitations**

In our study, we chose to use paper prototypes as they allowed us to understand practical situational factors related to the deployment of patient-facing technology without requiring costly IT support, and we were able to adjust aspects of the design without requiring software updates. This approach had several setbacks. First, the human “wizard” entered the room to post updates or replace handouts. After updates were made, the researcher switched from “wizard” to “interviewer” in the room. It was thus difficult to mitigate “good participant role” effects (Weber and Cook, 1972) (i.e., the participant might have guessed that our goal was to find the display to be beneficial, feeling obligated to respond positively so as not to disappoint us). While we could not eliminate the potential for this particular confound, we did try to focus on what the patient found useful and their *actual use* of the displays (e.g., by asking if they referred to it during their visit and how). These data then are just as important, if not more important, than the “positive responses” demonstrated by participants in our study.

Of course, in addition to our filtering criteria excluding very ill and hostile or aggressive patients, there were a few patients whom we approached who chose *not* to participate in the study. When we approached patients for participation, we showed them a sample patient
information display to demonstrate what they could expect. While it is not possible for us to know why certain patients choose not to participate (a number of reasons are plausible), it could be argued that those who did choose to participate did so based on finding the idea of the information display to be useful. In this way, a self-selection bias might have influenced the results we found related to patients’ positive view of the display (Lavrakas, 2008). In all, 22 patients were approached for our study, and 19 agreed to participate (three declined before or during the consent process). One who was enrolled was excluded during the interview as he was found to be inebriated, leaving 18.

**Larger Trial to Assess the Benefits of Patient-Facing Information Displays in the ED**

In order to quantitatively evaluate the design of a patient-facing information display during emergency department care, a larger field trial could be conducted to assess the effectiveness of such technology. This trial would compare the proposed design, made accessible on a large display, to a general-purpose large display. A larger sample of patients (e.g., eighty or more) could be divided equally into two demographically and clinically-similar study groups of forty, in which they are given either: 1) an electronic display with access to general consumer health information (T1); or 2) an identical display with added patient-specific information (T2). By supplying both groups with the display technology, a more appropriate baseline can be established.

In this study, health literacy would be assessed for descriptive purposes (Chew et al., 2004). Within a short period of time after each patient is assigned to a room in the ED (held constant across each patient), the patient would be invited to participate in the study. The sample size of 80 would allow the detection of a large effect size (.8) with a power of 94% and alpha for
significance set at .05. This effect is based on a statistical power calculation for the student’s t-test, the expected method used for data analysis of scored instruments.

To measure the impact of the personalized information, we could measure patient satisfaction, perceived patient engagement, knowledge of medications and lab tests during hospitalization for the intervention group (T2) as compared to the generic display group (T1). For example, to validate the effectiveness and quality of the personalized information display (T2), patients’ knowledge of their medications could be assessed using the Medication Knowledge Score (MKS) (Marks et al., 2010). Unlike other medication knowledge assessment tools, such as the Drug Regimen Unassisted Grading Scale (DRUGS), which assesses only the identification of the correct medication name, dose and timing and the ability to open medication containers, the MKS measures patients’ knowledge of medication indications and serious potential side effects. For each of a patient’s medications, the MKS could be used to measure the patient’s knowledge of the medication’s name, dose, indication (what the medication is for), and potential side effects. For each medication, the MKS score is the number of correct answers out of a possible four. These scores could be assessed at the conclusion of patient use of the personalized information view.

To measure perceived quality and perceived satisfaction, we could use patient and clinician surveys and analysis of information system audit logs. The patient and clinician survey instruments would be derived from the 26-item Telemedicine Satisfaction and Usefulness Questionnaire, described in Chapter 6 and included as Appendix C.1. This survey includes two scales that measure: 1) satisfaction with hospitalization and perceived engagement with health care providers; and 2) perceived usefulness of the display. The survey has 13 items on
satisfaction and engagement (six and seven questions respectively), and 10 items on perceived usefulness. All questions are measured on a 5-point Likert scale.

All study instruments would be scored and summarized using descriptive statistics. Experimental groups could be compared on socio-demographic and health literacy scores to assess the equivalence between the groups at baseline. Categorical data (e.g., gender, education, and race) could be compared using Chi-squared analyses. Instrument scores (e.g., health literacy) and continuous data (e.g., age) would be compared using t-tests. Summary scores from the Likert-type scales used for measurement of engagement, satisfaction, and perceived usefulness could be treated as continuous variables, allowing the hypotheses to be tested using t-tests. We could also conduct correlational analyses to examine associations between predictor variables, such as health literacy, and outcome variables such as medication knowledge scores, given that these might be important variables to control for in a future study.

As a separate study component, eye-tracking technologies worn by patients, when used in conjunction with skeletal and/or head motion tracking technologies to capture posture signals and direction of gaze (e.g., to detect if the patient is indeed facing the display) could be used to gather data on how the displays were or were not used during waiting periods, consultations with clinicians, and conversations with family members. Data from this technology could be assessed through analyses of fixations and saccades (using techniques such as velocity detection methods), vestibulo-ocular reflex (Duchowski, 2007) and smooth pursuits to understand the information types on which patients are fixating, reading once, more than once, or not at all. Video recordings capturing patient behavior in the room could be analyzed manually to detect references to the display. However, approval for continuous video monitoring would be difficult.
to obtain and the participation rate might be low due to patients’ or family members’ privacy concerns.

**Toward Fully-Automatic In-Room Displays**

Although we conducted our study using paper prototypes, with researchers serving as intermediates between the medical database and the in-room display, our study taught us that most components of our design could easily be implemented in a digital display. Medications, allergies, and primary complaints were typically pulled verbatim from the medical record; one exception was the insertion of a short description for medications, but in almost all cases these descriptions were well defined and easily culled from online sources. Care team information, while limited, was also available in the medical record, and no interpretation was necessary to assemble this section. We highlight that patients and providers found significant value in these components alone, which are trivially automated, suggesting that an automatic in-room information display may be practical already.

Other sections of the poster, as described previously, required input from physicians. The “What’s Next” section, for example, was typically assembled by collecting labs and imaging studies that had been ordered; this information was easily available in the medical record. However, physicians were also able to provide information about longer-term events and steps that would be taken contingent on other results, which were not easily available and would be difficult to automate. We highlight that the medical record did contain a field that physicians used to record precisely the type of information that was used to populate the “What’s Next” section. This information allows physicians to quickly assess the status of their patients, and to transfer status information at shift changes. Physicians were positive about the idea of defining a
mapping from this information to more patient-friendly terminology, which suggests a very promising avenue for future work.

Similarly, in the previous section, we highlighted concerns associated with the presentation of test results, which underscore the challenges associated with automatically populating the “We’ve Completed” section of our design. Given the degree to which our study demonstrates the utility of this information, a promising direction of future research points toward automatic simplification of medical test results. A large-scale version of the process we went through with each physician—presenting a candidate test result summary based on simple heuristics, and requesting an appropriate simplification—would provide a fascinating ground truth data set that would allow us to address this important problem from a machine learning perspective.

One interesting and unanticipated concern arose when we spoke with providers about automating an in-room display: patients in an emergency department move around frequently, and ensuring that information is presented to the correct patient is a fundamental problem. The EHR does contain information about patient location and room assignment, but this information is often “stale” or vague. One interesting approach is suggested by the fact that this particular hospital in fact has a hospital-wide, ultra-wideband (UWB) location tracking system, an increasingly common facility used primarily for equipment tracking. Embedding UWB tags, for example, in patient bracelets would allow relatively precise localization of patients, and alleviate this key concern around automatic displays.
SURVEY STUDY: PHYSICIAN RESPONSES TO PROPOSED DISPLAY

In our second study, we aimed to capture physician attitudes about sharing specific information types, temporal aspects of presentation of information during care, and preferences for language and data simplification. While the previous study elicited preliminary feedback from physicians who worked with us to construct our prototypes, it focuses primarily on patient responses to the in-room displays. Here, I present a survey study with attending physicians in the same ED, designed to explore in-depth preferences associated with a specific information display design.

Our survey study draws from accounts of early experiences designing PHR systems for online use. In particular, Halamka et al. highlight salient design considerations for sharing medical record contents with patients via online PHRs, describing candidate information types found in the medical record, such as the patient problem list, medication list, medical history, diagnostic test results, and clinical notes. They discuss clinicians’ perceptions of the unique challenges associated with each information type when made accessible to patients online (2008).

In this survey, we examined similar design considerations and challenges, focusing on real-time information sharing throughout an ED visit via personal, patient-facing computer displays. We also sought to understand opportunities and challenges related to new information types that are unique to a real-time display, such as care team information and information about a patient’s physical location within the hospital.

1 I created the IRB proposal and the survey and transcribed and led analysis and reporting of survey data. Dr. Gatewood provided guidance on the survey approach, handled the consent process, and distributed the surveys to clinicians. Dr. Eric Horvitz worked with me to conduct thematic coding and analysis and report results. Drs. Feiner, Gatewood, Morris and Tan also assisted with data analysis and result reporting.
The survey described a patient scenario representing a common ED presentation: a 52-year-old male with persistent chest pain, whose vital signs and relevant lab values are within normal limits. The survey (shown in its entirety in Appendix B.2) included a proposed patient information display (Figure 4.7) containing data stored in the hospital EHR, as well as information that could be composed through additional inference and cross-reference with supplemental databases (e.g., images of care team members). We presented information related to the status of the patient visit, such as what was expected next. This information was composed by inferring expected tasks based on current orders (e.g., if labs had been ordered, expected tasks include specimen collection, lab analysis, and lab review by a physician). The display was proposed with the inclusion of patient privacy controls (i.e., the patient could choose whether or not to use the display and could turn the display off at any time).

The proposed display was meant to generate responses to specific candidates for information to be displayed to patients. It contained varying levels of information: information typically relayed to the patient verbally (e.g., steps in work-up and next steps in care), information found in specific fields in the medical record, and associated metadata. For example, if a lab had been ordered for the patient, the name of the lab would be listed on the information display, along with the time that the lab had been ordered and other timestamps related to the progress and current state of that order.

The display included the categories and subcategories of information described in the prototypes we created for the first study phase. The survey included a combination of closed- and open-format questions about projected utility, sensitivity, and appropriateness of the level of detail of the information. The closed-format questions asked participants to indicate their willingness to allow each of the available information types to be shared automatically with
patients (willing or unwilling). For information types related to lab results, participants could indicate: “only after speaking with the patient”. Tables 4.2–4.4 in the Results section include the specific information types listed. Open-format questions (Figure 4.7 and Appendix B) solicited participants’ rationale for these responses.

Additionally, the survey asked open-format questions to collect further suggestions and considerations for an electronic patient-facing information display. These questions requested additional sections or information types to include, structural modifications, and alternative phrasing, and asked participants to annotate the sample display with any feedback.

PHASE TWO: RESULTS AND DISCUSSION

Physicians concur with patients in assessing the most important information display category.
Table 4.1. The number of participants selecting each information category as most important to the patient. Some participants mentioned multiple categories as being most important.

Table 4.1 summarizes participants’ selections of the most important section of the display.

“What’s Next” was most frequently selected as the most important section of the display to the patient. This corresponds to the category section that patients indicated as being the most important during a study conducted on a similar set of displays in our first phase.

*Overall, physicians were willing to allow automatic information sharing.*

Tables 4.2 and 4.3 indicate participants’ willingness to allow each information type to be shared automatically with patients on an information display. Table 4.2 presents results for general information types, Table 4.3 for specific information about lab results. These responses demonstrate that the perceived net benefit of information sharing—in terms of increased patient engagement and information availability—outweighed potential drawbacks. Vital signs, medication information, and care team information were almost ubiquitously assessed as appropriate information categories for automatic sharing. Many physicians commented that the value of making the information available extended beyond the role it played in diagnosis or decision-making. For example, P8 mentioned that, “*Vitals may be least useful but I think it is real medicine* for the patient.” However, reason for medication was judged to be more

Physicians were more cautious about sharing lab results and time estimates than other information categories. As indicated in Table 4.3, physicians were more willing to have information about labs (other than simple timestamps) available on in-room displays after speaking with the patient than before. Open-form responses suggest that this can be largely attributed to concerns about patients’ inability to interpret numeric values.
Table 4.3. Physicians’ willingness to allow specific information about lab results to be shared automatically with patients, with the option of indicating: “only after speaking with the patient”.

As indicated in For example, P13 mentioned commented that, “These [number]s should be interpreted in context. Context to be provided by members of the treating team. Also helpful to show trends based on historical values (e.g., last Hgb [Hemoglobin])” while P17 said, “Afraid
they might take it out of context (i.e., hemolysis) or we'd have to explain every small abnormality which maybe clinically less significant (i.e., BUN mildly elevated).” This raises a key challenge for subsequent research: automatic information sharing may be more feasible and more agreeable to physicians when some level of automated interpretation can be layered above low-level results.

A similar trend can be seen in Table 4.4: physicians are more concerned about sharing automatically-computed estimates of the time required for them to review test results. As P11 stated, “[the] ED [is] too dynamically busy, would share that procedure needs to be done, [but] time estimate is tricky.” While more concerns arose about wait times than other types of information, physicians supporting wait times explicitly mentioned the usefulness of these estimates. For example, P8 offered, “As a physician, I like the time estimate for order time to result back time. I think the patient may as well” while P3 also found these estimates to be important, but noted, "but I would overestimate.” Wait times are of particular concern to patients; physicians’ caution in presenting these estimates suggests a significant tension between a key information category and physicians’ preferences. This points to the need for further research on the development of methods for both accurate estimation of required times and carefully-designed guidelines for presentation of those estimates.

Participants suggested several additional content candidates and functionality.

Suggestions for additional content included information pertinent to navigating practical aspects of the current visit (food availability, restroom location, care provider roles), as well as personalized educational information, detailed medication summaries, and hospital activity information and wait time estimates (number of current ED patients, estimated time until bed is
Temporal considerations associated with electronic updates, beyond the choice to update before or after communication with physicians, were also mentioned. For example, P17 suggested that a system “wait until all labs are back to minimize multiple updates to patient.” However, our discussions with patients implied that receiving these updates, while they may be staggered, was useful as it helped them to understand that activities related to their care were happening on their behalf.

Table 4.4. Physicians’ willingness to share estimates of time until diagnostic events occur. Responses to three related questions are given: willingness to share time estimates until a diagnostic procedure begins (left), until results are available in the EHR (middle), and are finally reviewed by a care team member (right). Blank portions of the donut indicate that no response was given.

To shield or to share? The perceived role of patient-facing systems

We sought to understand associations among sentiments expressed in response to the sample patient information display, and perceived value of the display. We found an association between the physicians’ preferences about the appropriate level of detail of information on patient displays and their assessment of the role that the display would play in the clinical setting. In particular, we found that physicians who considered the information display to be too detailed (8 of 22) tended to consider the most important sections of the display to be those that could
address patients’ frequently asked questions—suggesting that they envision the primary role of the display as a way to offload questions. In contrast, physicians who did not assess the display as too detailed gave additional reasons for ascribing measures of importance to sections of the display. Two physicians in this group mentioned that the display might be designed to respond to patient questions, but they also discussed additional opportunities associated with the display that were not mentioned by the “shielders”. These additional reasons included the potential for the information to help with more in-depth education, to provide emotional support, to help with patient expectations, and to help ensure patient safety, as well as more general understanding and navigation of the clinical environment.

Physicians who found the information display too detailed, who had concerns about at least one information type shown, offered reasons for their choices based on patient competencies. They mentioned the potential for the information to confuse patients, given their lack of knowledge and context, more so than physicians who did not find the display too detailed.

Similarly, physicians who found the information display too detailed had suggestions for additional sections that were related to information pertinent only to the current visit (more about care team, etc.) and did not suggest educational resources or supplemental material for interpreting details or answering their questions. In general, with the exception of one physician who suggested the use of lists for follow-up tasks, these responses seemed to focus on content pertinent to navigating practical aspects of the current visit (food availability, location of restrooms, care provider roles). The group of physicians who did not think the display was too detailed proposed educational uses, the value of recall of information to use in consultation and
post-discharge support, and as an initial point of engagement in an ongoing conversation about the patient’s health and care.

These survey findings reveal a separation of physicians into those with a propensity toward sharing detailed information (14 of the 22) and those who preferred to suppress detailed information from the display (8 of the 22). We explored these different attitudes with questions pursuing deeper motivations for selecting important sections, withholding or presenting information for display to the patient, and concerns described around specific types of information to identify major contributors to information suppression in the ED, and how care to be taken to guide the design of safe, trusted patient information displays to ultimately accelerate their adoption. In particular, our analysis of the responses of physicians preferring to suppress information found six primary motivations for doing so.

**Patient protection**

Some physicians were concerned that certain information types might unnecessarily escalate patient anxiety (e.g., vital sign measurements that are higher than expected). Both emotional protection and concern for minimizing complexity factored into the responses to open-format questions. Information on the display could escalate concern (e.g., vital sign measurements that are higher than expected). Furthermore, patients could perceive their needs as being of lower importance with respect to other patients (e.g., if the information display provides evidence that their wait is longer than that of other patients). Concerns arose around “information overload”—in particular that providing too much information may disengage a patient from general involvement in his or her care, or distract them from information critical to decision-making.

**Adverse effects on patient behavior**
Some participants expressed concern that patients could respond irrationally to information delivered in the absence of a provider, potentially including anger targeted at providers. In these cases, concerns around providing physician names were significant: some participants felt that the persistent availability of provider names and photos could exacerbate hostility. Similarly, some participants feared that excessive information could lead to hostility and mistrust of physicians, (e.g., that patients would demand explanations that they believe fit the data).

Drug-seeking behavior was also a concern among a few respondents. In particular, fear that medication information could be used to encourage drug-seeking behavior. P14 commented on concerns that a patient complaining of pain, but seeking narcotic drugs, would challenge the choice to administer a non-narcotic pain reliever: “if [patient] wants a pain shot, I can give Toradol but if they see it on the screen [there could be] problems.” Finally, some physicians feared that patient dishonesty about symptoms, history, or behavior, would make it difficult to determine which ‘version’ of patient information to present on the display (patient-given, physician-perceived, or record-driven).

*Mistrust of technology*

Some participants expressed concerns that information may be incorrect in certain cases, leading to question profusion, patient dissatisfaction, and patient misinformation. This concern was particularly prevalent for the only information category we presented that required artificial intelligence: time estimates. Physicians were cautious about the automatic estimation of wait times, even those who were generally supportive of automatic information presentation.
**Added workload and cost**

Some participants expressed concern that information displays will require extended explanations by caregivers, negatively impacting ED efficiency. Similarly, concerns arose over question profusion about usage and maintenance of the display itself; the introduction of new technology into the clinic often places additional perceived responsibility on providers. Furthermore, some participants highlighted the potential expense of human monitoring and management that comes with the deployment of any new technology.

**Liability concerns**

Concerns arose over liability, namely that patients will be more likely to question physician actions in light of increased access to data.

**Disapproval of hospital procedure**

Responses indicated concern that patients without knowledge of the demands on hospital resources will disapprove of their care progress (e.g., a delay in processing a lab specimen due to high-priority resuscitation may be misunderstood).

**CONCLUSIONS**

In this chapter, I described two collaborative studies aimed at eliciting and assessing responses to patient-facing displays based on a hospital EHR in a large, urban ED. I presented a prototype design for an in-room patient information display, and used this design as a tool to explore patient and provider responses to this new information medium. We found that both patient and provider responses were overall very positive, suggesting that further studies at the intersection of HCI, medical informatics, and machine learning can better enable digital, automated versions of this concept.
Patients we studied suggested significant value in this design for information retention, post-visit review and archive, and within-visit communication. Most physicians we studied are supportive of the automatic presentation of most information types, recognizing that increased patient engagement and education may ultimately outweigh the risks of direct information presentation.

We found that the physicians we surveyed can be divided into those (the majority) who favor openness and transparency versus those who lean more toward protecting patients from informational details on the display. Our findings also highlight the concerns of physicians who are more hesitant about having information delivered directly, which we see as a call for further research in creating accurate, safe, and appropriately-filtered information displays.

While these findings point to promising initial results, our study is limited by both the size of the respondent pool and a focus on the ED setting. Later chapters describe research dedicated to comparing our findings here to an inpatient cardiac care context, and also focus on the development and testing of automated methods for decisions about if, when, and how to present EHR information to patients. In Chapter 9, I reflect on the collective insights and themes that emerged when considering the research described here and in subsequent chapters.
CHAPTER 5

ELECTRONIC MEDICATION INFORMATION NEEDS OF CARDIAC INPATIENTS

This study is documented in the following paper:


INTRODUCTION

This chapter highlights particular results that, together with the results of studies described in Chapter 4, form the characterization of the design space for electronic information delivery to hospital patients—the second contribution of my dissertation research. As I discuss in Chapters 2 and 4, there is evidence that hospital inpatients would like a timely, electronic view of the inpatient medications that have been administered to them during their care. Such a view can promote patient safety and participation in care (Longtin et al., 2010). However, electronic patient-facing views of medication information in the hospital have only recently begun to
emerge, and, to date, no prior studies detail patients’ needs for this information in electronic form, nor the effects of having it available.

Broad examinations of the needs of hospital patients through ethnographic studies and structured and semi-structured interviews offer many insights to directly inform the design of health information technology. A recent study focusing on a variety of present-day needs of hospital patients found that some patients are willing to go through considerable, sometimes painstaking efforts to find computers outside of their rooms to search for health information (Skeels and Tan, 2010).

But while previous work has identified clinical information types that are of interest to patients, more research is needed to explore patients’ information needs concerning details of specific information drawn from the hospital EHR. These information needs should influence the design of techniques for careful formatting, presentation, and timing of the ongoing delivery of detailed information to patients during a hospital stay. In this chapter, I describe a collaborative exploration of cardiology patients’ information needs related to their hospital medications. We assessed these needs to gain insights that can inform the design of interactive, electronic views of medication information for cardiology inpatients.

We report on results of in-situ interviews with 11 inpatients and 6 nurses in a cardiology step-down unit of a large, urban hospital. Our interviews were designed to examine medication information needs that are shared among cardiology inpatients, how these needs translate into design goals for technology that delivers medication information to cardiology inpatients during hospital care, and how such inpatient medication information differs from that designed for outpatient or transitional contexts. I discuss related research, describe our interview topics and key findings, and conclude by exploring some key implications of the results.
BACKGROUND

Recent research on medication information needs has focused largely on assessing needs related to medication management in outpatient or home settings (Bennett et al., 2003; Kaelber et al., 2008; Palen and Aaløkke, 2006; Reti et al., 2010) and tools have been developed to support long term medication management based on information needs (Wan, 1999).

Khan and colleagues report on an application to support medication management among older adults during care transitions (Khan et al., 2010) and address several important design considerations for such transitions. Their information-needs assessment focuses on older adults and caregivers, and their findings relate to medication education and information concerning medication regime (i.e., reasons for complex medication regimes, opportunities for alternative medications, and ways to maintain autonomy).

The inpatient care setting differs from transitional settings, and the differences have important implications for technology design. For example, in the inpatient setting, medications are more often provided for only a short time and then discontinued as new medications are started. Forms of medications are more diverse and include titrated intravenous medications in addition to other more familiar injections, pills, powders, and liquids. Furthermore, responsibility for medication administration and adherence is shifted to care-team members, rather than patients themselves.

SETTING AND PARTICIPANTS

We conducted in-situ interviews with 11 cardiology inpatients and 6 cardiac-care nurses to identify patient information related to medication.1 We used a semi-structured approach for

1 I created the IRB proposal and managed the consent process. I also led all fieldwork, interview analysis and reporting. Dr. David Vawdrey and Dr. Sarah Collins provided guidance related to the study approach.
patient and nurse interviews, to better tailor questions and discussion points to the specific situation of each patient, and the specific experiences of the nurses. All interviews were either audio recorded or conducted by two interviewers, with one taking written notes. After transcribing all audio recordings and notes, participant responses were thematically coded and trends in emergent themes were reviewed among the research team using the hybrid approach discussed in Chapter 1.

The study was performed on the medical and surgical cardiac units in the Milstein Hospital at Columbia University Medical Center (CUMC). CUMC is a large urban academic medical center that is part of NYP. The medical center is a Level I trauma center and a major teaching hospital with a busy cardiology service. We conducted interviews with patients and nurses in a 30-bed cardiac step-down unit. Patients on this unit are hospitalized with coronary or valvular heart disease, heart failure or arrhythmias and undergo the implantation of intracoronary stents, transcutaneous valves or automatic internal cardiac defibrillators (AICDs). Some patients may be undergoing evaluation for cardiac transplant or mechanical assist device and may be initiating therapy with intravenous medications. Patients on the surgical unit are recovering from coronary artery bypass surgery, valvular repair or replacement, or cardiac transplant. The typical length of stay in the unit is at least five days. Patients are generally coherent and able to eat and walk with assistance (critically ill patients are treated in the cardiothoracic intensive care unit). The research was approved by the medical center’s human subjects institutional review board and the Cardiac Step-Down nurse manager.

The nurse: patient staffing ratio is 1:7, and each patient has a primary nurse assigned. Each patient has an attending physician who oversees his or her care. Resident physicians (house

Andy Liu assisted in conducting patient interviews, transcribing data, and contributing thematic coding and analysis. Dr. Feiner assisted in result analysis and reporting.
staff) rotate in a staggered fashion through the medical unit in four-week cycles. Each unit is staffed 24/7 by physician assistants (PAs) or nurse practitioners (NPs) who cover patients that are not on the house staff services. Clinical rounds may be performed as a group or separately so that the resident, PA, or NP may see the patients separately from the attending physician. Nurses make regular assessments and use the EHR to document their findings, as well as medications administered. Patients are also visited by aides who document vital signs every four hours, lab technicians who draw blood, social workers, nutritionists, physical and occupational therapists, and other physician teams on consulting services.

We interviewed 11 patients (nine male, ages 23–79, mean = 53) during their stay over the course of approximately two weeks. All patients reported that they used a cell phone on a daily basis. Nine of the patients had computers in their homes with internet access, and used the computer daily. The remaining two used a computer with internet access on a regular, but non-daily basis, outside of the home. Each interview was designed to last thirty minutes. During the course of our study, two patients asked that we cut the interview short due to discomfort. Most patients spoke with us for 30–45 minutes.

In addition to the patients we interviewed, six cardiac step-down nurses (all female) in the unit were recruited for our study based on the recommendations of the nurse manager. The nurses had varying amounts of experience in cardiology, ranging from 2 to 12 years (mean = 6). All nurses had experience briefing patients about their medications, and assisting in discharge preparations requiring that medication information be reviewed with patients and family members. Interviews with nurses were conducted in fragments as their work allowed. Each nurse agreed to be shadowed for a period of about two hours, during which time interviewers followed
them as they conducted care activities. Interviewers engaged nurses in discussions during breaks and brief downtime periods.

FIELD STUDY

After briefing physicians and nurses in the cardiology step-down unit about the study objectives, we asked them to identify eligible patients in the unit. Screening criteria required patients to be able to converse with researchers, and to be medically stable (capable of ambulating with assistance or on their own, and off step-down monitors). If an approached patient was willing, we collected informed consent.

Patient Interview Topics

Patients were asked to describe various experiences related to learning about and taking medication. Each patient was asked questions that explored all of the following discussion points:

1. Managing medication information at home.

These questions explored patients’ experience managing their medications. Patients were asked to describe the number of medications they took at home, their methods for managing information about those medications, and their interest in accessing information about them through a variety of sources, including the internet.

2. Current medication status.

These questions explored strategies patients used to keep track of their medications. Patients were first asked to comment on their level of interest in keeping track of the number and types of medications they received in the hospital. They were asked to indicate whether they thought they
had a good idea of the number and types of medications they were currently receiving, and whether they wanted to access a list of current and/or discontinued medications.

3. Medication requests.

Patients were asked to describe any requests that they had regarding medications (that a medication be started, stopped, or adjusted) and to describe the circumstances around those requests and how they were handled.

4. Record keeping and interest in archiving.

These questions explored whether patients were keeping any personal notes related to their medications, whether they would be interested in accessing information about medication after their visit, reasons they were keeping or would like to keep a record of their medication list, and barriers they encountered to taking notes.

5. Preferences for medication explanations.

These questions explored the ways in which patients received explanations about their medications, whether they found the explanations too detailed or not detailed enough, and what types of information they were curious about related to medication. They were first asked to volunteer any type of information that was important to them. The interviewer then followed up by asking about their interest in several different information types. Patients were asked whether they would look up additional information about their medications if they had internet access in the hospital, and if so, what specific topics they would be interested in reading about in online articles. To gauge interest, they were asked whether, since their admission, they had experienced the desire to search for web content related to medication information that had been explained to them.

6. Questions about medications throughout their care.
Patients were asked to recall and recount any questions or concerns they brought to their doctors or nurses about the medications they had received throughout their care. They were asked to comment on their questions and concerns earlier on in their treatment (during and after initial step-down) as well as their current questions and concerns. They were also asked to reflect on how their concerns and questions changed throughout the course of their stay.

7. **Attitudes about computing technology at the bedside.**

Patients were asked to comment on their desire to use technology during their hospital stay.

**Nurse Interview Topics**

Interviewers sought an understanding of the information needs of patients, as experienced by nurses, and how aspects of the clinical context shaped those needs. Each nurse was asked questions that explored the following discussion points:

1. **Strategies for medication explanations.**

Nurses were asked to describe their strategies for explaining information to patients about hospital medications. They were asked to provide example explanations for common medications given in the cardiology unit, and comment on how they structured the explanations in terms of purpose, type, risks/benefits, side effects, and procedural information on administration. They were also asked to describe how they explained information on prescription medications patients would take after their stay.

2. **Medication requests.**

Nurses were asked to describe their experiences with requests by patients to adjust, start, or stop medications, how often these requests occur, and how information is exchanged between patients and care-team members to address these requests.

3. **Questions about medications throughout patient care.**
Nurses were asked to comment on the questions or concerns they frequently encountered from patients, including how these questions and concerns changed throughout a typical patient’s stay.

4. *Attitudes about computing technology at the bedside.*

Nurses were asked to comment on the perceived benefits and risks of providing technology to hospital patients that allowed access to detailed medication information and education.

**FINDINGS**

*Patient Interview Responses*

Patients discussed a wide range of medication information needs, expressing preferences supported by their experiences learning about medications in the hospital, and their desire to successfully manage prescription medications upon hospital discharge. We found that cohesive trends emerged in information needs across patients. Below, we outline and discuss key themes arising from our thematic coding of patient interview data.

*Tracking Changes in Medications*

Several patients expressed a desire to be able to keep track of their current medications. Each of the 11 patients we interviewed indicated that they thought having a list of current and discontinued medications in an electronic format, available at the bedside, would be valuable. Many patients also mentioned the importance of a list of home medications to verify that those had been noted. While we suspected that these lists would be useful as a memory aid and monitoring mechanism based on prior work on information needs (Palen and Aaløkke, 2006; Skeels and Tan, 2010; Wan, 1999), we found that the inpatient cardiology setting presented specific challenges and needs related to patient monitoring of medication changes.
First, medications change frequently during a patient’s care, and while patients are given verbal briefings describing updates to medications, they are not responsible for managing the actual change in medication regime. Medication types, doses, as well as methods of administration, can change to respond to patient preferences, current problems, and individual responses to drug therapy. The lack of supporting written or electronic materials to describe and explain these changes makes it hard for patients to remember current and previous medications and corresponding doses.

Second, medication changes are often tied to specific problems, procedure results, or clinical goals. The patients we interviewed were aware that close, dynamic relationships existed between results of their lab tests and other procedures and the prescribing of medication, but had trouble keeping track of the specifics of these relationships.

Finally, medications given in the hospital often relate to medications that patients are taking at home—but the relationships might not be clear to patients. Similarly, patients are unsure whether medications they receive in the hospital are “short term” or “long term”—whether or not an inpatient medication or a similar medication will likely be added to the regimen they manage at home. As P9 stated, “I want to know how long term the problem that the medication is treating will be expected to last—if the medication is a long term thing. And how it relates to the eight to nine medications I was taking before surgery.”

Medication Changes as Signals of Progress

Patients inferred changes in dose, type, and names of medications administered as signals of how their health and care were progressing. Three patients volunteered that seeing a record of changes in their medication might help them to “feel better about how they’ve progressed”. P7 commented that, “what I’d like to see is that as you go along, the medicine decreases. Makes it
easier for me to do things. Get used to the side effects.” In this case, P7 was experiencing uncomfortable side effects of a medication that he would receive only in the hospital. Since the medication would be administered only in the hospital, this patient was less concerned with medication alternatives and the discomfort of side effects and more concerned with understanding the relationship between his therapy and his progress toward hospital discharge.

Patients also suggested several benefits to including images of medication (pills, liquid, IV bags) with names in a record of their inpatient medication: to help them to remember their medications, to help them understand changes in their medication regimen, and to assist in identifying medications when vision is compromised. While the use of images to help patients identify medications has been studied (Khan et al., 2010), the use of images in the inpatient setting has the added benefit of assisting patients in understanding frequent changes to their inpatient medications.

Decision-Making and Education Timeframe

While all patients we interviewed indicated that they received adequate medication explanations from the care staff, most also indicated a desire to read educational information about their inpatient medications while in the hospital. Nine of the 11 patients indicated that they wanted educational content corresponding to each of their inpatient medications to be available. One of the two who did not want such content for himself suggested that making it available in the hospital room would be useful to family members—mentioning that his wife had brought printouts of educational materials, found on the internet, to the hospital when she visited.

Two of the patients we spoke with mentioned the importance of access to educational summaries to assist in making medication decisions. One described wanting information about pain medications before requesting that his current medication be changed. When asked about
length of educational content, patients indicated a preference for brief descriptions of the medications they were taking. They did not feel capable of searching through webpage results or long articles, as they might normally when managing their health information outside of the hospital. One patient commented that a summary be only a paragraph in length, the other preferred two paragraphs.

*Agreement on Medication Information Types*

Patients agreed on detailed information types that they valued regarding their inpatient medications. Each of the 11 patients interviewed volunteered that the name, type of medication, and purpose (in terms of what problem the medication solved, or the specific benefit it provided) was important to them. Several of the patients interviewed also mentioned that frequency and dosing of information were important to them. In some cases, having access to this information at the bedside might help patients to tolerate discomfort. P11 stated that “*he and his wife* ask what it’s for, how often to expect it, and how it will be used, especially pain medication—I’m interested in when the next dose will be.”

*Formatting of Side Effect Information*

We were surprised to find disagreement among patients about the importance of side effects as an information type to include in a description of inpatient medications. Five of the 11 patients we interviewed did not find the inclusion of side effects to be an important information type when asked about it specifically. For example, when asked about whether having access to information about side effects of medication was important to him, P8 stated, “*The risks pertain more to what happens if you don’t take them. I care about how it will make me feel physically—if it’s going to hurt in any way, but not about a list of side effects.*”
Another patient, P5 commented on the importance of organizing side-effect information by severity of risk. He mentioned that, “I want to know side effects, beforehand. But I don’t want to see a long list of possible side effects. I’d like them to be separated by risk. I don’t care if I have a mild headache. But I want to see that something may be hard on my kidneys or liver.” Similarly, P11 mentioned that, “I want to know the types of medications I am getting, what names, and if they are ‘life changing’.”

Nurse Interview Responses

Nurses we interviewed commented on a number of patient information needs they experienced through questions they were asked of patients. Below we summarize key themes in their interview responses.

Useful Information Types

We found that nurses agreed with patients on information that they believe patients value. Nurses mentioned that medication name, type and purpose/benefit of the medication were information types that most, if not all, patients would find most valuable for inclusion in a list of inpatient medications.

Criticality of Medication

Nurses mentioned questions from patients that explored the necessity and criticality of medications, especially when the number of medications increases or the side effects of medications are difficult to tolerate. For example, N2 described that stool softeners could be reduced for patients who had success with bowel movements, and that patients often questioned the necessity of this medication. Currently, a patient’s exploration of which medications are
critical for their care occurs through questions between patients, nurses, physician assistants, and physicians, which can be a lengthy process.

Alternative Medications and Methods

Nurses commented that patients were often interested in understanding when an alternative medication could be used. Similarly, patients might ask if a liquid form of a medication is available rather than a powder form. Often, patients explore options for alternatives to specific medications and methods of administration through verbal consultation with nurses.

Care-Team Awareness of Drug Administration

Nurses reported that patients asked questions about care providers’ knowledge of their medication orders. In some cases, patients did not realize that their attending physician ordered a change in their medications. Patients also expressed the desire to share medication administration details with extended members of their care team. For example, patients may not realize that the cardiologist they see at home was consulted and briefed on their medication list.

Value of Supplementing Verbal Information

Nurses also suggested that verbal briefings by the care staff, delivered without any additional information sources, might make it difficult for patients to keep track of changes in inpatient medication.

DISCUSSION

Through our interviews, we uncovered several important design insights that can inform the creation of medication information applications intended for inpatient use. In particular, we found that patients and nurses agreed on the value of interactive, patient-facing, inpatient
medication information views, available at the bedside. They also agreed on much of the specific medication information that patients value, such as dosage, frequency, and timing of medication administration events. Both patients and nurses also mentioned information needs related to patients’ understanding of the criticality of each medication. Nurses discussed common requests by patients to explore possible alternative medications and forms of administration, and to maintain awareness of care provider knowledge of medication orders.

In structuring detailed medication administration information for an electronic view, patients indicated that educational information summaries should be provided to complement this information. Information corresponding to that which patients value most, such as indication(s) (use or uses of the drug) and high-risk side effects, should be given precedence, while other information should be made available through a minimal number of interactions.

In our interviews, many patients commented on a desire for technology to support their understanding of changes in medication therapy throughout their hospital stay. They valued the ability to note the medications that had been discontinued or completed as a way to maintain a sense of health status and care progress, and they desired the ability to see relationships between medication changes and progress toward hospital discharge, as well as relationships between medication changes and other clinical data, such as lab and procedure results. These findings point toward novel opportunities to support views of changes in inpatient medication over time, and relationships between medication orders and other data types. Further research is needed to understand how to present these relationships without introducing complexity that diminishes the value of such information.

While our findings lead to important initial insights, our study is limited by both the size of the respondent pool and a focus on the cardiology setting. Our future work will explore
additional hospital environments, study the impact of patient-facing technology on clinician workflow, validate design guidelines formulated based on our interviews, and explore considerations for the design of automated approaches to presenting medication information from the EHR to patients.

CONCLUSIONS

As part of a long-term, user-centered design process focusing on the creation of computing technology for hospital patients, we pursued a deeper understanding of hospital patient information needs related to medication information at the point of care. Through semi-structured interviews with 11 cardiac surgery patients and 6 nurses in a cardiology step-down unit, we gained insights into specific information needs related to medication information, and how a computing device can be used in conjunction with current methods to keep the patient informed throughout their hospital stay. In the next chapter, I discuss how we built on these findings to create inpatient medication information views in a custom patient portal.
The pilot study described in this chapter is documented in the following paper:


INTRODUCTION

In this chapter, I describe a collaborative design study focused on creating tools to support patient interactions with health information technology during postoperative cardiac care. We created a custom portal to interface with the hospital’s electronic health record, enabling two communicative interactions. First, patients can use the portal to review selected “live” portions of their medical record, such as home medications, hospital medications (current, pending, and discontinued) and nurse-documented pain scores. Second, patients can use documentation tools in the portal to log responses to their data and care, including direct reporting of pain and
symptom data, and comments and questions. The custom portal was developed as a study prototype, to serve as a technology probe (Hutchinson et al., 2003), used to gain insights into whether and how patients would use the portal to access and contribute information during their postoperative care. Below, I situate the contribution of this work, my third dissertation contribution: *design and pilot evaluations of a deployed prototype PHR portal application providing live, inpatient-centric clinical information to hospital patients.*

In the following sections, I outline a two-phase study: a small pilot study focused on short but focused usage and a larger study of unsupervised use. In our small pilot study, we gave Apple iPad devices running our portal to five patients in a step-down cardiology unit, engaging them in 30-minute focused usage sessions followed by detailed semi-structured interviews to gauge initial acceptance of the portal software and the tablet computer. After capturing patient responses to the software on the tablet computer, we further refined our design and added additional features to prepare for a larger trial in the second phase.

In the second phase we gave Apple iPad devices with access to the portal to twenty patients in the cardiac surgery step-down unit, and assessed their unsupervised use over a 24–48-hour period. At the conclusion of each usage session, in both phases, we conducted interviews to gauge patients’ perceptions of the usefulness of the portal and the tools it contained. To complement this interview data, we reviewed patients’ activities in the system’s usage log.

After describing the development of the custom PHR portal, I describe insights yielded by studies, including 1) an increased understanding of whether and how patients access information from the EHR during postoperative cardiac care, 2) an increased understanding of patients’ electronic logging and reporting preferences during their postoperative care, and 3) a
preliminary design for tools that patients can use to note aspects of their care and log questions and comments to augment their electronic medical record.

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<td>medication information views</td>
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Table 6.1. An overview of the patient portal design and evaluation phases that follow the development of our custom portal infrastructure.

BACKGROUND

In Chapter 2, I reviewed prior work discussing the role of the EHR in collaborative information work, the benefits of different display modalities in presenting clinical information to hospital patients, and studies of patients’ electronic information needs in the context of cardiac care. Of the related interventions explored in Chapter 2, Dykes et al.’s bedside communication center is the most related to the software I describe here. Their usability testing asked patients to
speculate on the tool’s usefulness: the majority of participants said they would find it valuable if available throughout their stay. Patients and families reported that they wanted more detailed information about the professional roles of their care team members, and wanted a more comprehensive view of care team members that included any provider or hospital worker with whom they had contact during their hospital stay (2013). Different from our implementation of the custom portal, they did not include the ability for patients to log data to communicate with nurses, physician, nor did they study the technology by allowing patients to keep the technology with them throughout care.

Few studies look at inpatient use of the information over the course of a day or more of care—and none examine patients’ interest in documentation or seek to reflect on the potential for patients to contribute electronic data during care.

SETTING AND PARTICIPANTS

These studies took place on the Cardiac Step-Down unit at CUMC. This is the same clinical unit on which patients and nurses were interviewed and observed in Chapter 5. Approval for this study was obtained from both Columbia University’s IRB and the Cardiac Step-Down nurse manager. The hospital transitioned to computerized provider order entry and electronic nurse charting in 2004, and the electronic health record was also used extensively for results review and provider documentation. At the time of the study (March 2011–October 2012), approximately 1 million electronic orders and 100,000 practitioner notes were being entered in the her each month.

Due to the time and resource constraints of the proposed dissertation research, only English-speaking and English-reading patients were included in the study. The ability to speak
and read English was assessed by the research coordinator after the patient was identified as being in good enough health to participate. If the patient spoke and read English and agreed to participate, the research assistant administered the mini mental status examination (a validated and reliable instrument that is used routinely in clinical and research settings) (Folstein et al., 1975) to assess for cognitive impairment; a score less than 20 out of 30 on the exam resulted in exclusion from the study. At the time of enrollment, each patient completed a demographic survey to gauge their socioeconomic status, living situation, marital status, ethnicity, education level, and health literacy. This survey instrument is included in Appendix C.1.

In both the first pilot study with patients and the second study, interview participants came from a wide variety of educational and cultural backgrounds. In the first phase, five cardiothoracic surgery patients (all male) participated; their mean age was 55.4 years (this selection represented the patient demographic on the unit during our study). In one case, the patient’s spouse jointly participated in the interview; in another, the patient’s son participated along with his father. None of the patients had used a personal health record before. All patients reported having Internet access at home. Only one had previously used an iPad.

In the second study, twenty cardiothoracic surgery patients participated (eight female) and the mean age was 58 years. For patients in both studies, the average hospital length of stay at the time the interviews were conducted was 5.4 days (the range was 3 to 8 days).

CUSTOM PATIENT PORTAL INFRASTRUCTURE

In 2009, NewYork-Presbyterian launched www.myNYP.org, a personal health record portal that, upon patient request, stores demographic and clinical data in Microsoft HealthVault. The portal was made available to all patients at the institution (initially excluding adolescents),
but additional consumer health content was developed that specifically targeted cardiovascular health. The additional information included text, images, and video presentations to help patients understand their conditions, tests, and procedures.

Using myNYP.org as a foundation, we developed a prototype application targeted toward patients in the hospital who were physically and mentally capable of using a tablet computer. A diagram of the system architecture is shown in Figure 6.1. For the pilot, user authentication was handled locally and not through HealthVault (i.e., pilot users of the system were not required to create a Microsoft HealthVault account). We developed a Data Access Module following a “message broker” model (Brydon and Singh, 2010) that queried (using SQL) the inpatient EHR for patient-specific information such as demographics, care providers, active and discontinued medication orders, and detailed medication administration records. The information queried from the EHR was updated to reflect close to real-time data, providing the tablet application with a fluid, dynamic interface. For example, when a physician modified a medication order or a nurse recorded the administration of a medication, the tablet application displayed the new information almost instantaneously. We implemented an audit module to log user actions for research and security purposes.

Among our chief concerns when implementing the portal was how to authenticate users to the tablet computer application. We provided patients with a temporary user ID and password that was generated specifically for the pilot study, connecting the tablet to the study server via a

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1 I created and managed the IRB for the project. I also led the design of the custom portal and contributed guidance on its development. Jun Yang worked with Dr. Vawdrey to develop the tablet computer application. Drs. Feiner and Vawdrey provided guidance on the approach to the pilot study. I worked together with Drs. Vawdrey, Restaino and Collins to conduct patient usage sessions for the pilot study. I worked together with Dr. Vawdrey to transcribe and analyze pilot study data. Dr. Vawdrey led efforts to report on results of the pilot study.
limited-access, virtual private network (VPN). A future version of the application is planned that relies on authentication services provided through Microsoft HealthVault to be consistent with the outpatient version of our institution’s personal health record portal. While this method would add an additional burden on patients by requiring them to register for a HealthVault account, it will provide a long-term benefit of helping patients to enroll in the outpatient PHR application before leaving the hospital.

For the first phase of our software, certain information from the EHR, such as laboratory test results, radiology studies, problem lists, and progress notes were not accessible to patients using the tablet application. We focused first on two information types: the patient’s care team and inpatient medication lists. We chose these two based on results from our attending physician survey study described in Chapter 4, in which physicians agreed that they are willing to share these information types directly on an electronic display. Figure 6.2 shows a sample screen from the tablet computer application.

**Care Team Information**

Photographs of care providers were displayed along with the person’s name and role on the care team. Providing this information to patients presupposes that it is accurately documented in an electronic format, preferably in the EHR. While we prepared our study prototype to facilitate manual assignment of care team members, we investigated the feasibility of automatic detection of patients’ care team members. We looked at care team access to records of patients admitted to the cardiology wards who had a length of stay from 3–5 days, between March 28, 2010 and April 25, 2010 (121 patients). While 2-3 clinicians were assigned to these patients in the EHR system on average, over 30 different practitioners on average, including nurses, therapists, technicians, dieticians, and other staff, accessed their chart in the EHR system
(Vawdrey et al., 2011a). Chart access can signal participation in care, but sharing each person’s access to the record with a patient could cause undue confusion.

Figure 6.1. Block diagram of the modules used in the tablet computer application. Components outlined in blue indicate those that we created for the inpatient portal application.
can touch the "Hospital Medications" link to launch a view of their inpatient medications. Data shown are for a fictitious patient.

From the welcome page (1. above) the patient can log in (2. above) to access added care team views (3. above). From here, the patient can touch the "Hospital Medications" link to launch a view of their inpatient medications. Data shown are for a fictitious patient.
Figure 6.3. View of screens visited on the tablet computer application from screens active during patient session. The patient can touch the "Hospital Medications" link (1. above) to launch a view of their inpatient medications (2. and 3. above). Data shown are for a fictitious patient.
Furthermore, while record access can reveal much, it might not include all of the staff members with whom a patient communicates. For our prototype portal, photographs were accessed from a temporary, manually-updated database developed for the pilot study; we have since investigated the use of the electronic version of the photographs that are printed on the hospital’s staff identification badges.

**Inpatient Medication Lists**

By touching the “Hospital Medications” link, the patient’s active and discontinued medications were displayed alphabetically by name, along with information on the dosage, frequency, and last administration time for each. Touching the medication name launched MedlinePlus Connect, allowing patients to view context-specific medication information targeted to consumers that is freely available and maintained by the National Library of Medicine (Miller et al., 2000). Touching the last administration time for a medication opened a window showing the entire administration history for the hospitalization.

**PHASE ONE: SMALL PILOT STUDY**

With institutional review board approval, we conducted detailed interviews with five patients in a step-down cardiology unit. We selected patients to invite to participate in the study after consulting the patient’s providers and the physician member of our research team, Dr. Susan Restaino, an attending cardiologist. Patients were included based on their physical and mental capability to participate and their ability to speak English. After providing informed consent, patients were supplied with an iPad device and encouraged to use the application. The interviews focused on patient satisfaction with, knowledge of, and engagement in their hospital care, and specifically on how the tablet computer application might impact each. As part of a
structured interview, each patient completed a 25-item survey to assess the acceptability and feasibility of the survey for inclusion in a larger study of the technology. The survey was derived from the validated Telemedicine Satisfaction and Usefulness Questionnaire, which includes two sub-scales, satisfaction/engagement and usefulness, which have internal consistency reliabilities of 0.96 and 0.92, respectively (Bakken et al., 2006). The questionnaire is included in Appendix C.1.

Findings

Patients appeared to adequately comprehend and appropriately respond to each survey item. Based on these observations, the survey instrument was deemed acceptable and feasible for use in a broader evaluation of the tablet computer application. Themes that emerged from the structured interviews were: 1) patient satisfaction and sense of engagement in the care process, 2) perceived usefulness of the tablet computer application, and 3) desirable functionality to enhance the application.

Satisfaction and Perceived Engagement

Patients were generally very satisfied with the care they received at the hospital. Nevertheless, all five participants felt that the tablet computer application would improve their satisfaction with their care and help them feel more engaged in the process. One patient stated: “If I’m monitoring what’s going on, my care team will treat me better, because they know that I know what’s going on. There will be more honesty and better service.” Another patient commented on the benefit the tablet computer would have as a memory aid, particularly when dealing with the acuity of illness and the stress of hospitalization. P4 mentioned, “I have down
time when I’m resting and if I get information during that ‘down’ time—I won’t remember it. So I’d like to be able to get all that info when I’m more ‘up’ and not miss it.”

Usefulness of the Tablet Computer Application

The patients interviewed believed that the tablet computer application was very useful. When asked specifically about the utility of having access to their hospital medication history, all five patients rated this as “Useful” or “Very Useful” (4 or 5, respectively, on a 5-point scale). The full results of our survey are included in Appendix C.1. Most patients, when asked about the perceived benefit of the portal, offered reasons relating to feeling less of a burden to remember everything related to their medication management. One patient also mentioned safety implications of the portal—commenting that he found the administration record helpful because “nurses make mistakes too.” Others reflected on the application’s ability to help them track changes in dose or frequency of a medication. P4 commented that, “I liked seeing confirmation that certain things I asked about regarding medications were in there. Like, I asked for a Tylenol, and I can see that they gave it to me. And I asked them to stop giving me something that made me feel strange—and I see that they discontinued it. I like seeing that they discontinued all those drugs. It makes me feel better.”

The link to MedlinePlus to provide consumer-friendly literature about specific medications did not always work properly. (A string-matching search was used rather than RXNorm CUIs or NDC codes because of technical limitations of our EHR.) Patients were enthusiastic about the information available from MedlinePlus, but two expressed frustration with the functionality of this feature. One summarized his experience as follows: “When I clicked on meds, I got search results. I had questions about an injection and I never found out what it was. I still plan on asking the nurse, but I’d like a short definition without searching. When I’m
not feeling well I’m not going to go through search results or another web page even.” In the next chapter, I explain how we addressed this need for short definitions to supplement unfamiliar clinical terms in patient-facing views of their information.

We found that the information on care team members (name, role and photograph) was perceived to be extremely useful to patients. Most patients reported being well acquainted with certain members of their care teams (for example, a specific nurse-practitioner or surgeon), but others were not. In some cases, patients recognized care team members by their photograph, but did not know their names. Patients noted that having access to the names and photos on the tablet was preferred to listing certain team members (e.g., the nurse, physician assistant, and attending physician) on the whiteboard. One patient noted that the photographs helped him to feel more comfortable and confident that the team knew who he was: the team view made the connection between him and each of them explicit. As a result, the feature helped him to “not feel lost” in the busy hospital environment. P4 expressed optimism that having the care provider information would help him interact more with his care team “because I’d know who they are.”

Suggested Enhancements for the Tablet Computer Application

Interview participants provided a variety of suggestions for improving the tablet computer application. Several inquired whether it would be possible to use the tablet to send messages to their care providers. One patient was particularly sensitive to the time constraints of his attending physician, but felt that one of the PAs with whom he felt comfortable might be able to answer questions he sent to her using the tablet computer. As an example of the types of questions he might ask, he said, “I would email her to ask if this [a specific symptom] is something I should worry about.”
Four of the five patients mentioned a desire to access additional information about their care providers, such as their education and training credentials. One patient stated a preference echoed by other patients, commenting “I’d like to see background info: where they went to school, who has actually got an MD” Another patient suggested using the tablet computer as a means for patients to provide feedback on the quality of their care and their satisfaction with specific care providers. Other enhancements recommended by patients included a mechanism to help them coordinate follow-up appointments once they were discharged and the ability to enter their home medications and compare them with their inpatient medications.

PHASE TWO: REDESIGN AND ADDED FUNCTIONALITY

Following our small pilot study, I led the redesign of the portal user interface and worked with Dr. Vawdrey to add functionality based on patient feedback. The home screen of the redesigned portal is shown in Figure 6.4). Two goals guided our redesign of visual characteristics. First, we focused on easing navigation to inpatient features of the portal by making links to these features more prominent: placing them in a more central location, reducing branding and marketing content, and adding large icons and stylized fonts. Second, we increased font and image sizes of certain content to ease reading. We also added content and features to the portal.

Based on patient requests from our pilot study, we added biographical data to the repository of clinician identifiers and images (shown in Figures 6.5). We also added content to the views of hospital medications. In addition to increasing font sizes these lists, we added information on frequency of administration (e.g., “every four hours”) as found in the patient record by translating clinical codes to plain language (the translation table is shown in Appendix)
C.2). Later in this chapter, I discuss further refinements to these inpatient medication views that incorporate techniques to show an expected medication schedules, forms of administration, and short explanations of drugs, and allow sorting of medication lists by name, class, frequency, and other criteria.

**Designing for Patient Reporting and Responses to Data**

*Verification of Patient-Reported Data*

We also added views of home medications and allergies, as they are listed in the patient’s record, to allow verification of these data (shown in Figures 6.6 and 6.7). For allergy information, the allergy type, name and symptoms are listed. For medications taken at home, a description of the medication (e.g., “Lasix 20 mg”) is shown with instructions for use (e.g., “twice daily”) and any additional comments logged. Patients were directed to notify the care team if they had concerns about the accuracy of either the home medications or allergies listed. We did not support direct electronic “flagging” of medications or allergies at this stage, as hospital procedure mandates that a care team member resolve any discrepancies noted in a patient’s medical history to correct information in the record.

*Patient Documentation Tools*

Finally, in this phase of the redesign, we enabled two documentation tools. First, patients can use the portal to review and comment on patient- and nurse-documented pain scores, through a pain-reporting feature (Figures 6.9 and 6.10). Second, patients can use documentation tools in the portal to note comments and questions for their care team in a notebook feature (Figure 6.11). We were particularly interested in conducting a follow-up field study of the portal, incorporating early versions of these logging features, in order to 1) better understand how to design them to
accommodate patient preferences and 2) explore the benefits and challenges of sharing patient-logged comments and questions to the hospital EHR via posts (to be associated with the patient record) or another clinical communication artifact. In the next section, we elaborate on this investigation, reporting on the electronic documentation sharing preferences of patients who participated in a larger field study of the portal.

PHASE THREE: PATIENT USAGE STUDY

With our updated portal software, we ran a larger inpatient study to learn whether and how study participants used the portal, when not directly prompted to do so, during a longer period of their post-cardiac care. Our goal was to investigate which features patients did or did not access, and their usage associated with those features (e.g., determine the frequency with which people accessed certain features) and their perspectives on the role of the feature during their care. By incorporating preliminary documentation tools, we also studied whether patients used or did not use these tools, and their perceptions of the tools after their usage. As I discuss below, these perceptions yielded insights and considerations to guide the design of tools to capture and support communication of patients’ electronic input during care.

As in the previous pilot phase, we selected patients to invite to participate in this study phase after consulting the patient’s providers and Dr. Restaino, and applied the same inclusion criteria to determine eligibility. After providing informed consent, a study coordinator gave the participating patient an iPad, introduced the portal and its features, and provided training on the touch interactions and portal navigation. After training, we observed the patient for five minutes, encouraging them to “try out” the application, and helping to overcome any difficulties.

1 Dr. Alexander Sackeim, Jennifer Prey, and Janet Woolen conducted interviews, produced transcriptions of audio recordings of interviews, and contributed thematic coding. Drs. Vawdrey, Restaino and Feiner provided guidance on the field study methods.
Figure 6.4: Screenshot of portal’s redesigned home screen. Data shown are for a fictitious patient.
Figure 6.5. View of screens visited on the tablet computer application from screens active during patient session. From the welcome page (1. above) touching a care team member’s image brings up detailed background information (2. above). Data shown are for a fictitious patient.
From the welcome screen (1. above), the patient can touch the Allergies link in the sidebar to verify that reported allergies have been logged in the EHR (2. above). Data shown are for a fictitious patient.
Figure 6. From the welcome screen (1. above) the patient can touch the Home Medications link in the sidebar to verify that medications they take at home have been correctly reported and logged in the EHR (2. above). Data shown are for a fictitious patient.
From the welcome screen (1. above) the patient can touch the Hospital Medications link in the sidebar to monitor their active, pending, and completed or discontinued medication orders, as they appear in the EHR (2. above). Data shown are for a fictitious patient.
From the welcome screen (1. above) the patient can touch the Pain Information link in the sidebar to monitor their electronic pain reporting, and log current pain level (2. above). Data shown are for a fictitious patient.
From the Pain History screen (1. above) the patient can touch the Pain Information link in the sidebar to monitor their electronic pain reporting, and log current pain level (2. above). Data shown are for a fictitious patient.
Figure 6.1. From the welcome page (1. above) the patient can touch the Record Questions/Comments link in the sidebar to note questions and comments for their care team (2. above). Study participants were asked during interviews if they believed that the questions and/or comments should post to a view of their data in the EHR. Data shown represent examples of participant input.
Twenty participants (eight female) ages 26–79 (Mean=58) participated. After introducing the application, we gave these patients access to the portal for 24–48 hours of “unsupervised time”, defined as time during which patients were not directly prompted to use the technology by a study coordinator (the coordinator returned only to answer questions or to conduct the debriefing interview). However, when concluding the patients’ unsupervised usage session, the study coordinator conducted a detailed interview in which he or she walked through each of the features of the portal, asking the patient to comment on the perceived usefulness of the feature, to explain whether they used it, and to explain why they did or did not use it. The survey guide that we used is included in Appendix C.3.

To analyze data from our study, we compared user responses to data from audit logs that captured user interactions with the software (Farmer et al., 2006). Our auditing software logged patient selections of portal features (e.g., it did not capture individual gestures like zooming in or zooming out or individual keystrokes generated through typing in patient input fields). It detected state changes in the application, such as touch “Home Medications”, touch “Hospital Medications”, but did not detect browser-initiated state changes or selections of features of the standard myNYP.org resources that were inherited in our custom version. One limitation of our auditing methods is that the care team view is on the home screen of the application—thus we could not capture events in which the patient simply viewed members of their care team. Another limitation is that we were unable to differentiate between patient and visitor usage of the portal—we depended largely on our interviews to clarify whether a visitor had used the portal—and could not reconcile which selections corresponded to which user as usage analysis occurred after the inpatient sessions. However, we inquired in our interviews about visitor usage.
To analyze the audit logs, we matched the event timestamps on the logs with the interview initiation and conclusion (removing “episodes” of use at the beginning and end of the usage data). These episodes were defined based on average amount of time the introductions and concluding interviews took.

Patient survey data were analyzed by applying approaches from constructivist grounded theory (Charmaz, 2006). Five members of the research team\(^1\) participated in iterative, multi-stage coding, to analyze response data to inductively arrive at themes and sub-themes, until data saturation was reached.

**Results**

Of the twenty participants in our study, sixteen used the portal in an unsupervised manner—without presence of the researcher directly prompting use. This “active” use, although it represents only 80% of our participant pool, is an encouraging number: patients are in pain, in and out of procedures, and coordinating visits during their stay. Below I discuss our analysis of portal usage and themes emerging from our thematic analysis of interview data.

**Portal Usage**

Of the sixteen participants who were found to have used the portal during the unsupervised usage period, the average number of selections was 16.4. One particularly active user, a 45-year old female, logged 53 selections during her two-day period. A close runner-up to this user was a 69-year old female, who logged 42 selections.

As for the features of the application that participants selected, Table 6.2 shows an aggregated summary of participants’ total selections of each. The hospital medications feature

\(^1\) I provided guidance on data analysis efforts and worked with Dr. Alexander Sackeim, Dr. Vawdrey, Jennifer Prey, and Janet Woolen to contribute thematic coding and thematic analysis.
was selected the most frequently, followed by the pain documentation feature. Ten patients (of the sixteen active users) accessed features related to hospital medications more than any other feature during their usage session. Two of the sixteen accessed hospital medications as frequently as the pain-logging feature. Another two accessed the pain-logging feature more than any other feature. One patient of the 16 accessed the notepad feature the most. Finally, one patient, P5, accessed the home medications feature more than any other feature.

To understand more about patient selections with content related to Hospital Medications, we provide a breakdown of the collective selections in Table 6.3. In our discussion section, we comment on these data.

![Selections by Feature](image)

Table 6.2. Aggregated summary of content selected by study participants during unsupervised usage sessions.
Table 6.3. Detailed aggregated summary of content selected by study participants during unsupervised usage sessions.

Interview Data

During our interviews, two spouses participated in addition to the twenty patient participants. We note their comments by indicating the patients’ identification number and “Spouse” in presenting their responses. These spouses also answered questions about input, usefulness and information needs, and sharing preferences. When possible, we differentiate these responses.

Through our iterative, multi-stage coding of survey responses, we identified eight emerging themes in patient responses. Below, we list and elaborate on each. Table 6.4 offers illustrative examples of selected quotes associated with major themes. Since we were particularly interested in the design of the patient documentation tools—investigating patient preferences for allowing their documented pain data, questions and comments to post to their physicians’ views of their data in the EHR—we outline subthemes emerging in the interview responses related
specifically to these communication of patient-documented data. The comprehensive list of themes and corresponding subthemes that we coded is given in Appendix C.4.

We also reviewed answers to interview questions related to usefulness—particularly related to whether they found the documentation features useful. In addition we reviewed patients’ described preferences for sharing these data. We found that 12 of 16 active users indicated that they found the documentation features useful. Two did not comment, and two indicated that they would not find it useful. Of the 12 who found it useful, all twelve mentioned that sharing data in a “two-way communication” style was preferred. For example, participants desired to be able to post questions and comments to the EHR, to be associated with their record, and receive an electronic reply.

- **Access to Application** – Stated preferences and questions related to availability of the application, including how to access the application after discharge.

- **Communication of documented data** – Stated preferences of patients’ electronic documentation and sharing of logged pain information, comments and questions data, as well as accounts of how they used these tools.

- **Engagement** – Statement of current involvement and interest in managing personal health (to understand baseline) as well as comments suggesting the perceived role of the portal in influencing either interest or ongoing health management.

- **Information Needs** – Participants’ satisfaction with the information and their requests for additional information types.

- **Suggestions** – Participants suggestions for additional functionality and recommended usage contexts.
- **Usability and Ease of Use** – Reports of navigation difficulties, burden of input methods and other interactions, presentation of application status, and application responsiveness.

- **Use** – Accounts of how patients or their visitors used the application.

- **Usefulness** – Participants’ opinions about usefulness, including which features they found more or less useful to them and the ways in which they found the features useful.

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<th>Patient</th>
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<tr>
<td>P2</td>
<td>Access</td>
<td>I’d like to still be able to log-in and contact team, like ask the PT (physical therapist) about what level activity I should be doing.</td>
</tr>
<tr>
<td>P5</td>
<td>Communication of Patient-Documented Information</td>
<td>The patients… are probably more aware of the pain sometimes... the nurses go through routine you know what I mean where (we are) people in pain.</td>
</tr>
<tr>
<td>P8</td>
<td>Information Needs/ Suggestions (Features)</td>
<td>R1: Is anything missing that you would like to see? P8: I guess I would like to see progress notes. Maybe having the labs, the test results would be the next thing. Because that way, you know he's had x-rays, he's had blood drawn all the time. I guess the tests would be good.</td>
</tr>
<tr>
<td>P11</td>
<td>Information Needs (Medications)</td>
<td>I didn’t know half of the drugs because they are generic. I was taking non-generic at home.</td>
</tr>
<tr>
<td>P6</td>
<td>Use</td>
<td>I could only really go back to this this morning when I was feeling a little better and finally yesterday I thought I might be leaving today so I was in a different frame of mind, but if you gave this to me two or three days ago I wouldn’t have gone near it.</td>
</tr>
<tr>
<td>P5</td>
<td>Usability</td>
<td>Yeah, I kept pressing back and tapping the top. I mean like I know about computers but for some reason I couldn't figure out how to get back. But how would someone know, once they were on this page, how to get back to the main NYP page?</td>
</tr>
<tr>
<td>P6</td>
<td>Usefulness</td>
<td>(Referring to hospital medication feature) I was surprised I didn’t know it was so much. I love the notepad. And the pain scores— that’s cool.</td>
</tr>
<tr>
<td>P2</td>
<td>Suggestions (Features)</td>
<td>Those people who (help)—it should have a place to make comments about your stay. And you could (thank) those people who made your stay, who worked really hard to make your stay wonderful. Maybe a way to make a note of the people on it, so that they could be recognized, and then if anyone would have any complaints they could put it there too. Name, you could put names of people who made your stay worthwhile.</td>
</tr>
</tbody>
</table>
Table 6.4. Selected quotes associated with major themes.

<table>
<thead>
<tr>
<th>Patient</th>
<th>Category</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>P8 Spouse</td>
<td>Engagement</td>
<td>I like (this) because, you know, like I discovered yesterday a medication he's getting and he's getting it at home and they're actually giving him half the dose he's getting at home.</td>
</tr>
</tbody>
</table>

Table 6.5. Subthemes related to the major theme "Communication of patient-documented information" with selected quotes.

**Discussion**

Though our studies were limited in that they distributed the tablet computer application to twenty-five total patients in a single surgical cardiology unit, the feedback obtained through the patient interviews was encouraging. While patients who participated in the interviews were satisfied with their care, it was clear that many unmet information needs exist, and there is room for improvement in educating patients about their hospital care and engaging them in the process through the features introduced in our application. These applications, while responding to unmet information needs of hospital patients, may also be beneficial for improving patient satisfaction, a metric that could be measured using standardized satisfaction scores provided by organizations such as Press Ganey.
Patient perceptions of usefulness of documentation features

Most participants (12 of 16 active users) indicated that they found the documentation features useful. However, patients differed in their opinions of which they found useful. P5 commented that, “the pain score... I don’t find any benefit to me personally but that’s just me. But the notepad was good.” P17 described that the ability to separate notes or comments from questions to ask the care team was useful, indicating the she “liked being able to ask questions—since doctors are busy, it is nice (referring to question input window) to ask very specific questions.”

The patients who found the documentation features to be useful preferred that their logged data be shared directly in an electronic format, through the EHR. There were varied opinions about whether comments and questions should also post to clinicians’ mobile devices or generate alerts. Future work to investigate models of notification and communicative awareness are needed to design tools for patient input and sharing of information in the clinical setting.

Usability

Some of our participants had not used an iPad before; as a result, they exhibited some reluctance with using the device and some initial confusion in navigating through the application. In terms of the overall usability of the device and application, P4 (pilot study) stated: “After a minute of my son explaining it to me, I was able to use it easily.”

Several participants suggested that it would be difficult to use the device immediately after returning from surgery due to concerns about poor coordination and vision, but would appreciate having it later on in their stay. Making a range of presentation formats available, from the large format described in Chapter 4, to a personal, mobile format, could accommodate these needs.
Care team identification

Consistent with our previous ED study, patients mentioned the care team information and photographs as one of the most useful features of the tablet computer application. As I discuss in an earlier section, formulating a systematic definition of a patient care team is an open and important research question. Participants in our study, when asked if they wanted more information about other people involved in their care (in addition to the primary nurses, PAs, and physicians on their team) had different preferences. As P7 explained, “the only part that should be accessible is who is dealing with you...not everybody involved. Who were the PAs that were talking to you, giving you information. Nurses” while P2 noted that he preferred that physical therapists that were assigned to him be included. In Chapter 9, I discuss important avenues for future work to address this complexity.

Clinician attitudes about patient access to data

One of the remaining uncertainties associated with deploying the tablet computer application to hospital patients is the attitude clinicians could have regarding the technology and impact it may have on their work. The clinicians with whom the investigators had personal contact during the patient interviews—clinicians whose patients were involved—enthusiastically received the pilot project. Many volunteered to have their photographs taken by members of the study team and took time from their shifts to learn about the project and educate their patients. Once the technology has been deployed at a larger scale, we plan to investigate its impact on clinician workflow and patient-clinician communication. An anonymous survey, similar to the one described in Chapter 4, could further help us to assess physician attitudes about ongoing use of the system.
Opportunities to support multiple information needs

We found that patients volunteered several information needs that were not accommodated by the portal, and also mentioned types of content that could augment data on information that was available. For example, P5 when commenting on the medication view remarked that he would like to see, “What it causes and the side effects” while P8 mentioned that, “I want to see progress notes and lab tests.”

Patient Usage

We found that while the frequency with which participants accessed information varied, most found it useful to access the information, even if just once, during their usage session. P5 described how he used the portal, noting that his usage was brief, but that he accessed data as well as sought out educational materials. As he explained, “So last night I went on before I went to bed, researching WebMD for Coumadin and one or two [of my] meds. I'm more interested in the blood thinners than anything cause that's what I'm waiting for to get out of here. I researched what I could eat and what has vitamin K.”

We were also surprised to find that features containing what we expected to be “static” data (allergies and home medications) were accessed frequently—particularly home medications. Throughout patient interviews, we learned that patients shared this data with their spouses, and accessed it in resolving questions, as we found to be the case with P8 (shown above in Table 6.4).

Finally, several patient participants commented that the particular point during care, at which they receive the portal, would and did impact their usage. They also mentioned that they desired that the application be available in a persistent way during their care. As P4 states, “I really couldn’t access that much in the time I had it. I had to go for chest x-ray, then felt
nauseous. The time factor is important. I could only use it this morning when I was feeling better.” while P5 mentioned that even if he only used the portal to verify data once, “it is a good idea to have it available if you want it, in the room for a couple of days.” Family members who participated, however, requested that the portal be available to them as soon as possible. As P15’s husband commented that, “This is great! I needed this in the ICU. I wanted to check out all my medications they were giving my wife, and what they were for.” This suggests that an important and impactful direction for future work involves the creation of technology to support family involvement in patient care, through technologies that offer views into the patients’ status and care progress.

Some of the usage patterns revealed in the audit logs were unexpected. We were surprised to see in the usage logs that only a few patients access information on their hospital medication administration history. Given the interest by patients in seeing this data, expressed in our earlier interviews, we expected this number to be higher. However, reviewing usability-related comments revealed that the specific interaction we designed for accessing this data (touching the last administration time to see the administration history) was not apparent to users. We address this in our next section, where I discuss a refined design of the inpatient medication information views.

PHASE FOUR: REFINEMENTS TO MEDICATION INFORMATION VIEWS

During our inpatient studies of the custom PHR portal, participants mentioned additional content and functionality that could augment a view of their inpatient medication lists, along with aspects of usability that impacted their experience of this information. Guided by these findings as well
as findings outlined in Chapter 5, I have worked with two clinical pharmacists who have served as expert reviewers of user interfaces to inpatient medication information.

Iterative Design with Expert Review

Through an iterative design process, we explored chronological views as well as list-based views of medication data. Our ultimate refinements to these views are shown in Figures 6.12 and 6.13. Below I discuss how we arrived at our design decisions.

Information focus

Medications are grouped into “active”, “ordered today”, and “completed or discontinued” based on order data, as before, with collapsible views to allow focus on a single group. An analysis of the volume of medications ordered per patient, based on twelve typical cardiothoracic surgery patients in a retrospective review of EHR data, revealed that the average number of unique medications (when considering administration forms such as liquid versus pill) ordered for these patients numbered 63.5. This includes “as needed” medications and represents multiple stages of care. Still, for patients taking only a few medications at home (if any), this number can be alarming. In the refined view, only one group of the medication list is visible by default. This functionality might help to reduce feelings of overwhelm by patients viewing this data.

Recognition through class identification, administration forms, and explanations

The medication class is given as patients explained in interviews that while names were unfamiliar, classes might be more recognizable and could also help to clarify the reason a medication was prescribed. In addition, methods of administration are given to clarify which medications are IV drugs, and whether a familiar drug might be given, but in a different form than expected.
In addition, several patients in our studies requested short explanations of the indications (or uses) of the drug, which we determined to be the clinical data type closest to “why the drug prescribed”. At this stage, these explanations were manually extracted from pharmacist-reviewed sources for accuracy. In the next chapter, I discuss research toward the automated extraction of short explanations such as the ones included here.

*Sense of progress and expected course of administration*

In addition to dose information, an expected schedule, shown in the “frequency” view, provides an integrated schedule for each entry. While chronological “timeline” views were explored and implemented for evaluation, the volume of medication orders cluttered these views, making them difficult to read. Techniques to group drugs in the time necessitated that pre-determined grouping metrics be applied, which could limit patient exploration of the data. Through the expert review process, we determined that adding individual abstractions of a daily schedule, to signal approximate times for medication administration events yielded clearer views. Using a table provided the benefit of allowing the information to be sorted according to different fields, which allows grouping of information according to each. In using an abstract representation of a daily schedule, expectations that a drug be given at a specific time can be mitigated. Medications are often ordered to be given at certain times, however; strict adherence to a schedule is often not necessary as long as administration events occur within a short time range. The frequency field is generated based on parsing of the instructions of the medication order (e.g., “9am daily”, “twice daily”) and analysis of administration history (i.e., if given twice daily and historically given at 10am and 8am, dots are drawn at places corresponding roughly to these times on the line).
To create the refined medication information views, I created software\(^1\) based on JavaScript libraries for the interactive user interface, and PHP to handle data access and processing (Figure 6.14). The software is able to present data extracted in the format provided by the EHR system. Future work is needed to incorporate this software into the existing portal infrastructure. The refined user interface shown was used in a subsequent study, described in Chapter 8.

![Refined medication view](image)

Figure 6.12. Refined inpatient medication view for a cardiothoracic surgery patient. Three collapsible panels include inpatient medications that are active (either “as needed” or given on a schedule), new medications ordered, and completed or discontinued medications. Above, a partial view of completed and discontinued medications are shown.

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\(^1\) I designed and developed this software, in parallel to the development efforts of Dr. Vawdrey and Jun Yang.
Figure 6.13. Partial view of the active inpatient medication list for a cardiothoracic surgery patient.

Figure 6.14. Block diagram highlighting modules used in the redesigned medication information views and user interface of tablet computer application.
CONCLUSIONS

To our knowledge, our study was the first to provide hospital patients with a tablet computer application intended to improve their engagement in the care process through tools to both review and document symptoms and input comments and questions. From the detailed interviews conducted with 5 patients in our small pilot, and 20 patients using the portal for 24–48 hours during their post-cardiac surgical care, we learned that the application was perceived to be a useful tool for providing information and increasing patients’ engagement in their care. While patients exhibited varying levels of comfort with using the tablet computer, all were enthusiastic about the concept. Through an analysis of patient usage of the portal, informed by usage log data and semi-structured interview data, we learned that applications of the kind we introduced here can address inpatient information needs, enable patient engagement in their care, and provide an added level of verification to enhance patient safety.

Many patients in our study also made use of tools to electronically record and comment on pain information, and to take notes and log questions to ask their care team. Through interview questions focused on preferences for sharing these data, we learned that most patients desire two-way electronic documentation and sharing of questions and responses through messaging features. In Chapter 9, we propose an agenda for future research to address these goals.
This study is documented in the following paper:


INTRODUCTION

In this chapter, I describe research that introduces *micro-explanations*, short explanations suitable for real-time delivery in clinical settings\(^1\). These explanations can transform patient care by giving patients greater awareness of key events in their electronic medical record. I present results of a survey study indicating that it may be possible to automatically generate such explanations by extracting individual sentences from consumer-facing Web pages. The research

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\(^1\) I conceptualized the study and worked with Drs. Morris, Tan and Horvitz to create the survey instrument. I worked with Dr. Gatewood to arrive at realistic clinical scenarios given in the survey instrument. Dr. Morris managed administration of the survey and data transcription. I worked with Dr. Morris to code and analyze survey results. I worked with Drs. Morris, Tan, and Horvitz to interpret study results.
described here further informs future work by characterizing physician and non-physician responses to a variety of Web-extracted explanations of medical lab tests.

While physicians routinely explain symptoms, diagnoses, conditions, and treatments to patients verbally, such in-person explanations are not available to meet all patient information needs, nor are they as readily accessible as other materials. Educational materials about tests, procedures, and medications can provide useful information for patients. However, such materials can be overwhelming amidst the distress common in hospital environments. Furthermore, a great deal of medical information is inaccessible to those lacking health literacy; information packets are rarely tailored to a specific patient, and traditional delivery media such as paper make dynamic delivery difficult.

Online health resources (e.g. WebMD.com) provide comprehensible, patient-friendly health literature, but target patients who are cognitively and logistically able to formulate a search query, then comprehend detailed results. Results typically contain much more information than is necessary to provide basic understanding, and often include facts that are irrelevant or even needlessly worrying to a specific patient. Consequently, much online content is often ill-suited for delivering information in the small chunks demanded by patients who are in a cognitive state to receive only limited information or who are using space-constrained media such as in-room displays and mobile devices.

In the collaborative work described in this chapter, we propose that leveraging multiple information sources – specifically existing online health resources and the EMR – can provide concise, patient-friendly, and personalized explanations of medical events. Such medical micro-explanations would be suitable for real-time presentation to patients on mobile devices or in-room displays, or for offline presentation through a personal health record.
As a first step toward fully automatic generation of explanations, we investigated the hypothesis that current consumer-facing Web resources, although not designed for this purpose, contain sentences that are suitable for presentation as standalone explanations. Furthermore, situation-specific extraction of appropriate sentences from these resources, based on information already available in the EMR, can circumvent the need to create explanations “from scratch”.

First, I present preliminary validation of our hypothesis that the Web is a source of concise, patient-friendly explanations of lab tests, suitable for automated extraction. I first report on a survey study that characterizes the properties of “good” Web-derived explanations, according to both physicians and non-physicians. Our survey was targeted at defining features for automated Web content extraction. I follow this with discussion of the similarities and differences between how doctors and patients view these explanations. The study results form the basis for my fourth dissertation contribution: *characterization of quality of short explanations of medical events and demonstrated feasibility of extraction.*

In the next chapter, I discuss an approach to extracting, from the Web, short explanatory sentences for a particular class of consumer-oriented medical information, and I discuss how I applied the approach to build a set of tools to help consumers locate information online using short, explanatory sentences.

**BACKGROUND**

Parallel work has explored natural-language generation and extraction techniques for summarizing medical content. Delegér used parallel medical and lay-person corpora to map specific phrases between “patient-speak” and “doctor-speak” (Deléger and Zweigenbaum, 2009); a similar approach is taken by Portet et al., who attempt to create textual summaries of
continuous signals (e.g. EKG traces) in hospital settings (Portet et al., 2009). Di Marco addresses the problem of semi-automatic personalized educational materials, using physician input to tailor generic materials to specific patients (Di Marco et al., 2006). This and other work in medical summarization complements our proposed approach, but no work to date has explored the unique properties of short, real-time explanation delivery, or the opportunity to base such explanations on existing consumer-friendly sources.

PARTICIPANTS AND METHODS

To pursue insights about the value of consumer-facing Web pages serving as a source of explanations for medical events, we conducted a survey to evaluate physicians’ and non-physicians’ opinions of Web-extracted sentences, presented as explanations for diagnostic lab tests. We scope the present work to lab tests, given findings that show patient interest and appreciation about diagnostic test results in a personal health record (CHCF, 2010). The survey took about an hour and participants were given a software gratuity.

Physician Participants

Seven physicians (six male) participated. All were actively practicing in U.S. hospitals and indicated that explaining tests to patients was a part of their responsibilities. Participants’ specialties were emergency medicine, oncology, cardiology, pediatrics, surgery, and internal medicine (2).

Non-Physician Participants

Twenty-three non-physician participants (9 male) from the U.S. (14 states) were recruited based on having had recent hospital experiences as patients or family members of patients. Sixteen participants had hospital experiences in the past two years; all had hospital experiences in the
past ten years. Participants’ ages ranged from 21 to 63 (mean=41), and education ranged from high school to postgraduate.

**Survey Design**

We prepared four “patient profiles” based on common ED presentations, chosen via review of patient records in a large, urban hospital. Each profile (approximately one paragraph) included the sample patient’s current symptoms, current medications, and a summary of their medical history and was reviewed by two non-participating experts for content validity. For each profile, experts provided a list of four lab tests that would likely be ordered. For each of these lab tests (16 total), we collected nine alternative one-sentence explanations (144 total). Appendix D shows instructions for both lay and expert versions of our survey and illustrative samples of survey questions.

To select the sample explanations for our survey, we performed a Web query for each lab test and chose the first three HON-certified1 Web pages appearing in the results. From these pages, we hand-selected sentences that would fit the micro-explanation format. A large set (hundreds) of candidate sentences existed, so we selected sentences that spanned the space of possible explanations to ensure a representative sample of explanatory content (i.e., removing redundancy across sites while diversifying information).

Each participant responded to two of the four patient profiles. Each participant was thus presented with 72 explanations total (9 explanations for each lab test, 4 lab tests per profile, 2 profiles). Participants rated each explanation according to how appropriate they found the explanation to be for the patient described (physicians) or how helpful they would find the explanation if delivered to them in a hospital (non-physicians).

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1 The “Health on the Net” (HON) Foundation certifies the credibility of health-related sites through physician review.
Participants used a rating scale of 1–5, and were instructed to use scores above 3 to indicate that the benefit of the explanation outweighs any concerns about its flaws. For each rating given, participants elaborated on the rationale for their choice using free text. Additionally, after all lab explanations had been examined for both sample patients in the study, both participant groups were asked to reflect on their preferences and describe characteristics of meaningful explanations, again in free text.

RESULTS AND DISCUSSION

Not surprisingly, the most consistent theme in all responses was a desire for “simplicity”. In fact, 23 of 30 participants mentioned this explicitly in their end-of-survey reflections, including 6 of 7 physicians. Despite this common high-level goal, however, a deeper analysis of our results reveals that participants have widely-varying concepts of what makes a “simple”, patient-friendly explanation. Here, we explore this complexity, along with several additional themes that emerged in survey responses. Coded results and summaries of top and bottom rated explanations, by physicians, non-physicians, and both groups, are also included in Appendix D.4.

Web-Extracted Sentences as Explanations

One core research question in this work asks whether consumer-facing Web pages can serve as the basis for extracting single sentences, suitable for delivery as micro-explanations. This is not obvious, however; Web sites are composed as a whole, and single sentences may lose meaning out of context.

Our results suggest that at least one “good” explanation was found, although our sampling was limited to nine candidate sentences per lab test (an automated system would examine many more). For both physicians and non-physicians, every lab test had at least one
explanation for which both physicians and patients mean score was higher than 3.0; participants were instructed that “A rating of 3 or higher means that you consider the explanation of enough benefit to display”. This suggests that extracting individual sentences from Web pages, despite the loss of context, is promising for micro-explanation generation.

Features of “Good” Explanations

Another goal of our study was to understand the relationship between participant preferences and characteristics of explanation text. To investigate correlations between measurable features and survey responses, we manually coded several features of the survey explanations, including:

1. Mention of symptoms
2. Mention of organs, systems, or body parts
3. Mention of problems or diagnoses
4. Sentence length in words
5. Use of acronyms and medical terms
6. Number of medical terms or acronyms defined

Through our coding, we found that mention of a specific symptom and the mention of an organ or system in an explanation correlated with participant preference: the top five most-preferred explanations across all labs (i.e., the explanations with the highest mean scores) all contained both a symptom and an organ/system reference, and none of the five least-preferred explanations contained either of these features. The most-preferred explanation overall is illustrative of these properties:

*The troponin test is used to help diagnose a heart attack, to detect and evaluate mild to severe heart injury, and to separate it from chest pain that may be due to other causes.*
Interestingly, despite participants’ overall desire for simplicity, longer explanations were preferred overall by both physicians and non-physicians. The five most-preferred explanations overall had a mean length of 30.0 words (±8.0), while the five least-preferred explanations had a mean length of 15.8 words (±9.2).

This preference for somewhat long sentences was explained differently by physicians, whose rationale for high ratings for more complex sentences were based on accuracy, and patients, who frequently explained high ratings for more complex sentences based on “sounding like a professional answer” and “sounding like something a doctor would say”.

The preliminary correlations observed between encoded features and participant preference suggests that a feature-driven approach to scoring and ranking explanations could underlie a micro-explanation system.

**Sources of Divergence Between Patients and Physicians**

We also aimed to understand differences between physician and non-physician responses to Web-extracted explanations. To explore this, we calculated the differences in mean ratings between physician and non-physician participants, for each explanation (72 had ratings by both groups). We ranked (in descending order) each explanation by the difference in mean ratings, and considered the top 20% (15 explanations). For these 15 with the highest difference in mean score, we also investigated whether a group effect was found to be statistically significant at $p < .05$ using the Mann-Whitney's U test, a non-parametric test evaluating the independence of the responses of two groups (treating the data as ordinal). We found that a group effect was present for several of these explanations, and we paid particularly close attention to both the scores of the groups and the reasons given for them. We list the explanations found to yield divergent scores, along with a summary of the differences in mean for each, in Figure 7.1. Examining these
explanations yielded insights into how physicians and non-physicians approach these explanations differently.

13 of these 15 explanations were cases in which physicians rated explanations lower than non-physicians, and in fact 8 had means above 3.0 (“acceptable”) for non-physicians but below 3.0 (“unacceptable”) for physicians. Most of this divergence was caused by explanations that physicians felt were inaccurate in this specific case: although the sentence was true, it reflected a narrow application of the test that was not appropriate for the particular patient profile being examined. For example, regarding a test that is sometimes used to diagnose clotting disorders (easy to understand) but was really being used here to assess liver function, P3 (physician) responds to an explanation about clotting by saying: “This is a reason to order this test, but not necessarily in this patient”, and P1 (physician) states: “True, but not applicable to someone presenting in the ER.”

This presents a challenge for automated extraction techniques: even given credible information, it is critical to target explanation selection to a specific patient. This need for patient-specificity reaffirms our hypothesis that drawing from multiple information sources – specifically the Web (for candidate content) and the EHR (for patient-specific selection among candidates) – is necessary for automatic generation of explanations.

Another surprising reason emerged for physician preference of several explanations relative to non-physicians: physicians thought the explanation was too complicated for non-physicians to understand, but non-physicians appreciated the technical detail and saw it as “professional”.

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Table 7.1: Explanations with highest difference in mean ratings between physicians and patients. Green numbers in the rating columns indicate mean ratings above neutral (indicating that the explanation is “acceptable”). Those in red show mean ratings below neutral (the explanation is “unacceptable”). In the rightmost column, statistics are given for responses with a group effect with $p < .05$ (the responses of the patient group and physician group differ significantly from each other), as evaluated using Mann-Whitney’s U test.
In some cases, physician gave lower scores to explanations that they described to be “too wordy”, while non-physicians often preferred these explanations, using phrases such as “it’s detailed” and “something a doctor would say” to explain their rating. For example, the following liver panel explanation was rated significantly higher by non-physicians:

*A liver panel or one or more of its component tests may be used to help detect liver disease if a person has symptoms that indicate possible liver dysfunction or if a person is being monitored or treated for a known condition or liver disease.*

The two explanations that physicians rated highly but non-physicians did not were both explanations for the “lipase level” test, and both used the term “pancreatitis”. While physicians were generally concerned about conforming to a patient-friendly level of technical detail, they did not expect patients to be unfamiliar with this term. This presents another interesting challenge for automated extraction: understanding patient vocabularies and finding the boundary between layman and medical terminology.

**Emotionally Sensitive Information**

Both patients and physicians noted that while detail is critical, in certain cases, too much information not only limits clarity but creates risk and confusion. This particularly applied to the mention of diseases in explanations. Responding to tests that clearly and concisely stated these goals—referring specifically to diseases—non-physicians in particular expressed potential fear. P17, for example, states: “*The mention of all of these diseases while already under duress would cause more stress.*” P20 similarly expresses: “*You are using medical terms that as a confused and disoriented individual are just scaring me. The longer the words are [...] the scarier it sounds.*” These findings suggest other challenges for automated extraction, including balancing
specificity and patient comfort, and minimizing inappropriate anxieties that may come with mention of low-probability risks.

**Need for Personalization**

In many cases, even among non-physicians, participants disagreed significantly on the quality of an explanation, suggesting a need for automated systems to recognize various aspects of personal preference.

In fact, 49 of 135 explanations were “polarizing”. We define polarizing to mean that at least 25% of non-physician participants assigned score $\geq 4.0$ (“good” to “excellent”), and at least 25% assigned scores $\leq 2.0$ (“poor” to “unacceptable”). Exploring the rationales for these ratings highlights several sources of variation in non-physician responses.

Many lab tests are used as broad initial screenings, but non-physicians varied significantly in their willingness to accept “broad screening” explanations as useful. An explanation for one such test referred to “determining general health status”, yielding scores of 1 (“I would hope any lab test would provide information on general health status”) and 5 (“I understand that this kind of test is used to rule out many medical issues”) from non-physician participants.

Another common explanation pattern that polarized non-physician respondents was the use of *indications for a test* that did not refer specifically to diagnostic outcomes. The following explanation is illustrative:

*If a patient is having symptoms such as fatigue or weakness or has an infection, inflammation, bruising, or bleeding, then the doctor may order a CBC to help diagnose the cause.*
P14 (who assigned a 4.0 rating) specifically liked “that this answer tells me why the test might have been ordered for me”, but P7 (who assigned a 2.0 rating) responds, “Only states causes of the test, does not say what the test does”.

A third source of significant disagreement among non-physicians emerged from varying health literacy: some explanations were concise and complete but used a term or acronym not familiar to some participants. The explanation “to determine if your blood glucose level is within healthy ranges” prompted responses of “This is straightforward and easy to understand” (P17, rating 5.0) and “If you don't know what blood glucose is, this explanation is useless.” (P27, rating 2.0).

Finally, some respondents expressed a strong dislike for explanations that were not grammatically complete, even if they were conceptually correct (e.g. an explanation beginning with “To determine if your lungs are functioning well enough…”). This need for personalization opens a further challenge for automated extraction systems: personalization based not only on EHR data but on user preference as well.

CONCLUSIONS

In this chapter, I discussed opportunities for sourcing medical micro-explanations from consumer-facing Web content. After exploring physician and non-physician responses to sentences extracted from Web pages and presented as micro-explanations for medical lab tests, we found that information on the Web is suitable for this type of explanatory content. We also gained insight into structural and semantic features that correlate with perceptions of explanation quality. Finally, we learned a number of considerations, based on non-physician perceptions of quality, that should influence the automatic extraction of these explanations, including the need
to accommodate varying health literacy levels, accommodate varying preferences for level-of-detail, and balance emotional impact with specificity.
CHAPTER 8
SUPPORTING PATIENT SENSEMAKING OF ONLINE HEALTH INFORMATION

This chapter elaborates on the following paper:

INTRODUCTION

In the previous chapters, I described technologies and studies designed to explore patient interactions with their clinical and health-related information, largely during their care. Up to this point, I have conceptualized this interaction as occurring primarily between the patient (or their family members) and the artifacts that we have introduced to them in our studies. While this has been useful in addressing our research goals thus far, another facet of patient information access can dramatically impact how patients access and make sense of health-related information: use of the Web to learn about symptoms, conditions, procedures and tests, and treatments (Anderson et al., 2003). Increasingly, patients are bringing mobile devices into clinical settings (Pfeifer Vardoulakis et al., 2012) and referencing web materials in discussion with their caregivers (Diaz et al., 2002).
A recent Pew Poll surveying the online behaviors of US adults over a 12-month period found that 81% of adults use the Internet and of these users, 72% say they have looked online for health information while 43% have looked for information on specific treatments or procedures (Fox and Duggan, 2013). Searching for information of this sort often involves making sense of multiple web documents. Users may access a range of sites created by a variety of institutions and companies—from international online pharmacies, to personal blogs, to government-agency–supplied literature. The use of social media also influences health education and decision-making in ways that researchers are only beginning to discover. A survey by the Health Research Institute at PricewaterhouseCoopers (PWC, 2012) found that 45% of US consumers report that social media would affect their decision to get a second opinion, while 42% of US consumers say they read health-related reviews by other consumers online.

As helpful as reviews by other patients can be, they can also bewilder laypeople if they contain claims from well-meaning but misinformed individuals. Laypeople also face other challenges as they sift through sites, attempting to differentiate between fact and fiction—it can be difficult to detect sensationalistic journalism or purely commercial material that is disguised as educational content or personal stories (NLM; NLM). As I discuss in Chapter 6, patients conducting searches while experiencing illness or receiving hospital care might also be limited by cognitive, physical, and temporal constraints when searching for relevant health information (Wilcox et al., 2011). In response to these issues, recent research has explored features of health website credibility (Eysenbach and Köhler, 2002; LaRue, 2008; Rains and Karmikel, 2009; Schwarz and Morris, 2011), while third-party organizations have been established to certify or recommend health-related websites (Marcus, 2010).
Credibility assessment is of enormous importance in supporting health information search, but it is only one of a larger set of tools needed to determine the applicability of a webpage to a consumer’s information needs. In this collaborative research project, I worked with colleagues to explore the potential benefits of tools specifically tailored for patient-centered medication information search¹. We created a prototype search system by applying text processing techniques, and probabilistic generative topic modeling approaches, to retrieve and organize medication information across a variety of online sources. We determined specific website signals and document topics that we used to annotate medication information search results, with the goal of helping lay consumers to more accurately assess webpage suitability.

Reviewing the existing literature on consumer health information needs and information seeking (detailed in Chapter 2), I identified four high-level principles that affect consumers’ valuation of online health information: credibility, readability, consumer perspective, and topical relevance. I describe how I applied these principles in the design and development of Remedy, a high-fidelity medication information search prototype. Remedy embodies patient-centered tools for conducting health information searches (shown in Figure 8.1). I engaged hospital patients and their family members, along with pharmacists, caregivers, and other domain experts in a user study of Remedy—using it as both an artifact to facilitate comparison with standard online web search interfaces and as a technology probe (Hutchinson et al., 2003) to gain insights into how search tools can better meet consumer needs.

¹ I created the IRB proposal and managed the consent process. I conducted the literature review, drawing on the results to lead the design of the prototype, incorporating feedback from Drs. Tran and Feiner. I created the research corpus, conducted topic modeling experiments, and developed the prototype. I also conducted both phases of the study. I collected, transcribed and analyzed data. Dr. Elhadad provided guidance related to the text processing and topic modeling approaches. Dr. Feiner provided guidance on the study approach.
This chapter outlines three project-specific contributions that together form the last primary contribution of this dissertation: *design, implementation, and evaluation of tools to support users searching for medication information*. The three project-specific contributions include:

1. A set of search tools supporting rapid filtering and comparison of medication information search results, based on a number of website features and content topics.

2. Findings from a field study with cardiothoracic surgery patients and their visiting family members using these search tools during a post-operative hospital stay. This study explored the use of Remedy’s tools in comparison with an existing general-purpose search engine, and elicited recommendations for refinement.

3. Discussion of preferences and recommendations of domain experts for designing tools to support non-expert, online medication information search, based on Remedy usage sessions.

In the remainder of this chapter, I discuss related work and describe how our tools were informed by a literature review of consumer health information search practices and patient information needs. I then present the results of our studies and conclude with a discussion on how the insights gained through our work contribute to knowledge of how to support laypeople in locating and making sense of relevant health information resources.
Figure 8.1. Web search results returned by Remedy for the medication Amiodarone. Each result includes topic, site and page feature annotations. Topic browsing tools (top left) and filters (top right) allow the user to refine the results. Here, the user selects the filter “Reviewed by experts” to narrow the search results to those that satisfy that criteria. Figure 8.2 shows a close-up of a sample result, while Figure 8.3 shows a close-up of the topic browsing tools and filters.
RELATED TOOLS AND INTERVENTIONS

Website and Page Content Credibility

Schwarz and Morris recently explored how credibility signals can be used to assist end users in evaluating website search results, for a number of information domains (Schwarz and Morris, 2011). We strive in this work to support end-user assessment of website credibility, by presenting information relevant to this decision, tailoring our metrics to address medication-information search. Furthermore, we also explore the importance of topical relevance and readability.

Enabling Sensemaking across Web Documents

Making sense of online health information often involves browsing multiple webpages to compare explanations, descriptions or opinions about a single topic—a time-consuming and cognition-intensive task (Billman and Bier, 2007) described by the term “sensemaking”. To assist end users with sensemaking tasks, researchers have designed technologies that combine document summarization techniques with presentation techniques. Tools to allow end users to create and manage their own tabular document summaries, created from website-specific extraction patterns, enables users create and manage their own custom collections of online information and media (Dontcheva et al., 2007). A complimentary approach to end-user-driven tools includes browser technology that recommends web document content, at the page-unit level, to end users to assist them in finding relationships among webpages (Cheng and Gotz, 2009). In contrast, we focus on determining and presenting salient topic information, with the specific goal of augmenting the medication information search experience.
REMEDY DESIGN GOALS

In this section, I identify key themes that emerged in my review of existing literature on enabling patient-centered health information search. I outline four high-level principles that capture these themes: credibility, readability, patients’ perspectives, and topical relevance. I also describe how the tools embodied in Remedy draw from each.

**Credibility**

*Enabling Awareness of Expert-Reviewed Webpages*

Recent research focusing on how laypeople seek health information online highlights a heavy reliance on general-purpose search engines (Fox and Duggan, 2013). Unfortunately, earlier work in this vein found that once search results are returned, information from the first page is selected, often without awareness of the actual selection criteria (Eysenbach and Köhler, 2002; Peterson et al., 2003). In one study, participants claimed to be concerned about the quality and source of online health information, but did not verify source information, disclaimers, or disclosure statements during page-viewing tasks (Eysenbach and Köhler, 2002).

In 2007, the U.S. National Library of Medicine released a guide recommending specific strategies for searching for online health information (NLM, 2012a). These guidelines recommend that site visitors seek out author credentials, contact information, and evidence of authority. An important area of future work includes the design of automated approaches to flagging inconsistent or unsubstantiated information. For example, Abbasi and colleagues have proposed algorithms that demonstrate the potential to detect fraudulent health sites (2012). In the present study, our goal was to “inform end users” (Schwarz and Morris, 2011) by exposing
relevant website and content signals of web search results, rather than attempt to predict credibility.

*Enabling Preferences for Non-Commercial Sites*

Peterson et al. found that the ability to select sources of information from government agencies, non-profit organizations, and educational institutions was a key preference expressed by consumers (2003). Parallel work found that the brief site descriptions included in the search results of widely used web search engines are inadequate for enabling selection of an objective and reliable health information site. They have argued that descriptions of health sites should display more information regarding the source of the site content as well as its commercial intentions (Slater and Zimmerman, 2003).

*Annotating Search Results with Quality Indicators*

Sillence et al. observed that patient study participants sometimes rejected high-quality content because of its poor visual design (2007). This finding is consistent with prior findings showing that graphical design characteristics of a site greatly influenced users’ perceptions of credibility (Fogg et al., 2003), motivating the need for tools to increase recognition of quality indicators (Greenberg et al., 2004).
Readability

Enabling Transitions from English to Spanish Resources

Berland et al. argued for the availability in the US of online health information topics in both Spanish and English and stressed the importance of signaling accessibility, quality, and readability of web resources (2001). Thus, a key design goal for Remedy included support for locating Spanish language materials, even when a query is initially performed in English.

Enabling Awareness of Advanced versus Basic Material

In a recent study of the health information needs of older adults, study participants expressed the desire for web-based information to provide “medical knowledge in less technical language” (Xie, 2009). While health information search technology should indicate the literacy level at which a web document was written, readability measures are currently difficult to determine. Health literacy screening instruments used to evaluate an individual’s health literacy (Collins et al., 2012; Davis et al., 1993; Parker et al., 1995) do not provide a comprehensive assessment, and developing tools for “grading” online resources according to the health literacy level of the text is an important area for future work.
Enabling Navigation to Multi-Media Content

In designing Remedy, we explored the decision to integrate multi-media previews into the search result interface. Khan and colleagues highlight the value of displaying pill images in medication management applications, to aid patients in identifying their drugs (Khan et al., 2010) This can be challenging, as many medications are available in formulations involving different shapes, imprints and sizes for varying strengths and brands. We included in Remedy information about image availability on the linked page, rather than attempting to select a representative image to display in the search results.

Patients’ Perspectives

Enabling Navigation to Consumer-Contributed Information

The 2013 Pew Internet Poll on the use of online health information found that one in five Internet users have consulted online reviews of particular drugs or medical treatments (Fox and Duggan, 2013). Caregivers are even more likely to seek out medication reviews: 38% of these Internet users have consulted online drug reviews (Fox, 2011). A similar survey study conducted by the Health Research Institute at PricewaterhouseCoopers US indicated that 34% of respondents report that social media would impact their decision about taking certain drugs (PWC, 2012).

The quality of patient-contributed information is a contentious topic (Jadad and Gagliardi, 1998), as I discuss further in section 6, below. Still, the sharing and viewing of peer perspectives is a growing trend that many are embracing to guide them in assessing health information (Collins et al., 2012; Eysenbach, 2007; Fox and Duggan, 2013; Kitchens et al.,
2012). We sought to enable awareness of the presence of patient reviews during the search process, noting that such awareness can help patients to either locate or avoid this information.
Figure 8.3. Display (partial view) presented by Remedy after the user selects “How To Use” from the topic menu of Figure 3 to see relevant snippets related to Simvastatin.
Topical Relevance

Enabling Recognition of Concepts

Berland et al. showed that most users searching for online health information searched inefficiently when using simple key terms with general-purpose search engines (2001). This inefficiency was due in part to a lack of vocabulary to describe health concepts. A key design goal for our Remedy included the display of relevant topics to users during the search process, to permit recognition of terms and concepts (Figures 8.1 and 8.2).

Enabling Comparison of Sites Based on Topical Coverage

Tasks essential to health-information–sensemaking include the discovery and synthesis of trustworthy information, spread across multiple locations, and the recognition of contradictory information. Sillence et al. propose a multi-stage web resource evaluation process, in which rapid, heuristic processing based on superficial heuristics precedes in-depth examination and information processing during health information search (2007). Based on these findings, Remedy includes techniques for browsing topically-related page excerpts of web documents (Figure 8.3). We included this ability in order to support synthesis and comparison of information, which are key elements of the sensemaking process Sillence and colleagues describe.

REMEDY DEVELOPMENT

Tools Included in Remedy

Drawing on the design goals I described in the previous section, we included the following search tools in our medication information search prototype.
• **Result-specific topic map**

For each webpage result, a set of horizontal bars indicates the relative amount of page content in each of the set of topics (shown in Figure 8.1) as determined by our topic analysis.

• **Result-specific feature annotations**

For each webpage result, certain binary characteristics are listed, including whether the page was reviewed by experts, contains commercial content, or includes patient reviews.

• **Topic Menu: Browse All Results by Topic**

Selecting a topic (e.g., “Dose” or “How to Use”) from the topic menu (shown at the left of Figure 2) displays topically-relevant page excerpts from all page results for the queried medication. For example, Figure 3 shows the “How to Use” excerpts for Simvastatin.

• **Filters to Select Results Based on Page Features**

Selecting one or more filtering criteria (shown at the right of Figure 2) narrows the search results to results that satisfy all of the selected criteria.

**Topic-Based Browsing**

The past decade has seen advances in computational methods to identify and cluster both structured and unstructured text. In particular, several techniques have been developed to discover salient aspects or topics discussed across multiple documents (Blei and Lafferty, 2009; Pang and Lee, 2008).

Topic modeling is a class of techniques that is often used to determine topic-based information, synthesized across documents with varying structure and organization typically in an unsupervised manner (i.e., without any pre-determined labeling on the documents). Specific topic modeling techniques include latent Dirichlet allocation (LDA) (Blei et al., 2003; Steyvers and Griffiths, 2007) which treats each document in a collection as a mixture of topics—
determined by a probability distribution over words. However, while topic modeling is beginning to play a role in webpage indexing and search, conventional user interface designs do not expose this information when it is available, even though it could be valuable to users (Blei and Lafferty, 2009).

To develop Remedy, we explored approaches to combining topic-modeling techniques with presentation and interaction techniques, to support topic-based browsing of information across medication information webpages. To generate topic clusters, we applied LDA-based topic modeling algorithms, based on evidence of their effectiveness for similar content types (Brody and Elhadad, 2010).

We supplemented these techniques with additional text processing and manual content curation (described below) to approximate what we could expect from a fine-tuned, fully-automated system. The development and evaluation of fully automated topic modeling techniques for the medication information domain is an important goal, but not one that we focus on here. Our goal was not to develop a robust, fully-automated topic modeling pipeline, but rather to create a research prototype to explore the future potential of topic-based browsing techniques and the role they might play in assisting patients in medication information search.

Sources of Information for Modeling

We sought to draw from a variety of online medication information materials, to simulate what a layperson might encounter during a medication information search using general-purpose search engines with basic keyword queries. To collect representative information, we employed Mechanical Turk (MT) workers (Amazon, 2005). We provided the workers with the names of a total of 100 unique medications (listed in Appendix E.1), which were selected by extracting
common inpatient CT Surgery medications from our academic medical center’s hospital information system.

MT workers were asked to use their preferred general-purpose search engine to query a subset of the medication names, and report up to 10 URLs that contained consumer or patient-oriented information for each medication. Two members of the research team then manually reviewed the list to verify reported results and resolve broken links.

Next, I wrote basic webpage text processing scripts that utilize C# libraries to perform DOM parsing, capturing website titles, webpage article titles and description information provided in the website meta-data for the full list of curated URLs. I also wrote basic webpage processing scripts to harvest page contents for the curated URLs. In all, 993 webpages were collected. Using sentence and paragraph extraction tools (Brody and Elhadad, 2010) on the harvested webpages, we prepared a text corpus containing 205,685 distinct excerpts, with which we ran topic-modeling experiments. I used MALLET (McCallum, 2011) to apply LDA-based topic modeling, using 10–200 topics (with default parameters for the others). Dr. Elhadad and I reviewed the results of the experiments, selecting results and labeling strongly-agreed-upon resultant clusters. Determining the optimal number of topics for any given modeling task is an open research question. Thus, I ran topic modeling with 10–200 topics and selected the model that resulted in the most semantically meaningful topics from a qualitative standpoint (Chang et al., 2009). With this model, Dr. Elhadad and I also agreed on three categories describing the “strength” of the topic. This was based on the principal topic for the excerpt (for each excerpt, a range of topics with associated weights is calculated by the LDA-based algorithms we employed.)
Content Analysis and Inclusion in Remedy Prototype

We identified clusters in strong topics (relevant clusters of excerpts describing side effects, medication precautions, etc. representing less than a third of the corpus), weak topics (clusters with excerpts containing marketing statements, social network information such as “follow us on Twitter”, etc., representing more than half of the corpus) and ambiguous topics (e.g., information on certain side effects such as “weight loss” conflated with an advertisement to “lose weight now”).

We further refined topic clusters using techniques that utilized structural features of the web documents to detect lists, menus and submenus and ads (Brody and Elhadad, 2010), applying these techniques to content in all three “strength” categories. These techniques allowed us to detect when side effects, precautions, interactions and symptoms (relevant content) were in list form, to differentiate them from advertisements, disclaimers and copyright information, navigation content and certain page headings (irrelevant content).

After applying these techniques, we identified excerpts that contained structural features that yielded information of relevance. We separated these excerpts, placing them into one of two categories, labeled as: strong structure (for relevant content), and weak structure (for irrelevant content). Information in the strong structure category was slated for inclusion in the prototype. The full content analysis pipeline we used is depicted in Figure 8.4.

After applying the structural text-processing techniques, we applied filters to the remaining excerpts grouped in the strong topics category to identify irrelevant content that might have been incorrectly clustered. The filters were chosen based on categories described in Appendix E.2 and constructed with a combination of keyword phrases (e.g., “forgot password”) and regular expressions.
Figure 8.4. Content analysis pipeline for Remedy. The pharmacist who audited the information for the prototype reviewed excerpts that made it into either of the two “Include” categories shown above (for 18 medications).
If the keyword filter applied to content in an excerpt consisting of more than one sentence, the excerpt was parsed into individual sentences and re-evaluated. Sentences matching the filter were slated for exclusion.

Next, we applied heuristics to the remaining excerpts grouped in the weak topics category to identify any relevant content that may have been incorrectly clustered. These heuristics included rules that largely detected when an excerpt not in the strong topics category was positioned between two excerpts in the strong topics category. In this case, we separated these excerpts, placing them into a strong heuristics category, and slated them for inclusion. Otherwise, as shown in Figure 8.4, they were slated for exclusion.

After resolving all excerpts for either inclusion or exclusion, we reviewed the resultant clusters in inclusion categories (approximately 50) and joined related clusters (through manual review) by the same two researchers conducting the initial evaluation. In all, twelve resultant clusters were formed. As I describe in the next paragraph, NYPH pharmacist Dr. Tran audited each to determine appropriateness of cluster label and excerpts assigned to it.

I selected a subset of 18 medications with Dr. Tran, from the initial 100 to include in a prototype for evaluation (shown in Appendix E.4). We made our selection basing our choice on a review of medications commonly utilized during and after cardiothoracic surgery, conducted with an experienced clinical pharmacist.

Tran created the “gold standard” for validating content clusters, manually reviewing the website excerpts assigned to each cluster, for all 18 medications (described by 148 associated webpages). Tran reviewed each excerpt included in a cluster and marked whether the explanation was incorrectly assigned to the cluster. In addition, the pharmacist noted, using the instrument, whether the explanation was more appropriate for clinicians, and whether the excerpt could also
be assigned to another topic clusters. An excerpt of this instrument is shown in Appendix E.5.

Final refinements were then made to all topic-based information, based on the pharmacist’s review.

**Site- and Page-Content–Based Features**

Guided by the work of Schwarz and Morris, we also identified on-page and off-page features of the webpages included in Remedy, based on their relevance to our design goals. On-page features included information about the domain type (e.g., .gov and .edu), the number of ads on the page, and the availability of patient testimonials or reviews of the medication on the page (noting their binary existence, rather than the number of reviews). Off-page features included the detection of Health on the Net (HON) certification and Utilization Review Accreditation Commission (URAC) accreditation of the hosting institution. HON (www.hon.ch) and URAC (www.urac.org) are nonprofit organizations promoting healthcare quality by verifying that patient-friendly quality guidelines are followed. The “page rank” score of the webpage, as made available on the Google Page Rank toolbar, was also collected. If no score was made available on the page, the rank of the hosting site was used. We ordered the search results in Remedy according to this page rank, to approximate as best we could the order of search results one might expect from a general-purpose search engine.

While automated approaches to detecting on- and off-page features have been demonstrated to be technologically feasible (Schwarz and Morris, 2011), we collected these data manually to minimize the likelihood of error.

To populate Remedy, we created a SQL database to store webpage address and description information, webpage article titles, URLs, on- and off-page features that we collected, and all associated topic information, including topic clusters containing relevant
webpage excerpts. The search interface was created using HTML with JavaScript and PHP and hosted on one of our institution’s secure web servers in a password-protected directory.

PARTICIPANTS AND METHODS

Utilizing Remedy as a high-fidelity prototype allowed us to elicit and analyze open-ended, free responses, which can reveal valuable information about patients’ self-perceived information needs that otherwise may be overlooked (Xie, 2009). Remedy also allowed us to observe whether and how study participants used the novel tools that we introduced, during actual search tasks.

Inpatient Participants

We conducted the inpatient portion of our study in the surgical cardiac unit (Cardiac Step-Down) at NewYork Presbyterian-Columbia University Medical Center (NYP-CUMC). This is the same clinical unit in which we carried out the studies described in Chapters 5 and 6. Approval for this study was obtained from the Columbia University Institutional Review Board (IRB) and the Cardiac Step-Down nurse manager.

Patients were invited to participate in the study after consultation with their providers and were included based on their physical and mental capability to participate and their ability to speak English. While the current study was limited to English-speaking participants, we hope to include Spanish-speaking participants in a subsequent study to explore the usefulness of the “Spanish Available” filter in Remedy.

Twelve patients (eight male) age 48–88 (mean=66) participated. In two of the twelve cases, visiting spouses (both female) performed the search task, indicating that they were the most likely to search for information at home. In another two cases of the twelve, family
members participated along with the patient in interviews. All participants reported that they used a cell phone on a regular basis. One of the patient participants did not have a computer at home and had limited experience with web search. All other participants had internet-enabled computers at home and used them regularly to perform web searches. A review of the patient participants’ medical records indicated that each had previous experience managing a heart condition requiring the use of medication.

**Inpatient Field Study Methods**

Patient and family member participants engaged in study sessions lasting 40–60 minutes, the variation in time being largely due to the need by some patients for additional training, and interruptions for the administration of care during the study interview. After providing informed consent, patients were given a first-generation iPad slate computer. The slate was set up for each patient to display a password-protected webpage with the patient’s inpatient medications (Figure 8.5). The medication views were created by software described in Chapter 6. Each patient had three views of their hospital medications available. The first view showed standing, or active, medication orders, as shown in Figure 8.5. The other two highlighted the new medication orders as of the current day, and hospital medications that had been discontinued or completed.

Since experience with technology usage was not a factor in recruitment, users with limited technology experience were given a brief training session on how to use the iPad, including training on the use of the touch-screen.

After presenting patients and participating family members with the three medication information views, we asked them to comment on medications in the list that they had experience taking, and to point out medications that were unfamiliar to them. The study
coordinator noted unfamiliar medications as query candidates for a later search task (described in below).

Semi-structured Interviews: Experiences with Medication Information Search

We asked participants to describe their prior experiences with using the internet to search for medication information, following a semi-structured format addressing the following discussion points:

1. Medication-related topics of interest. These questions covered specific topics for which participants had searched, related to their medications.

2. Medication information search methods. These questions explored participants’ search strategies when searching for web-based medication information. For example, participants were asked to comment on which search technology they use for seeking information, how they identify relevant sites to visit, and how many resources they consult during a typical medication information search.

Inpatient Search Task

After discussing participants’ previous experiences with medication information search, we introduced and demonstrated the filtering tools and topic browsing tools in Remedy by querying a drug on the inpatient medication list. When possible, we queried a drug already familiar to the participant.

We then selected a medication from the patient’s inpatient medication list, from those that were unfamiliar to them, and explained to participants that we were interested in observing them during a web search for information about the medication. We explained that we were comparing a few different technologies to understand their applicability to medication
information search in an attempt to mitigate, at least in part, “good subject role” effects (Orne, 1962) (i.e., we did not inform them that we created Remedy). We chose a general-purpose search engine as a baseline to explore how search tools can support consumers in evaluating a range of sites according to their needs. However, we note that the tools we studied in Remedy could be added to search functionality found in specialized sites like WebMD.com and Drugs.com to allow users to narrow-in on certain sites with certain features, returned by these health-specific sites (these sites do not currently include the tools that we studied in Remedy).

Participants were asked to use both Remedy, as well as a single general-purpose search engine (Google, Bing, or Yahoo) of their own choosing to perform a query on the same medication information topic. Thus the same search task was conducted in Remedy and the general-purpose search engine. All searches were conducted using the Safari browser.

We counterbalanced the order in which Remedy and the general-purpose search engine were used to perform the medication information search task. Participants were randomly asked to search for information on either uses, precautions, or on factors affecting the dosage, and to find this information on a credible health information site. While participants completed the search using both search technologies, the study coordinator manually noted the time each participant spent on the search task using each technology.

We wished to compare participants’ experiences evaluating search results and locating information relevant to the task. To complete the task using each search technology, participants were told to point out to the study coordinator information relevant to the query, on a page they found to be a credible source of information, as soon as they identified its relevance. For example, if the task involved searching for precautions for the medication Metoprolol, the patient was told to point to text that they identified as listing or describing precautions for the
medication, from a credible web resource. We started timing them once the search results were returned, and stopped timing when the patient pointed to information they thought was relevant to the task. In one case, the task clock was restarted because the patient misunderstood the task and needed clarification.

Client–server communications and page loading times can vary depending on the strength of the network in the hospital; however, we noted that there were no cases in which pages took an unusual length of time (over 2–3 seconds) to load. In addition to the time spent on the search task, we also noted individual steps that the participant took (e.g., scrolling through the first page of results, reading result title information, selecting a result, returning to the view of search results).

Finally, participants were asked to comment on which search engine they preferred to use for the task they had completed. Specifically, we asked them the following questions related to their preferences:

1. If you were given a new medication and wanted to search for web-based information about that medication, which of the two search engines would you choose to use? Why?
2. If these tools were part of the current search engine that you use, would you use them? Why or why not?

**Domain Expert Participants**

We recruited a total of eight domain experts: two nurses (each with two years of experience), four pharmacists (with four to six years of experience), and two fourth-year PhD candidates conducting HCI research in the areas of Health and Wellness (each had conducted research on the display of medication information to patients).
Domain Expert Study Methods

We engaged each domain expert in individual study sessions lasting 30–45 minutes each. These sessions were conducted either in-person in a private conference room or using web conferencing software. We demonstrated the features of Remedy by first querying for a drug that they selected, and explained the search tools, including the filtering tools and topic browsing capabilities.

Domain Expert Search Task

As in the inpatient field study, we explained to the participants that we were comparing a few different technologies to understand their applicability to consumer medication information search. They were asked to use both Remedy, as well as a single, general-purpose search engine (Google, Bing, or Yahoo) of their own choosing to perform a query on the same medication information topic. We counterbalanced the order in which Remedy and the general-purpose search engine were used to complete the medication information search task. Searches were conducted in the participant’s preferred browser either on their own personal computers (if using web conferencing software), or on an iPad that we provided. The user experience of Remedy was consistent across IE, Firefox, Safari, and Opera browsers.

For the search task, we asked domain experts to use the search technologies, as they would imagine a non-expert consumer would. We randomly selected a medication from the list of available ones and for consistency with the inpatient search task, asked them to search for information on either precautions for using the medication, or factors affecting the dosage.

While participants completed the search using both search technologies, the study coordinator manually noted the time each participant spent on evaluating search results and
locating relevant information in the selected search results. Steps that the participant took were also noted, as in the inpatient task described above.

Participants were then asked to comment on which search engine they preferred to use for the task they had completed, adopting the role of a non-expert. Specifically, we asked them the following questions related to their preferences:

- If you were asked to recommend a search engine for finding web-based information to a patient or caregiver, which of the two search engines would you recommend? Why?

Debriefing Interview

After completing the search task, experts were asked to interact with each of the search tools featured in Remedy (described above) and to comment on their perceptions of the usefulness of each. They were also asked to recommend improvements to the tools, or design refinements.

RESULTS AND DISCUSSION

Inpatient Search Behavior

Navigating to the Right Information

All inpatient participants chose to use Google as their preferred general-purpose search engine for the task. In general, most participants had a domain vocabulary that differed from standard usage—even on consumer-oriented pages. For example, when using the standard search engine to find information on medication precautions, participants used keywords that were technically incorrect, such as “side effects” and “interactions.”

As Table 8.1 shows, we found that participants took longer to find the requested information during the search task when they used the general-purpose search engine. They also struggled with incorrect, keyword-based results (e.g., “using the drug” versus “uses of the drug”), which we found were conflated in standard search results. To compare their task
completion times, we analyzed results using a Wilcoxon Matched Pairs test (we chose a non-parametric test due to the small sample size). This analysis found that completion times differed significantly between the general-purpose search engine and the tools embodied in Remedy ($p < 0.01$). When using Remedy, participants made heavy use of the topic map included with each result, and the browse-by-topic options.

![Bar chart showing completion times for various medications](chart.png)

Table 8.1. Inpatient medication information search task completion times (in seconds). The asterisks after the medication names (three total) indicate that an error was made during the task. In all three cases, the error occurred with the general-purpose search engine.
Patient and Family Member Responses to the Tools in Remedy

Search Interface Preferences

Two participants, both patients, did not choose Remedy over the general-purpose search engine, when asked which experience they preferred. Of these, one patient asked us to conclude the interview before he chose, while the other mentioned that without more information about how Remedy would be maintained, he felt more comfortable using a well-known search technology. However, all participants mentioned that, given the opportunity to use Remedy’s tools as part of their current web search experience, they would do so.

Meeting Multiple Information Needs

While study participants mentioned that the results delivered by Remedy were relevant to their search query, several also proposed that complementary resources be included in the search result interface—either integrated into the results, or included in a sidebar. These included links to resources to help manage the cost of a medication or treatment, tools to simultaneously compare summaries of consumer reviews with professionally-written materials, and tools to locate articles dealing with differences between generic versus brand-name drugs and alternative and complementary drug therapies. A few patients also suggested that site ownership information be made clearer in the search results. As P11 stated: “I’d like to know the tie-in to a corporation, [or] who owns the company promoting the site.”

Search Tools Preferences

Participants were uniformly positive about both the display of topic-based information and filtering tools in the Remedy search interface. Several mentioned that, while they might not choose to use certain filters, they found them important to include. Most participants preferred
the topic-specific tools. Five participants of twelve indicated that the topic map was the most important, while four of twelve indicated that “Browse by Topic” was the most useful. Two participants of twelve found the topic map and “Browse by Topic” equally important, while one found the filtering tools the most useful for them. Below, I illustrate how inpatient participants made use of the topic-based tools.

Inpatient participants also commented on page features that they thought were or were not important to see with individual search results, and the importance of corresponding filtering tools. Five participants of twelve thought that the “Reviewed by experts” feature was the most important one to see while evaluating the results of medication-information–related searches, while four of twelve found that the availability of pill images on the site was the most important. Table 8.2 shows a summary of inpatient participants’ attitudes about site and page feature annotations and corresponding filters in Remedy. The following sections further elaborate on patient responses to these tools.

**Topic-Based Browsing**

When commenting on the importance of the short snippets viewable in the interactive topic map, P1 explained that, “Verbosity drives me crazy. I don’t want to look at a ton of pages. But I want to see where sites agree or disagree. This is concise. I like these [snippets] better.” P3, a family member who participated in the search task, highlighted similar benefits of the topic-based browsing feature after doing a search for Amiodarone dose: “It’s comparative and very specific. I can see the range. I like to know... the dose, how it's defined—about any medication. Numeric is fine. But, if I'm ignorant, that number doesn't mean as much to me unless it’s reinforced by a judgment type word, weighted. I like seeing the combo.” P11 also appreciated the ability to see multiple topic-related excerpts from the returned results, indicating that she liked “seeing
multiple page excerpts because when I search, I don’t just go to one. There [is] always something new in each site I visit unless it’s just stats. But even that, I cross-check. It helps to see that sites have the same info.”

While browsing multiple topic-based excerpts was important to these patients, they also commented on the ability to use the topic-based tools to help find specific information when if keywords were unknown. P6 commented on the importance of quickly locating the specific information he needs, explaining, “I like this ‘Browse by Topic’ because I can zero in on it.”

![Graph showing inpatient participant preferences for viewing each website feature in the search result user interface.](image)

Table 8.2. Inpatient participant preferences for viewing each website feature in the search result user interface. For each feature, the bars show the number of study participants who indicated that the feature was useful, not useful, or might or might not be useful to them when conducting medication information searches online.

**Advanced Content**

Patients are often considered a lay audience, yet all patients in our study had previous experience managing a heart condition, and several had experience reviewing a plethora of information related to one or more conditions. While Remedy does not currently allow users to filter out advanced content, it does annotate individual results that contain higher-level information, to indicate this to the user as they evaluate the results. We were interested in patient responses to
the annotations in each result, as well as the “Advanced Content” filter. We found that half of the inpatient participants in our study anticipated that they would filter results to include only advanced content during some of their medication-related web searches. Four did not find the filter useful, and three of the four mentioned that they would prefer instead to be able to remove results containing advanced content. This difference in opinion sheds light on the diversity of patients’ needs, reinforcing the need for health-specific search tools for specifying health-literacy-related preferences. Once experienced in managing a condition, patients often conducted further research to clarify side effects versus symptoms, or determine if they should request a change in their medication. P8 commented that he searched for information online, rather than consulting only one credible site, to find more in-depth information on his medications. As he stated, “I would go to an FDA site, but you know they don't really provide that much info.”

**Pill Images**

Inpatient participants frequently commented on the usefulness of a filter to display only results that contained pill images. Such a filter could be used in conjunction with other filters, such as “Reviewed by experts” to ensure that the sites returned not only had images, but that the content is of high quality. P2 discussed the importance of locating pill images quickly: “There was a time when my husband went to pick up a prescription for me, for antibiotics. And he came home with the littlest things and I said, no, those things are too tiny. Most antibiotics are pretty big. And it ended up being that they gave me someone else’s medicine. And I know because I'm in the business—but someone else, they might not know.” P8’s wife also commented on the “Pill Images” filter, explaining that, “for me and my husband, I use the Physicians’ Desk Reference to verify the pill is the right one.”
Patient Reviews

We were very interested in learning whether inpatient participants would value tools to help them locate patient reviews of medications. Five participants of twelve did not find the “Patient Reviews” filter to be useful, mentioning that they would not wish to navigate to such reviews. P1 commented that: “I don’t want just generic reviews. People don’t know what they’re talking about.” However, five inpatient participants mentioned that they found patient-contributed reviews particularly useful to them, and two indicated that this filter was one of the most important to include in the search tools. These patients also noted that caution might be needed in interpreting peer advice. As P13 explained, “I also want to see, what are good reviews.”

Patients who valued the ability to easily locate patient reviews mentioned compelling reasons for doing so. In particular, they felt that learning from peers could help them to make decisions about changes in therapies or treatments, and gain encouragement for pursuing complementary therapeutic goals. As P7 expressed, “I’m interested in the effectiveness of the brand versus generic. The patient reviews would be useful for that.” P13 mentioned his desire to learn from similar patients, but mostly about measures they took to reduce their reliance on pharmaceutical drugs when exploring therapies for his condition. He commented, “I would like to see, this person, he walked more and so he doesn’t need the medication now.” This comment points to the need for tools to help consumers to not only locate trustworthy information about a specific therapy, but to also explore, in the context of health-related information search, the experiences of peers who have related conditions, therapeutic regimens, and goals. Creating these tools will require concerted research efforts by the HCI community. As Lau and colleagues note, the impact of patient-contributed experiences, including its quality and safety, is a crucial area for future research (Lau et al., 2011).
Expert Review

We found that all patients expressed interest in tools to permit greater verification of information and selection of trustworthy resources. Five patients found the “Reviewed by experts” filter to be the most useful, while several volunteered that using the “Non-profit/Academic” filter to view non-commercial information would help them to find credible content. For his search task, P15 looked for information from a credible source, on uses of the antibiotic Vancomycin. After the search task, he commented that when searching using Google, the first result returned was a Wikipedia page. “[Wikipedia] might give me a snapshot, but I wouldn't rely on it.” Using Remedy, this patient filtered results using the “Reviewed by experts” filter. Interestingly, some patients expressed their feeling that the non-commercial content filter (labeled “Non-profit/Academic”) might yield more trustworthy results than certain commercial sites—even commercial sites certified by an expert review panel. P11 did not find the “Reviewed by experts” filter to be useful, but valued the “Non-profit/Academic” filter the most. She said, “Who is the expert? Bogus things happen.” Her preferences, along with those of the other participants, point to a valuable area of future work focused on refining consumer-oriented health information search tools to better support recognition of trustworthy information based on user-defined criteria.

Awareness of Advertisements

During the search task, P2 encountered difficulty while searching for Heparin precautions. Thinking that an advertisement was a movie that would explain information on the page, she was redirected to a multi-media advertisement after clicking on the media link. The patient had initially navigated to a site not deemed credible by organizations such as HON, but that appeared in the top set of results of the general-purpose search engine. Unfortunately, the patient was even
more confused by the advertisement and struggled with the task. P3 had an easier time with the task, but recalled cases during the interview in which she was confused by ads: “I've gone to pages where there are a lot of ads,...and I just turn the whole thing off.” We found that most people appreciated that Remedy included annotations showing the number of ads on the page of each result. While P4 commented that these annotations were not particularly useful since “ads are unavoidable”, several other patients, such as P14, thought that supporting awareness of ads in the search results would help him “to go to sites without too many ads.”

**Expert Responses**

*Search Tools Preferences*

Experts were also uniformly positive in their review of the tools. However, three of the four pharmacists objected to allowing easy navigation to consumer-contributed information. These pharmacists mentioned that reviews describing negative experiences might originate from patients who incorrectly followed treatment instructions, or who took additional medications that were not accounted for in the review. These pharmacists also had concerns that reviewers might confuse symptoms related to their illness with side effects of medications, making it harder for the reader to objectively weigh the risks of the taking the medication. As E8 explained, “It’s just too hard to tell how reliable it is.”

Expert participants in our study viewed the remaining tools favorably. Two experts found the topic map included with each search result to be the most helpful, while the remaining six highlighted the importance of the “Reviewed by Expert” filter, the non-commercial content filter, and the pill images filter. Many of the expert participants thought that more information about
how the filter worked should be included directly in the user interface (e.g., explaining HON and URAC accreditation for the “Reviewed by experts” filter).

Recommendations for Medication Information Search Interfaces

Experts made several recommendations for improving the medication information search user interface. Four of the eight recommended that a static view be provided when medication search results are returned, including a summary of uses, the generic name with popular brand names of the drug, and its drug class. One nurse in our study, E1, mentioned the importance of the order in which the topics are listed in the “Browse all results by topic” section of the user interface (Figure 8.3). This nurse commented that, “For different meds, the relative importance of the topic might change. It might be good to reflect that somehow. For example, for Tylenol ‘overdose’ is really important, maybe the most important topic, because acetaminophen is in so many OTC [Over-the-Counter] drugs.”

Pharmacists recommended that medication search results indicate whether or not the queried medication is included in the therapeutic guidelines of organizations such as the American Heart Association. Pharmacists also recommended that web resources addressing different strengths of medication, and immediate versus extended release formulas be more clearly indicated. As E6 mentioned, “Some people have more difficulty than others when switching from the ‘immediate release’ form [of a medication] to an ‘extended release’ one.”

Web-based Information Quality

Several experts in our study mentioned dissatisfaction with the quality of the online medication information they came across during the search task. Pharmacists and nurses stated that they would encourage consumers to avoid a general-purpose search technology, preferring
instead that consumers rely on experts to supply information from resources such as PubMed (pubmed.gov), UpToDate (uptodate.com), and Micromedex (micromedex.com). Interestingly, these preferences stress the inclusion of an expert to vet these resources and overlook the role of credible consumer resources (e.g., WebMD, and MedlinePlus). Previous research on the information-seeking behaviors of consumers shows heavy reliance by the public on general-purpose search engines to access health information (Eysenbach and Köhler, 2002; Fox and Duggan, 2013; Peterson et al., 2003). Our study results echo these findings: all inpatient and family member participants mentioned the importance of web search for health-related information. Only two of the twelve patients in our study indicated that they preferred to rely solely on their healthcare provider for information.

SUMMARY AND CONCLUSIONS

In this chapter, I presented patient-centered tools for evaluating web search results, embodied in Remedy, a prototype medication information search system. Through an inpatient field study with cardiothoracic surgery patients and their family members, and expert usage sessions and interviews, we found that the tools provided in Remedy support consumer-centric evaluation of web search results. Inpatient participants indicated that the topic-based tools in Remedy were useful and they appreciated filters that enabled them to view results according to criteria such as technically advanced content, sites deemed credible through certification boards facilitating expert review, and availability of patient reviews. These participants also located specific information related to their inpatient medications more quickly and the majority indicated that they preferred Remedy to an existing general-purpose search engine, suggesting that adding the tools to either a general-purpose or specialized search engine could help consumers evaluate
search results. Patients also suggested several additional tools to consider, including links to resources to help manage the cost of a medication, tools to simultaneously compare summaries of consumer reviews with professionally-written materials, and tools to locate articles dealing with differences between generic versus brand-name drugs and alternative and complementary drug therapies.

Experts in our study also expressed that they favored consumer use of Remedy over general-purpose search engines, but generally discouraged consumer search of online medication information, finding many of the resources designed for consumers to be of low quality. In Remedy, they emphasized the usefulness of the “Reviewed by experts” filter, and suggested additional features, such as static summaries of pharmacological information in the view of search results, information about inclusion of the medication in established therapeutic guidelines, and tools to help locate information on various strengths and release formulations of a single drug.

Our study findings add to a rich body of existing literature describing consumer needs during online health information search. They suggest that, regardless of whether experts are satisfied with the quality of health information available through standard web search engines, consumers will continue to use these general-purpose search technologies because they make it possible to compare and contrast information across multiple sources, provide quick access to multi-media content such as pill images and medication identification tools, and include consumer perspectives.

As discussed in the literature review in Chapter 2, tools to support consumer evaluation of online health information are currently limited. The positive responses we observed in our study suggest that this problem space is important to investigate further. Work at the intersection
of HCI, machine learning, public health, and health informatics is needed to address the fundamental asymmetry in the current digital health information landscape, through the development of tools to better aid the consumer in locating relevant information. The studies presented here suggest avenues for these advancements, while demonstrating that it is technologically feasible to develop tools that can be added to familiar search technologies now, to help end users themselves detect poor quality and determine relevance. I outline further opportunities for future work to support consumer assessment of quality and relevance of health information in the next chapter.
CHAPTER 9
DISCUSSION

OVERVIEW OF STUDIES

In this dissertation, I outlined principles for applications designed to promote patient engagement in care settings. These principles were distilled through findings of a series of studies conducted in multiple care contexts with patients and clinicians. I discussed how these principles are underscored by data derived from studies including field observations, interviews and surveys, as well as findings related to the design and deployment of three technology applications. I described measurable impacts of augmenting HIT, through novel approaches to designing technology for patient use, arguing that designing such technology according to the principles outlined promotes patient engagement in their care. In particular, I argue that such use of patient-centered technology, during care, can enable patients to understand and participate in decision-making about treatments, and offers opportunities to clarify and correct electronic data in the medical record.

Results of studies comprised by this dissertation offer evidence of the potential for novel computational applications to impact patient engagement in measurable ways. They also distill
considerations, guidelines, and preliminary software solutions for creating patient-facing applications. Each study builds upon findings from the previous study or studies within this dissertation. Each of the six studies focuses on a particular facet of enabling electronic communication of patient status and care progress to patients.

In Chapter 2, I outlined the socio-technical foundations of the dissertation. In Chapter 3, I explore how data in a typical Electronic Health Record (EHR) system informs working representations of patient status and care progress. I first described fieldwork including observations and both semi-structured and structured-interviews in two ICUs. I then described the development of a novel note-taking application, with which ICU physicians created and managed sample progress notes, to yield insights into how clinical data in typical EHR is used in formulating conceptualizations of patient status and care progress.

Next, in Chapter 4, I described two studies addressing the discrepancy between the structure and terminology used in the EHR and the abstracted, plain-language views that are useful to patients, by gauging both patient and physician responses to a patient-centered information display prototype. This prototype, a large-format display placed in patient rooms, included abstractions of selected clinical information based on the patient’s medical record.

In Chapter 5, I described a field study designed to offer a detailed assessment of the electronic information needs of patients during inpatient cardiac care. Chapter 6 outlined the design and development of a custom PHR portal to communicate information about the patient’s inpatient medications, home medications, allergies, and care team, and to provide a mechanism for capturing patient feedback on pain levels, aspects of care, and patient questions. I described a study with cardiology step-down patients to understand whether and how they used a custom PHR portal, software that was guided by principles outlined in four prior studies. This study
collected a combination of data from survey instruments, semi-structured interviews and logged usage data for the purposes of data triangulation to clarify findings from each method. It offered insights into patient preferences for the design of tools to verify, track, and input data during inpatient care, and distilled eight central themes related to the design of interactive, patient-facing systems. Before concluding Chapter 6, I discussed techniques, guided by established EHR usability and information design guidelines, to present inpatient medication information. These techniques were refined through iterative review by pharmacists, from which additional guidelines for their design emerged.

In Chapter 7, I discussed a study with physicians and lay people assessing the feasibility of using online sources to select short, plain-language explanations to include in patient-centered views of clinical data. I followed this chapter with an exploration of approaches to identify topic-based explanations of medication-related information from consumer-facing webpages. Finally, in Chapter 8, I introduced a design for novel search tools in a user interface for medication-related web searches. These search tools include topic-based explanations and other topic-based browsing tools, identified previously from consumer-facing webpage content.

IMPORTANCE OF EVALUATIVE APPROACHES

In Chapter 4, I describe a study with emergency department patients, in which my goal was to uncover knowledge about how these patients perceived the role of technological artifact, designed for their use, in a clinical context. I focused on capturing participants’ subjective experiences rather than validating supposed phenomena through an experimental design. This “patient experience” is necessarily tied to the specific personal episode experienced (i.e., the need for emergency care) and the organizational context (i.e., a complex information-rich
environment). It was necessary to first understand this experience to better identify how phenomena of interest might be isolated. The scenario (i.e., hospital patients supplied with electronic information) precipitated opportunities and challenges—but both its significance and parameters as a problem domain were not yet understood. This dissertation research clarified its significance, characterized the problem domain and offered concrete principles, design goals, and preliminary architectures for technology research to address it.

In general, formative studies need not be qualitative (and qualitative studies need not be formative). However, qualitative approaches to the formative research I describe in this dissertation allowed me to gain access to data that would be otherwise undiscoverable. A quantitative analysis could provide information on the impact of an intervention on patient satisfaction and engagement and knowledge of treatments. Furthermore, if one can track such measures using a large sample size, assessing the impact of patient-facing technology on adherence to medication or other treatment regimens could make a large societal contribution. Such efforts are certainly pursuits of mine in my ongoing research.

However, at this stage of research, understanding themes in patient responses allowed me to better understand possible reasons why, in terms of the patients’ articulated point of view, a specific feature was or was not useful. It allowed me to understand how patients and their family members envision these technologies—to give them a “voice” in the design of these tools. Such information can only be gleaned by analyzing patient-reported responses and observed patient reactions, to capture their experiences with and emotional responses to the technology to frame our analysis of data and our design goals moving forward.
IMPLICATIONS

Engaged patients have higher levels of patient satisfaction, increased understanding of their care, greater motivation to adhere to their treatment plans, and better patient health and outcomes (Street and Millay, 2001). In this thesis, my interest lies primarily in computational approaches to promoting patient engagement in care. The studies and technologies described contribute to our understanding of how to design such tools. Work on the advancement of PHRs is promising and impactful, but much of the design and functionality does not directly translate to the inpatient space.

In the hospital, patients begin a journey toward understanding how their illness, and the way they manage it, will affect their lives. Questions abound about medications that are new to them, lifestyle changes, when and with whom to follow up, and even clarifications about care they received that will soon become a part of their medical history (Fremont et al., 2001). Technology can provide tools to answer these questions in the context of care, when patients can resolve concerns with physicians managing their health and treatment plans. As I discuss in a comprehensive literature review in Chapter 2, understanding how computing technology can best support the presentation, reasoning about, and sharing of clinical health record data—to support patient–clinician communication—is critical for effective care and positive long-term health outcomes.

WHO BENEFITS FROM THIS CLASS OF TECHNOLOGY?
The technologies explored in this dissertation could play several roles in patients’ lives. They can provide conversational assistance by acting as references for questions, and serve as reminders and memory aids to assist patients in piecing together complicated puzzles of what their care
entailed. In many cases, they could foster a sense of progress and status in care to simply help patients cope with complex and dynamic care situations. In fulfilling these roles, they can provide the stimuli needed to spur ongoing engagement in one’s own healthcare, and, ideally, promote ongoing monitoring and management of one’s own health. However, the technologies that I describe and suggest in this dissertation might not be appropriate for all patients. Thus, clarifying who might benefit from these technologies is important in assessing the larger contribution of this work.

While patient-facing technology can act as an access point into a world of information that might otherwise be too daunting to approach, these technologies, as they are currently designed, might be inappropriate for patients who are experiencing end-of-life care, or who experience unfortunate turns in which prognoses that are expected to be manageable take an ill-fated turn. Research focused on modeling trends in progress and current status could help in determining whether patient-facing technology is beneficial given the patients’ situation. Making the technology “opt in” is also a design choice that can reduce the risk that bad news would be delivered that might exacerbate an already difficult situation.

Patients might be too sick to be expected to use technology during their care. Efforts involved in logging into software applications and touching on information—that might otherwise seem minimally burdensome—can be difficult for patients who are recovering from surgical procedures, on heavy medications, or experiencing great degrees of pain. However, these patients might still appreciate the availability of the technology, and we expect, based on the family participants in our studies, that visitors of these patients will benefit in using it to stay on top of their loved one’s care. Still, future work that captures signals from the patient without requiring effortful input (e.g., using facial recognition technology, sensors in bedding and
clothing, sophisticated skeletal tracking and voice commands) could reduce the current burden required for patients to interact with software.

It is also important to clarify that, even under ideal environmental and physical conditions, certain patients will not experience the benefits that could result from well-designed patient-facing technology. While some benefits might be experienced from presence of the technology alone (as a gesture of inclusion of and respect for the patient), patients with low self-efficacy might not perceive or act on the opportunities provided by patient-facing technology (Rimal and Real, 2003). In designing these technologies, it is important to consider previous studies of public health promotion, in which knowledge-behavior correlations increase with increased self-efficacy (Rimal, 2000).

DIRECTIONS FOR PATIENT-CENTERED TECHNOLOGY RESEARCH

Technology Research Agenda

Care Team Identification

As we found in our analysis of care team member identification in our institution’s EHR (referenced in Chapter 6) capturing accurate information about a patient’s care providers is an open research question. Prior investigators have described similar difficulties in determining such information, noting difficulties due to the frequency of shift changes and the large number of individuals participating in hospital care (McKnight et al., 2002; Patel et al., 2000). It is little wonder that patients are sometimes confused as to the names and roles of the people taking care of them. EHR vendors can help address this challenge by supplying tools for designating care team membership that are efficient and useful to clinicians; this information could be integrated with electronic processes to supporting patient transfer between clinicians supervising their care.
Emotional Sensitivity

In our studies, we collected and reflected on patient comments related to anxiety. As our studies were formative in nature, we could exercise control over when to approach a patient for enrollment in our studies, and we received guidance by clinicians to assess patients’ mental, physical and emotional fitness. When patient-facing technology is widely deployed, it will reach people in fluctuating emotional states and might deliver information that has life-altering implications. Research focused on the development and testing of automated methods for decisions about if, when, and how to present EHR information to patients, particularly considering emotional sensitivity, is a critical next step in designing effective patient-centered systems and applications.

Social Support

As we discuss in Chapter 8, peer perspectives play an increasingly important role in personal health management. They influence patients’ trust of information, offer perspectives to help them evaluate their health status and lifestyle, and aid in managing decisions about risky treatments and procedures. Much existing research examines the ways in which people currently draw on this support in online forums, blogs, and social networks. Looking ahead, opportunities are rife for computing research focused on recommending patient-contributed content based on its potential to provide peer-based psychosocial support. For example, research focused on recommending social connections, personal testimonies of illness and recovery, and peer reviews of treatments and therapies, based on similarities in patients’ lifestyle preferences, courses of illness and treatment, and wellness goals, could have a profound impact on patients’ management of illness, recovery and ongoing wellness.
Family-Centered Health Information Technology

The patients who were interviewed in our pilot study were selected based on the stability of their health condition and their ability to read and communicate in English. In situations where a patient is not physically well enough to use computers, these devices may still be beneficial if they can be configured for use by family members or other caregivers. Research focusing on how family members can access information about the care of their loved one, within clinical settings as well as remotely, is an important next step.
REFERENCES


A. Physician Documentation of Patient Status and Care Progress

A.1. Data Monitoring, Updating and Use Survey

(Responses shown after each question)

Please answer the following questions as an *Attending Physician in an ICU*

1. How long have you been an attending physician in an ICU? (in years)
   - 2.5-3
   - 21
   - 20+
   - 5
   - 2
   - 21
   - 2
   - 2-3

2. How long is your typical day in the ICU? (in hours)
   - 12
   - 12
   - 11
   - 9
   - 12
   - 11
   - 10-12 (10 SICU, 12 CTICU)
   - 10-12

3. How much time do you spend on rounds, on average, each day? (in hours)
   - 2.5
   - 3.5

4. When do you begin the Attending Critical Care Note for each patient?
   - after rounds (described "note taking" by paper, then type formal note later, typing during rounds doubles rounds time, residents are stuck in rounds...less time for pt. care)
   - before rounds collect, after rounds compose
   - handwriting during rounds, type later
   - on rounds
   - on rounds
   - on rounds (during)
   - on rounds (during) type into laptop
1. How long have you been an attending physician in an ICU? (in years)
   2.5-3
   21
   20+
   5
   2
   2-3

2. How long is your typical day in the ICU? (in hours)
   12
   11
   9
   12
   11
   10-12 (10 SICU, 12 CTICU)

3. How much time do you spend on rounds, on average, each day? (in hours)
   2.5
   3.5
   4
   4.5
   4.5
   5
   5
   7

4. When do you begin the Attending Critical Care Note for each patient?
   after rounds (described "note taking" by paper, then type formal note later, typing during rounds doubles rounds time, residents are stuck in rounds…less time for pt. care)
   before rounds collect, after rounds compose
   handwriting during rounds, type later
   on rounds
   on rounds
   on rounds
   on rounds (during)
   on rounds (during) type into laptop

5. What is your greatest challenge in composing the Attending Critical Care Note? (responses shown are coded)
   updating
   collecting, updating, typing
   typing
   collecting
   collecting
   collecting, updating
   navigating, updating
   navigating prev. notes, updating

6. How many Attending Critical Care Notes do you compose, on average, per day?
   13
   15
   16
   16
   16
   16
   17.5
   18
7. How much time elapses between the point at which you begin to compose the Attending Critical Care Note and the point at which this note is printed out for insertion into the medical record?

- 1.5-8 hours
- 1-6 hours (depends on order of visiting patients)
- 1-7 hours
- 2-4 hours
- 3 hours (typing-printing), 6 hours (note-taking on paper - printing)
- 3-4 hours
- 5 hours
- 6-8 hours

8. What is your method for recording items to include in the Attending Critical Care Note?

a) Type the note using word processing software on a laptop during rounds, revising the note later in the day
b) Write items that I will include in the note on paper and use the paper later in the day to compose an electronic copy of the note
c) Verbally record the note to be transcribed later
d) Other (please describe)
   a) (always update electronically until note is printed out, then after print out updates would be handwritten in chart 99% of time )
   a) (edit throughout day)
   a) (b is rare)
   a) b)
   a, b (a: if old patient, type fresh info, if new patient, copy/paste from previous sources including admission note and WebCIS, b: limited to X-rays review)
   b) d) remember as best as possible

9. What are your information sources for items that are inserted into the Attending Critical Care Note?

- WebCIS/Eclipsys directly, written record including previous notes, residents/PA/Nurses labs, x-ray, history, current condition of patient, day-to-day changes
- WebCIS/Eclipsys directly, written record including previous notes, residents/PA/Nurses, history, current condition of patient, day-to-day changes
- Resident oral presentation on rounds, WebCIS print out, previous notes,
- WebCIS (labs), 24-Hr Events, Physical Exam, admission history, house staff (residents, physicians), PAs Eclipsys, residents and fellows, X-rays system
- WebCIS, Eclipsys (access directly), radiology reports, oral reports from residents residents and fellows oral presentation on rounds, WebCIS, Eclipsys, X Rays, look during rounds, wheel computer around (enter orders immediately instead of after rounds)

10. If residents provide you with information that is included in the Attending Critical Care Note:

a) How often, on average, do you ask a resident a question that he or she does not have an answer to at the time that you ask?

   everyday many times, 1-2/patient/day
   almost always, 30 min out of 5 hrs of rounds
   everyday, frequently, innumerable
   30% of questions
25% for each pt. Depends on level of training, could be as bad as 30-40% frequently per pt., can't estimate
3-4 questions/pt, less experience beginning of yr 50% of Qs, end of year 20-30% of Qs
10% of total questions, depends on resident

b) How often, on average, does a resident follow up with you throughout the day to provide you with or an answer to a question that you asked at an earlier time?
1-2/patient/day
almost always
rarely
50% of the 30% unknown are answered later
frequently
frequently
3-4 x a day per resident, about 6 residents
usually follow up DURING rounds, won't finish rounds until the resident looks up the information or puts an order in for missing information, won't leave rounds until answer known

c) How often, on average, does a resident follow up with you throughout the day to provide you with the most up-to-date information about a patient?
unknown
frequently
occasionally: 1/pt/day
2/day/pt
frequently
occasionally, can't estimate
3-4 x a day, per resident
1-2 interactions w. each resident after rounds, total about 5 interactions

11. Which of the following types of updates to patient information do you think are important to review before completing the Attending Critical Care Note? Circle all that you think are important.
a) Most recently measured information (most up-to-date labs, vitals, vent settings, etc.)
b) Most irregular, abnormal or concerning information (a peak or dip that occurred at some point in the day, in a trend of measurements)
c) Most accurate information (an average value over time vs. a random measurement at one point in time)
d) Other

a, b, c
a, b, c
a, b, c
a, b, c (a: labs, physical exam, c: range, median)
a,b,c,
a,b,c, d (trend) (a: BP, hemodynamics, drips, labs; b: renal; c: in/out)
a,b,c,d (error checking in particular medications)
b, d (of most clinical importance)

12. When updating a piece of information in the note, when do you think the update should be performed? Please choose one:
a) Throughout the day, at regular intervals
b) Once before I print out the note
c) Periodically, when I think it is necessary
d) Other

a (part of patient management, when print it out, should apply to last 24 hours at that point)
b
b
b addendum to note can be written in chart
c
constant editing, each new piece of information should be entered as soon as it becomes available
d at time that information is known

13. Currently, how convenient is it to make updates to the Attending Critical Care Note that you started
during rounds after you’ve completed rounds? Please choose one:
a) Very convenient
b) Somewhat convenient
c) Somewhat inconvenient
d) Very inconvenient

a (but I have to erase, rewrite, add to note)
b b (writing) (typing is inconvenient for him)
c c, involves an addendum
d d
d (don’t do it)

14. Which of these sections of an Attending Critical Care Note contain information that you would like to
update before printing out the note, if you could do so conveniently? Please check all that apply:

Problem List 24 Hour or Current Events Physical Exam Vital Signs, Vent Mode, Labs Medications
Assessment and Care Plan
Other(s) ________________________________________________

24 Hour Events, Physical Exam, Vital Signs
24 Hour Events, Vital Signs, Meds, Assessment and Plan
Problem list, 24-Hour Events
Problem list, 24-Hour Events, Physical Exam, Vital Signs, Vent
Mode, Labs, Meds, Assessment and Care Plan
Problem list, 24-Hour, Vital Signs, *Assessments and Care
Plans
Vital Signs, Assessment and Care Plan, Other (anything that
has changed)
Vital Signs, Meds, Assessment and Care Plan should be
updated by physician (Problem list, 24 Hour or Current Events,
Physical should be updated by system)
Vital Signs, Meds, Assessment and Care Plan, Other
(diagnostic studies), (anything that has changed)

15. Currently, what is your process for remembering which specific items to update in a note, for each
patient?

by memory
by memory
handwritten notes, previous patient note, consultant’s notes
health, sickness (severity) of patient, type of problem and
severity
helps to break down what to follow up on and the order
memory, pen and paper (if given info and no laptop), go over
current and
prev. patient note
previous note (plan from previous note), memory
reference the note
use note, keep going through note at certain time intervals,
use to follow up on pertinent items
A.2. Note Data Characterization

1. Past Medical History (unstructured, or list)
   Can get from previous note, admitting note

2. Current Issues (unstructured or list)
   Can get some from previous note

3. Recent Events (unstructured or list)
   Can get from sign out sheet, verbal report, eclipsys, webcis

4. Physical (table)
   Can get from sign out sheet, verbal report

5. Vitals/Vent/Meds (table)
   Can get from sign out sheet, verbal, eclipsys, webcis

6. Impression (unstructured or list)
   Free-form text, physician composes, might consult previous day’s impression and current issues, health score

7. Care Plan
   Free-form text, physician composes, might consult previous day’s care plan, vitals, vents, etc. and impression.
A.3. Patient Note Templates

<table>
<thead>
<tr>
<th>BARCODE</th>
<th>Last, First</th>
<th>MRN.</th>
</tr>
</thead>
</table>

**ATTENDING CRITICAL CARE NOTE**

**DATE OF SERVICE:** Thursday

- LL Lobectomy
- L Bronchial Artery Embolization
- IVC Filter
- TVR/RV/PA Thrombectomy
- ECMO

**Past History:**
- admitted with SOB found to have Large RV PA thrombus and underwent TVR/Thrombectomy IVC Filter On

**Problem List:**
- respiratory failure - postoperative (518.5)
- systolic heart failure (428.21)
- cardiac rhythm disorder (427.89)
- pneumothorax (512.8)
- acute respiratory failure (518.81)

**24 Hour Events:**
- Patient is in critical condition
- drip list: Noradrenaline, Dex insulin, Fentanyl, Vasopressin, Propofol

**Physical Exam:**

<table>
<thead>
<tr>
<th>RA/SAY</th>
<th>NEURO/PSYCH</th>
<th>CVS</th>
<th>RESPIRATORY</th>
<th>GI</th>
<th>UPPER EXTREMITIES</th>
<th>LOWER EXTREMITIES</th>
<th>WOUND</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MAE bilaterally, PERRL app 3 mm bilaterally</td>
<td></td>
<td></td>
<td></td>
<td>Warm, Radial +, 3+</td>
<td>Warm, DP +, 3+</td>
<td>Warm clean, dry and intact</td>
</tr>
</tbody>
</table>

**Vital Signs, Vent Mode, Labs, Fluid Balance, Medications**

<table>
<thead>
<tr>
<th>CXR</th>
<th>EKG</th>
<th>ANTERIOR</th>
<th>POSTERIOR</th>
</tr>
</thead>
<tbody>
<tr>
<td>as stated above</td>
<td>as stated above</td>
<td>as stated above</td>
<td>as stated above</td>
</tr>
</tbody>
</table>

Figure A.3.1. Attending Critical Care Note template (CTICU) with sample data in selected fields (certain data has been expurgated).
Figure A.3.2: Data characterization linked to an expurgated Attending Critical Care Note template.

<table>
<thead>
<tr>
<th>Plan (free text)</th>
<th>Labs (table, data)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vitals/vent settings (table, data)</td>
<td>Meds (table, data)</td>
</tr>
<tr>
<td>Free text</td>
<td>Physical exam (table, data)</td>
</tr>
<tr>
<td>Free text or list (unstructured, includes data)</td>
<td>24 Hour Events</td>
</tr>
<tr>
<td>Free text or list (unstructured, free text or list)</td>
<td>Past History</td>
</tr>
</tbody>
</table>
| Free text or list | section to larger section from physicians about agreement with 3 physicians - outlined section with 3 physicians discussed needs for support in each characterisation with 3 physicians - outlined section and data

Plan of care: Evaluation and management.
Figure A.3.3. Physician-annotated progress note template (CTICU). Annotations used by physician to guide discussion during rounds.
Figure A.3.4. Physician-annotated progress note template (SICU) (annotations added to clarify related labs and their names in the EHR for benefit of researcher).
Figure A.4.1. Detailed IR architecture and interaction with activeTag components. Descriptions follow below.
Figure A.4.1 (above) depicts a schematic drawing of an information system illustrating the relationship of activeNotes with activeTags to the core IR infrastructure (originally developed by Lu et al.). The core IR infrastructure obtains a user’s specification of rules to identify automated actions to perform upon system-generated content when a user-chosen condition is satisfied. Given a user-generated command to create or manage tags, the Notes UI Processing component interacts with the Tag Event Handler to present the user with a graphical user interface to capture user input that is used to create and manage tags (stored in the Tag Set, shown above, and indexed by the Tag Manager, shown above). The rules and associated actions, given by tags, are used in formulating data retrieval criteria.

Figure A.4.2 (below) depicts a schematic drawing of an information system illustrating details of the activeTag components and the types of data passed between them. For example, based on input from the user, the Tag Event Handler updates the Tag Manager with information on the user request to add a tag, edit a tag, remove a tag, or group current tags (each of which is an example of Tag Action), and associated tag data (e.g., data in the note that the user tagged, and data retrieval preferences and conditions).
Figure A.4.2: Detailed activeTag event-driven architecture and relationship to IR architecture.
A.5. activeNotes Prototype Study Scenario Describing Fictitious Patient

Peter Jones is a 72-year-old male with a history of hypertension and diabetes. He was admitted 3 days ago for a cardiac catheterization prior to cardiac surgery. The patient has no family history of heart disease or diabetes and no prior surgical history. At home, he takes blood pressure medication, including Norvasc for hypertension as well as beta-blockers, and diuretics. The cardiac catheterization procedure showed severe multi-vessel coronary artery disease.

The cardiac catheterization resulted in cardiopulmonary arrest, requiring intubation, mechanical ventilation and pressor agents. Hypotension occurred after the first injection of dye requiring Levophed. The patient was also given Lasix for hyperkalemia.

You are now seeing this patient admitted to the ICU with low urine output, congestion and impending renal failure. He was admitted prior to open-heart surgery for management and evaluation of his clinical condition. A note was taken yesterday, (1 day post-catheterization) for the patient in the ICU by a different attending physician. You are the current attending physician and will be taking a note for the patient today, 2 days post-catheterization.

A.6. activeNotes Sample Note for Training

Task involves taking a note for today (e.g., 9-16-2008)
You are given a note for the patient from yesterday (e.g., 9-15-2008)

Attending Critical Care Note
CTICU Bed 2 (Dr. Lu)
Date of Service: 9-15-2008

PROCEDURE
Angiogram, Cardiac Cath on 9/14/08 showed severe multivessel CAD

MEDICAL HISTORY

PROBLEM LIST
Systolic Heart Failure, Renal Insufficiency, Hyperkalemia, Metabolic Acidosis

24 HOUR EVENTS
Patient is in critical condition, **Temp:** F 98.2, **Heart Rate** 110
**Chest:** Vent Settings: **FiO2** 40%, **Resp Rate** 21, **TV:** 605 ml
**Cardiac:** Arterial BP: 92/81
**Abdomen:** Bilirubin-Total 5, **Bilirubin-Direct** .5 mg/dl
GU: I/O: 1.5/1 lt. bal +500ml, U/O 25ml/hr, Input: Oral 50ml, IV 20ml, Crystalloid 50ml, No Colloid, Drips 20ml
Heme: INR: 1.3, APTT 50 sec, HHCT 45%, PLT 400k
Endocrine: Glucose 125 mg/dl, Insulin 100 units

VITAL SIGNS, VENT MODE, LABS, FLUID BALANCE, MEDICATIONS
ID: WBC 15k , Temp: F 98.2
Meds: Drips: Lasix 5ml/hr, Vasopressin 2 unit/hr, Norepinephrine (Levophed) 3 micro/min

PHYSICAL EXAM

CARE PLAN
Follow labs, monitor neuro status, continue diuresis, repeat chest x-rays, follow urine output, continue Lasix, patient pre-op for transfer to OR, planned CABG for A.M.

FACE TO FACE / TOTAL EVALUATION: 55/65 min

A.7. activeNotes User Study Script

Why you’re here – we’re focusing on ways to make composing the Attending Critical Care sheet easier. We are currently exploring features to include in a note taking application and want your feedback. We designed this prototype taking our best guess. We’d like you to share your thoughts about it while you interact with it. Speak your mind. We want to make sure it works for you.

In this scenario you’re taking a note for this patient (see Appendix A.2). Our goal is that much of the information that you’d need to assess the patient’s condition and take the note can be retrieved within the application in real time. Dr. Jordan is also standing by as a fellow who has been treating the patient.

In the activeNotes application, you will see the note taken for the patient yesterday, 1 day-post catheterization, in the panel on the right. You can begin to note items for the patient for the current day on the left. We’ve filled in some of the note for you to get you started. You can edit anything in the note on the left that you wish.

There are a few differences between this application and word processing applications like Microsoft Word. The differences follow:

- You can submit an information request for items that you usually look up in WebCIS or Eclipsys, directly from the note that you are typing, by first typing a heading or abbreviation for that information (eg. “U/O”) in the note and then pressing both the Ctrl key and the Spacebar at the same time. Once you submit an information request, you will see both database search results (e.g., data that would usually come from Eclipsys or WebCIS) as well as any text matches in the previous note. These will be shown in the Results View, the
panel on the right. Once you see results in the Results View that correspond to the information in your note, you can click on database results to add them to your note.

• You can also submit information requests to find where the term you’re searching for has occurred in the previous note. When a term generates database results and is found in the previous note, the result pane will show you the occurrences in the database and in the previous note.

• The printed out sample note shows you where the valid information requests occur. For any of these terms, you can press cntrl-space after typing the term to indicate to the system that you’d like to see information. In the note, these won’t be underlined.

  (EXAMPLE)

• Now, I’d like to introduce an important feature, tagging. Tagging is a special control that allows you to enter information in the note and treat it as a placeholder. The system will automatically insert data for that information, into the note, for you. You can set these updates in a few different ways: for a few hours (don’t know when note will be printed) or at a certain time.

• You can specify that if the database receives a value that is a certain number, or changes by a certain amount, that you be notified. You would be notified in a way of your choosing: text message, email, visual indicator inside the note.

• If you think that data that you inserted into the note might change throughout the course of the day, you can highlight the information request in the note, right click on the item, and specify that you would like the system to assist you in updating that value. You can tag an item with an update if that item was an information request.

The application can:

  o Show you an updated result in the Results View, when you manually tell it to update the information

    and/or:

  o Update the value in the note for you. If you would like the application to update the value in the note for you, it will replace the data that is currently in the note for that request. You can update the data in intervals, or at a certain time. You can also choose to update the data with a signal such as highlighted text if the information you wish to update reaches a certain value, or changes by a certain value.
Please “think aloud” as you write your portion of the note with activeNotes, so that we can learn more about what your experience using the system.

A.8. activeNotes Usage Survey

1. What is the greatest benefit of system?

2. What is a major drawback of our system?

3. In your opinion, would physicians use this? If so, why? If not, why not?

4. What additional features would need to be included to make it usable and useful to you?

5. What do you think is the least important feature in the system, if you had to pick?
6. If you had to keep a feature, what would it be?

7. What would you change in the high-level design of our system?

8. Do you think that other types of tags would be useful? For example, right now we've included update and alert control mechanisms, can you think of any other controls that you'd like?
B. Patient-Centered Information Displays in Emergency Care

B.1. Patient Display Study – Full Transcripts Given as Example Interviews

B.1.1. Interview Transcript and Example Displays for P7

Items shown in red were removed to maintain privacy.

X-X-2009 ~1PM

P7, 54F, wife + husband consented and in the room. * answers given by husband.

Obtained consent, conducted preliminary interview (before poster deployment):

R: How long do you expect to be in the ER?

* Hard to say, maybe a couple of hours

R: What is the care team waiting for right now?

* Blood work, maybe get an xray

R: How long do you think the blood work will take?

* ~1 hour

R: Did anyone tell you how long you’d be here?

No. *No

R: Did you ask the care team any questions?

* They answer questions when we ask, but she’s been here before, so we didn’t ask questions today, since we know the routine.

R: Is there anything you’d like to be more updated about while you’re here?

*There’s a lot I’d like to know, but we’ve got to find out what the condition is first. Then I’d like to know how long the visit will take.

R: How many people have been taking care of you today?
* About 12, 6 in the ambulance, 3 nurses, 2 doctors

**R:** Did you learn any of their names?

*They all introduce themselves, but it’s hard to remember all their names.

**R:** What things need to happen before you can go home today?

XRays, talk to the doctor

~1:45 PM

**Poster introduced**

[Husband did all the talking during this visit]

[Appears to be glowing] “I Love it”, “Wonderful idea”

**R:** Anything that you would you like that isn’t here

H: “medical history”.

*One very interesting point that came up during this discussion was that he had not been present for her vital measurements, so even though this might not be very informative in many cases, it was specifically very informative to him. In general, he read every character and was deeply engrossed, even though the patient was not.*

**R:** What’s most useful to you?

H: (checking poster) “Vitals….Meds” (checked the timestamps on the poster and the clock in the room, seemed to be re-orienting himself). “Knowing her vitals – I was with her when they ran the lab work, so I know that they were taking blood tests, but I didn’t see the vital signs.”
(started talking about what to add)

H: “For ‘Your Health Profile’ I see that you’ve reviewed it. But I’d like to know what did you review. Is she off- or on-target with where she’s supposed to be.”

R: If you had to choose, what one thing would you want to keep on this poster?

H: Medical Profile (as he proposed above – a bit more detail about how she is or is not on-track). Maybe Care Team. I’ve been focused on her, even when they introduce themselves. But I want to know their names.”

Husband volunteered a lot of information at this point

H: “I’d like to take this to her primary doctor – to show him what’s going on, especially with the health profile. I think she had a memory loss—some things, experiences we’ve shared together, she can’t remember. I’d like to keep something like this, and she can show it to people, to her doctors, cause she might not remember what happened.”

R: Would you share it with anyone else?

H: “I’d let my children see it, it’s nice to show family ‘What’s wrong with her’, ‘when did this go down’, I’d like a record. This is a nice profile. I love it.”

R: Anything else?

H: (Speaking for P7) Probably, “when can I go home, right?”

H: “Oh, when can I consult the physician again? I see the vital signs, that’s interesting (mentioned vitals section at least twice). I was concerned that she had a fever, cause she was vomiting. That’s interesting that her temp is normal. And now I can see that she doesn’t have a fever.”
H: “We know where we’ve been and what we done. Only thing-it doesn’t show where she was in the hospital.”

H: “Everything here has been on time, but not in the other areas (places in the hospital).”

Dr. X walked in – we excused ourselves observing from afar. Dr. X started looking at the poster, we re-entered.

Dr. X: “The complaint isn’t the whole story. You had that complaint (referring to patient) but the thing we’re really looking into is the fact that you fainted. You broke your arm when you fainted.”

Dr. X used poster to finish conversation with patient. She then took two new actions based on her views of the poster.

1. The “Health Profile” part reminded her to ask the patient if the patient had any allergies.
2. The “What’s Next” portion reminded her to tell the patient about the decision that the patient would be admitted to the hospital.

Dr. X then commented to us that the patient was a good candidate for the inclusion of a section entitled ‘Who We’ve Contacted’. In this care, two doctors were contacted on P7’s behalf.

Another tough decision involving how to present the contacted parties was discussed. Dr. X spoke with the doctor “on call” on the care team of the doctor actually listed. When we discussed how to word this to be accurate while conveying information without confusing the patient.

Dr. X [on ‘We’ve Contacted’ section] “What we’re trying to avoid is more questions”.

Dr. X [on ‘Your Vitals’ section]: “Sometimes blood pressure escalates concern”.

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During a discussion about how to phrase the information that the patient would be admitted, Dr. X suggested that, “You will be admitted to WHC” would be most appropriate.

Dr. X [on admission information]: ‘Don’t use ‘transferred’. Patients get confused when seeing different doctors and getting different procedures. They wonder if they’ve been moved or transferred to a different unit. This could be helped by these displays. And ‘Dr. X will be your inpatient doctor’ is better than ‘under care of’ which might be confusing.

~2:15 PM

Husband answering, patient heavily medicated (arm fractured, on pain meds)

R: Have you talked to family since the poster went up?

H: Yeah, I’ve been talking to family.

R: Was the poster helpful in that discussion?

H: Yes, I [used it to tell them] told them her vitals, and who was on her care team, and what went down and the reason. I was able to use the poster when I talked to them, so I told them a lot of what was on it.

R: Did you use it when talking to Dr. X?

H: Yeah, she asked about allergies when she saw the Health Profile section. She also mentioned that as a next step she’d check a defibrillator.

R: How have you been keeping track of time since you’ve been here?

H: Time doesn’t bother me, I’m more concerned with my wife.

H: (Went back to talking about family) Now, if family calls, I can tell them everything.
R: (Redirect to talk about sense of time) Are the timestamps on the poster helpful?

H: Yeah, they helped me understand where things happened (think he means ‘where’ as ‘at what point’ in visit).

R: Were the lab descriptions helpful?

H: “Yeah, especially the heart profile” (earlier when poster was brought in, he had mentioned to P7 that they had already had a heart profile lab done during their previous visit. He wondered out loud why they had performed another test and what the result would show).

R: Anything surprising to [P7]?

H: “She was surprised, it’s good for her memory. Now she knows what’s been going on. She now knows what time she had things. She might not be able to keep track.”

R: Did she look at anything in particular?

H: “She looked at the Meds section, to check on pain medication, and the Reason for Visit”.

H: “Something else I’d like to know: when will they give her the cast?”

(the patient had fractured her right arm—she and her husband were concerned about receiving care for the injury, as it was causing pain while she was in the ED. However, her care team was much more concerned with the reasons for her fall. It occurred to us that the care team’s concern, which they followed up on through phone consultations, more procedures and labs, might have been somewhat opaque to P7 and her husband. Had steps in their process to determine cause of fainting not been explained, it could appear to the patient that the care team is not in touch with her immediate concern: to have her arm set in a cast and to relieve her pain. A med student put on the cast. The attending was much more concerned with the P7’s fainting).

This exemplifies one of the differences in the mental models of ‘necessary care’ between patient and physician.
R: If you had a pen and could write on the poster, would you write anything down? Any questions for the care team?

H: Maybe profile info, still “room to grow” (not sure H understood the question).

H: I’d like phone numbers to contact people, a number to follow up with.
Figure B.1.1.1. One instance of P7’s poster shown during interview.

~3:42 PM
Med students also commented to us that they really liked the poster.

H mentions his intentions to fill in family. Mentioned that care providers commented that it was nice. H asked for a paper copy of the poster to take home with him.

Figure B.1.1.2. Next instance of P7’s poster shown during interview.
~5PM

H: *(Approached us at our work stations)* I like the completed section, I like that you list things, like EKG, but I want to see what was ‘done’. *(think he means, what the result was)*.

P7: *(now lucid, but not in a position to comfortably read the poster after her cast was set)*: “I like it”.

R: Do you have a favorite section?

P7: “I like the whole board”.

---

**P7 Demographic Info (Conducted prior to poster interview)**

**What do you do?** Housewife

**Highest ed?** 7<sup>th</sup> grade

**Cell phone?** Every day

**Computer?** No

**How long do you expect to be here?** 2 days
B.1.2. Interview Transcript and Example Displays for P3

No visitors in room.

We started interacting with this patient when the “comments” field had already been assigned as “HOT”, meaning the patient was awaiting transfer to the Heart Observation and Treatment unit. This meant that very few subsequent updates would take place, that the patient might be leaving soon, and that – on red team – the patient might be moved into the hallway, we decided to do an 8.5 x 11 instead of a full poster. In fact we had plenty of time with the patient and she was not moved out of her room, but the 8.5 x 11 worked fine for this case. It also was much easier to do given that the attending was supportive but very busy, so it was convenient that we only had to do a single check on everything and did not disrupt the red area at all.

~ 5:00PM

**R:** How long have you been here?

**P:** “Since two o-clock” [pm]

**R:** How long do you expect your visit to take?

**P:** “I’ll be here overnight. (The doctor preferred if I stay, but told me it was okay to go home; I chose to stay to be safe).”

**R:** What is the care team waiting for right now?

**P:** “Waiting for a bed upstairs”. [in HOT]
[The following quotes are not in response to verbal questions, but are in response to seeing an example handout shown during the consent process. Recorded after consent but before receiving her own handout]

P: “Doctors use big words and you don’t really understand what they’re talking about. I want to know why I have the same symptoms, they give you an x-ray and send you home, but then you have to come back”.

P: “I could put it on my computer” [unprompted, before any discussion of technology at all].

You could send them home in letters or on the computer”

**R:** What questions have you had for your doctors today?

P: “Are the gonna keep me?”, “Is that my blood pressure?”, “Why is that needle so big?”, “Can I eat yet?”, “What’s your name again? (They did tell me their names, but was in too much pain to remember.) “

*This is especially interesting, since later conversations showed her to have an amazing memory and even remembered our names.*

**R:** How many people are on your care team today?

(Came by ambulance, there were 6 people at my house, 3 doctors (2f, 1m), one nurse (f) (“doing a great job”), EKG tech [interesting that she remembers so many roles and no names]

**R:** Who did your initial physical exam?

P: “A male doctor who went home.”

**R:** What is your care team waiting for right now?

P: “Trying to find a bed for me.”

**R:** Do you know how long that will take?

P: No.
R: Have you been updated enough today?

P: Yes.

R: Have you spoken with anyone outside the hospital today?

P: “Haven’t called anyone, haven’t had access to a phone”.

P: “Faster than most hospitals, jumped right on it, pleased with staff”. [generally satisfied with her care]

Figure B.1.2.1. Initial handout provided to P3.

**Interview along with initial handout**


~5:30PM

[The following quotes were not verbally prompted, were in response to the 8.5 x 11 handout]

P: “This is perfect. This tells me something I didn’t know, where they were transferring me to. This is great.”

R: What is most useful to you?

P: “‘What’s next’ is the most useful. They only told me I’d be ‘here’, didn’t know where I was going to be. I’ll share this with all the senior citizens in my neighborhood. They don’t know what medicines they get in the hospital.”

R: Anything else it is useful for?

P: “Something like this I can take to my primary care physician”

R: Is there anything missing?

P: “I would have wanted to know why blood was drawn. Most of the time when they draw blood they don’t tell you why. Doctors and nurses are busy, get tired of answering questions, this cuts back on the questions.”

[Interesting how patients are really very sympathetic with the staff’s level of business]

[Generally glowing with enthusiasm, said “that’s great” many times]

R: Anything else you’d like that isn’t here?

P: “I’d want it laminated, or in a folder, so I can keep it safe when I go home”.

R: Is there any information here that’s uncomfortable?

P: “No.”

R: Would you be okay with having this up on a poster?

P: “No, my business is my business. People in my neighborhood would know what happened to me before I got home.” (prefers not having name on the handout) [it’s not]

P: “I’m amazed. This is great, this is something. My pain was coming back and I was wondering why, now I see how long it’s been since my last dose of medicine and I know why.”
Figure B.1.2.2. Final handout provided to P3.

**Final interview, accompanying two minor updates: name of receiving physician @ HOT.**

“For further observation”

~6:30 PM
Patient noticed and commented immediately on both minor updates.

P: “This is great. I always want to know why doesn’t the doctor let me know what’s going on? What’s going on right now?”

R: Anything you’d like to be different?

P: “Smaller laminated card, like to put in your bill folder.”

R: “Like a medical alert bracelet.”

P: “Got it to a ‘T’”.

R: Anything on here that you didn’t know already?

P: “Times are new. I can’t really pinpoint times.”

[Saw how long it had been since a previous dose of a medication]

R: Did you show this to anyone?

P: “I showed it to [patient named her nurse]”

[Interesting that she now referred to her by name, but couldn’t before].

P: “This is useful to give feedback about specific docs, and people on care team members.”

[could improve hospital feedback process, useful for surveys].

P3 Demographic Interview

Age: 42

Occupation: unemployed

Highest level of education: high school (12th grade)

Have a cell? Yes

How often do use your cell? Almost never. Once a month.

Have a computer? Yes
Use it frequently? Yes

What for? Games and music, no Internet

Use a computer anywhere other than home? No
B.2. Physician Survey

Patient A – A 52-year-old male, visiting the ED complaining of chest pain that has increased over the last three days. Patient is visiting the WHC ED for the first time. Blood pressure in normal range and labs: CBC with DIFFI, Heart Profile, and D-Dimer all returned values within normal range.

The image, Poster A, shows an example of a Patient Information Display that would be shown to the patient on a large computer screen during the course of their visit to the ED. Patient A has privacy controls at his bedside to turn the screen on and off and has agreed to use the screen for his visit. The information display updates as new information becomes available (for example, the ‘What’s Next’ section may initially have contained information such as ‘Bloodwork labs will be ordered’, ‘Dr. [removed] will review the results of your labs’, etc. Sections may change to represent content as it is known, for example ‘We’ve Completed’ might have been labeled ‘Pending’ as the event was in progress (e.g., as patient was waiting to see a doctor for a physical exam).

Please answer the following questions about Poster A.
1. Which section of the information display (indicated by purple heading, e.g., “Your Health Profile”, “Vitals”, etc.) do you think Patient A will find most useful? If you think that several would
be important to the patient, please list the sections in order of importance.

2. Please briefly explain your reason for selecting important sections.

3. Are there sections of the information display that you are concerned about showing to Patient A? If so, which sections? Why are you concerned about showing these sections to the patient?

4. For the following sections, please indicate whether or not you would share the following information with Patient A on the information display for the patient (noting the patient has privacy controls):

Labs – Bloodwork

- Names of labs that have been ordered (e.g., ‘Basic Metabolic Panel’, ‘CHEM8’, ‘Liver Function Tests’)
  [ ] Before or after speaking with patient
  [ ] Only after speaking with patient
  [ ] I wouldn’t share this information (please explain reason below)

- Time at which specimen was sent to laboratory
  [ ] Before or after speaking with patient
  [ ] Only after speaking with patient
  [ ] I wouldn’t share this information (please explain reason below)

- Time at which lab results were returned from laboratory
  [ ] Before or after speaking with patient
  [ ] Only after speaking with patient
  [ ] I wouldn’t share this information (please explain reason below)

- Quantitative lab results without descriptions of ‘normal’, ‘abnormal’, ‘high’, or ‘low’ (e.g., “Complete Blood Count: Hemoglobin: ”)
  [ ] Before or after speaking with patient
  [ ] Only after speaking with patient
  [ ] I wouldn’t share this information (please explain reason below)

- Descriptions of lab results, in the form: “Elevated BUN”, “Low Hemoglobin Level”, “Elevated Potassium”, or “High Potassium”.
  [ ] Before or after speaking with patient
  [ ] Only after speaking with patient
[ ] I wouldn’t share this information (please explain reason below)

Time at which lab results were reviewed by a physician
[ ] Before or after speaking with patient
[ ] Only after speaking with patient
[ ] I wouldn’t share this information (please explain reason below)

For the following sections, please indicate whether or not you would share the following information with Patient A on an in-room information display for the patient, which the patient could control for privacy:

**Vitals signs (Blood Pressure, Respiratory Rate, Heart Rate, O2 Saturation, Temperature)**
Measurements of vital signs at time of triage
[ ] I would share this information
[ ] I would not share this information (please explain reason below)

Measurements of vital signs, updated periodically
[ ] I would feel comfortable sharing this information
[ ] I would not share this information (please explain reason below)

**Your Health Profile**
Aspects of the patient’s medical history that you have noted and may relate to the current complaint, and/or current findings (e.g., “Your care team has noted a history of hypertension” or, “You care team has noted previous cardiac stents”)
[ ] I would feel comfortable sharing this information
[ ] I would not share this information (please explain reason below)

**Medications (given in the Emergency Department)**
Names of medication given
[ ] I would share this information
[ ] I would not share this information (please explain reason below)

Reason medication was given (e.g., “for pain”, “to control blood pressure”)
[ ] I would share this information
[ ] I would not share this information (please explain reason below)

**Care providers who have been contacted or consulted**
Names of care providers who were contacted
[ ] I would share this information
[ ] I would not share this information (please explain reason below)

Care team contacted (e.g., ‘The Oncology team at WHC’, ‘The on-call physician on the Oncology team’)
[ ] I would share this information
[ ] I would not share this information (please explain reason below)

Reason care provider was contacted
[ ] I would share this information
[ ] I would not share this information (please explain reason below)

Wait time estimates for common procedures and labs (e.g., CT Scan, Chest X-Ray, time before physician conducts a physical exam)

Time estimates for time until the procedure begins
[ ] I would share this information
[ ] I would not share this information (please explain reason below)

Time estimates for time until the procedure results are available to the physician
[ ] I would share this information
[ ] I would not share this information (please explain reason below)

Time estimates for time until the procedure results are reviewed by the physician
[ ] I would share this information
[ ] I would not share this information (please explain reason below)

If you could add your own section, what would you add? Please be as specific as possible.

Which section do you think the patient will find the least useful? Why?

Do you think that the word choices and phrasing used in the information display, describing the patient’s visit, should change? If so, what headings or information items would you change? How would you change them?

Does the information display match the topics and level-of-detail that you typically discuss with the patient? How does it follow or differ from the way in which you structure your discussions with patients?
Do you think that the information on the display is currently too detailed? Or not detailed enough?

Please write on the sample information summary to comment on each section. What do you consider important to keep in mind when designing each for an in-room information display?
B.3. Physician Survey Data

Q1

"Which section of the information display (indicated by purple heading - e.g., "Your Health Profile", "Vitals", etc.) do you think Patient A will find most useful? If you think that several would be important to the patient, please list the sections in order of importance."

P1

Vitals

Medications

PMH

P2

Current Status

What's Next

We've Noted

We've Completed

P3

Labs

Care Team especially nurse

We've Noted

P4

What's Next

We've Completed

Current Status

P5

Your Care Team

Your Profile

Vitals

Reason For Visit

P6

Time to expected disposition

Location of bathroom, phone, visitors

Your Visit

P7

Visits

Your Profile: Vitals, Health Profile

Reason For Visit

P8

We've Noted

We've Completed

Current Status

P9

We've Contacted

Your Care Team

Reason for visit

P10

We've Completed

We've Noted

What's Next

Current Status

P11

Whether they can eat (later said: Important)

Have visitors

How long they will be here

P12

How about past medical history? Especially that which is relevant to the patient. Please list the medications especially if they are of present concern or interest."

P13

1. Vitals

2. Medications

3. PMH
Q1. Which section of the information display (indicated by purple heading - e.g., “Your Health Profile”, “Vitals”, etc.) do you think Patient A will find most useful? If you think that several would be important to the patient, please list the sections in order of importance.

P14. Your Health Profile

Current Status, What’s Next

Results

We've Completed, We've Contacted

P15. Vitals

Reason for visit

Instructions about CC/medications they are taking

P16. Current Status, What’s next

Vitals

We've completed - results

P17. What's Next

We've completed, We've contacted

P18. All

Vitals

Reason for visit

P19. Reason for visit

Blood Pressure

P20. Medications

Is there a way to display the medication list they are on or tab to a separate screen? That way patients could add, way patients could add, lab to a separate screen? That medicaton list they are on or lab to a separate screen? That medicaton list they are on or lab to a separate screen? That medicaton list they are on or

P21. Current Status

What’s Next

P22. Results

We've completed.
Q2: Please briefly explain your reason for selecting important sections (most useful sections mentioned by participant)

P11

Patients are obsessed with blood pressure readings

P16

Everybody wants to know their BP and the trend

P10

remind the patient why they are here and the questions to be answered

P17

To make sure the RN, MD is addressing their concerns correctly.

P13

I think that the attending MD is aware of the past experiences that may impact

P19

I like how the medical history is not listed, it just states that we have reviewed it.

P18

everybody wants to know their BP and the trend

P20

vitals can be helpful but honestly we'll be in the room explaining what each one means. Normal

P11

Chief compliant can be vague and already established, so to have it displayed is not as important (in my view) as other info like vitals & health profile

P21

Chief complaint can be vague and already established, so to have it displayed is not as important (in my view) as other info like vitals & health profile

(All) Vitals, Medication, PMH

Your Profile:

(Recommended: PMH)

I think that the attending MD is aware of the past experiences that may impact

(Vitals, Reason For Visit)

Remind the patient why they are here and the questions to be answered

(Vitals, Recommended: Medication Info/Ed)

Point of discussion for patient

(Recommended: interactive med list)

Vital signs can be helpful but honestly we'll be in the room explaining what each one means. Normal

(Recommended: Past Medical History)

I think that the patient are reassured in knowing that the attending MD is aware of the past experiences that may impact

(All) please explain how the medical history is not listed, it just states that we have reviewed it.

(Vitals, Current Status, What's Next)

To make sure the RN, MD is addressing their concerns correctly.

(Blood Pressure, Reason For Visit)

remind the patient why they are here and the questions to be answered

(Recommended: Past Medical History)

I think that the patient are reassured in knowing that the attending MD is aware of the past experiences that may impact

(All) please explain how the medical history is not listed, it just states that we have reviewed it.

(Vitals, Current Status, What's Next)

To make sure the RN, MD is addressing their concerns correctly.

(Blood Pressure, Reason For Visit)

remind the patient why they are here and the questions to be answered

(Recommended: Past Medical History)

I think that the patient are reassured in knowing that the attending MD is aware of the past experiences that may impact

(All) please explain how the medical history is not listed, it just states that we have reviewed it.

(Vitals, Current Status, What's Next)

To make sure the RN, MD is addressing their concerns correctly.
These provide the information the patients most frequently ask in the ED. What's the next step? And will I be admitted or will I go home?

Seems that patients are least informed about what is to happen next and they complain about being in the dark.

I think it makes patients feel secure when they know what is about to happen, and of who they are "allowed" to ask questions. Also, I think they feel more secure when they know that their doctor is on the case.

'What's Next' provides the patient an idea of the process and why they may be waiting.

People want to know what they are waiting for. People become frustrated when their expectations aren't met. This tool can help guide expectations.

Patients often want to know where we are in the workup and what is the final disposition. They also meet so many providers that they often cannot recall names or services and would find the care team tab very helpful.

Entire 'Your Visit' section seems to be useful to a patient. Considering other tools of this type, time till expected disposition would be helpful.

Keep patient informed of progress of workup. I think all of the sections are good, especially the photos of who will be taking care of them - it empowers the patient. Location of bathroom, phone; visitors would also be helpful.

Logically this order seems to work best in my mind because this is same order I use to communicate plans/strategies to patients.

Entire 'Your Visit' section (Vitals, Health Profile, Reason For Visit) (3) (Recommended own sections, Care Team) I think makes patients feel secure when they know what is about to happen, and when.

Reason For Visit, Vitals, Current Status, What's Next (3) (Recommended own sections, Care Team) Seems that patients are least informed about what is to happen next and they complain about being in the dark.

People want to know what they are waiting for. People become frustrated when their expectations aren't met.

This tool can help guide expectations. They also meet so many providers that they often cannot recall names or services and would find the care team tab very helpful.

Current Status, What's Next, Where's Next (current status), Your Care Team (2) (Recommended own sections, Care Team) Seems that patients are least informed about what is to happen next and they complain about being in the dark.
<table>
<thead>
<tr>
<th>Page</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>P3</td>
<td>We've Noted tells pt what is important to F/U</td>
</tr>
<tr>
<td>P18</td>
<td>(Recommended: PMH) Perhaps also one full list of meds (for the same reason given above) — I think that the pts are reassured in knowing that the attending MD is aware of the past hx/events that may impact work-up and treatment of their presenting symptoms</td>
</tr>
<tr>
<td>P20</td>
<td>(Recommended: Medication Info/Ed) Use as opportunity to teach Vitals, (Recommended: Interactive medication list) Medications/allergies are something that frequently impacts care and pt can clarify. We've Noted (1) That way patients could add medication or remove medications from the list (by telling their care team).</td>
</tr>
</tbody>
</table>

Medications (4)

<table>
<thead>
<tr>
<th>Page</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>P13</td>
<td>(Recommended: PMH) Perhaps also one full list of meds (for the same reason given above) — I think that the pts are reassured in knowing that the attending MD is aware of the past hx/events that may impact work-up and treatment of their presenting symptoms</td>
</tr>
</tbody>
</table>

Vitals, (Recommended: Interactive medication list) Medications/allergies are something that frequently impacts care and pt can clarify. We've Noted (1) That way patients could add medication or remove medications from the list (by telling their care team).
<table>
<thead>
<tr>
<th><strong>Q3:</strong> Are there sections of the information display that you are concerned about showing to Patient A? If so, which sections?</th>
</tr>
</thead>
<tbody>
<tr>
<td>None (7)</td>
</tr>
<tr>
<td>None. It's their information. The only problem is confidentiality in shared patient rooms.</td>
</tr>
<tr>
<td>None.</td>
</tr>
<tr>
<td>None.</td>
</tr>
<tr>
<td>None. It will drive accuracy.</td>
</tr>
<tr>
<td>None.</td>
</tr>
<tr>
<td>None objections to any sections. However, if status suggest that patient workup is completed (i.e., admitted or to be discharged) it puts greater pressure on Attending (if they get side-tracked (?) trauma, resuscitation or sicker patient) to expedite dispo. just a thought.</td>
</tr>
<tr>
<td>I would not be concerned showing any of above sections</td>
</tr>
<tr>
<td>None.</td>
</tr>
<tr>
<td>None.</td>
</tr>
<tr>
<td>None. It's their information. The only problem is confidentiality in shared patient rooms.</td>
</tr>
<tr>
<td>None (7)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Reason for Your Visit</strong> (1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The vitals need a normal range for reference. I wouldn't time stamp labs as often there are problems with the labs.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>We've Noted</strong> (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Out of curiosity - why is the RN's last name not displayed?</td>
</tr>
<tr>
<td>We've noted - only concern is that patients without medical knowledge not know how to read or understand (?) labs. For example glucose 215 reading high, that being on the screen may cause some people to over-react.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Reason For Your Visit</strong> (1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reason for visit is captured by quick reg clerk, often misspelled and wrong. I would delete it.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Vitals</strong> (1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>It could become very time consuming although I do think it has value. Who will be responsible for keeping the information up to date on a moment by moment basis?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>No categories named, other concerns (2)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>We've noted - this might inspire more anxiety (ie more questions) for the patient. What does ‘noted’ mean? Do I have the disease? Is this...</td>
</tr>
<tr>
<td>Who will be responsible for keeping the information up to date on a moment by moment basis? The we've noted section is concerning b/c how does this get populated? If something concerning pops from the chart and you haven't had a chance to look to the patient I would be upset. Bad news should be given in person.</td>
</tr>
<tr>
<td>None (7)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>We've Noted</strong> (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>None (7)</td>
</tr>
<tr>
<td>Why are we doing about what we noted?</td>
</tr>
<tr>
<td>My diagnosis? What are we doing about what we noted? None (7)</td>
</tr>
<tr>
<td>None (7)</td>
</tr>
<tr>
<td>None (7)</td>
</tr>
<tr>
<td>None.</td>
</tr>
<tr>
<td>None.</td>
</tr>
<tr>
<td>None.</td>
</tr>
<tr>
<td>None.</td>
</tr>
<tr>
<td>None (7)</td>
</tr>
</tbody>
</table>
### Lab Info

#### P7

The specific names of tests and the result. I don't think pts would understand this and could get confused. Example: false elevation "why did you do a test that you don't trust" Example: Normal (T/I)N - "But its normal?"

#### P10

The interpretation of lab defined as normal vs. abnormal without clinician input or review. Context is very important. For example, d-dimer inadvertently sent-abnl but other cause identified - pneumonia by CXR (chest X Ray?)

### Medications

#### P14

Medications: helpful for dis/nurse - are these patients drug seeking? Want pain shot - can give Tylenol but if see on screen then problems.

#### P15

Labs - normal, abnormal - many are insignificant abnormalities that could require lengthy discussions.

#### P17

Also, if there is a significant delay between when current status reads "MD will review your labs" and patient is informed of lab results because...we're busy with other patients, will the lab results cause problems/complaints?

#### P18

What time shows up under "complete" for labs as back. Concerned that patients may begin to pick about what time or start seeking out the MD without realizing...time of meds might have on time of labs - suggests what is normal or abnormal (L: associating this with labs)

#### P21

Time of meds - might have on time of labs. The interpretation of the status as normal or abnormal vs. abnormal which could lead to review. Context is very important. For example, d-dimer isn't always normal. You do a test that you don't trust. Example: Normal (T/I)N - "But its normal?" labs (amounts of labs and the result I don't think pts would understand this and could get confused. Example: false elevation with did...
C. Custom Personal Health Record Portal Studies

C.1. Patient Satisfaction and Engagement Survey

<table>
<thead>
<tr>
<th>Question</th>
<th>P1</th>
<th>P2</th>
<th>P3</th>
<th>P4</th>
<th>P5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  In general, I am satisfied with my care.</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>2  I am more involved in my care than before my hospital stay.</td>
<td>4</td>
<td>5</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3  This hospital stay has helped me to better manage my health and</td>
<td>5</td>
<td>5</td>
<td>2</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>medical needs.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4  This hospital stay has helped me monitor my health condition.</td>
<td>4</td>
<td>5</td>
<td>3</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>5  My health care team uses information I provide to them.</td>
<td>4</td>
<td>5</td>
<td>5</td>
<td>N/A</td>
<td>5</td>
</tr>
<tr>
<td>6  I follow my health care team’s advice better since this hospital</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>stay</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7  I can explain my medical problems well enough.</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>8  My health care team answers my questions.</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>9  My health care team deals with my problems.</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>10 My health care team engages me in my care.</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>11 Most of the time I know who my nurse is.</td>
<td>3</td>
<td>5</td>
<td>4</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12 Most of the time I know who my resident physician / PA is.</td>
<td>4</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>13 Most of the time I know who my attending physician is.</td>
<td>3</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td><strong>Perceived Use and Usefulness Scale</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 The computerized tablet is easy to use.</td>
<td>4</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15 I can always trust the computerized tablet to work.</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>16 It was easy to learn to use the computerized tablet.</td>
<td>4</td>
<td>1</td>
<td>4</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>17 Using the computerized tablet is as satisfying as talking to a</td>
<td>4</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>N/A</td>
</tr>
<tr>
<td>member of my health care team.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18 My health care team can get a good understanding of my medical</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>problems from the computerized tablet.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19 My privacy is protected during my use of the computerized tablet.</td>
<td>4</td>
<td>5</td>
<td>.</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>20 The lack of interaction with my health care team when I use the</td>
<td>3</td>
<td>5</td>
<td>2</td>
<td>5</td>
<td>N/A</td>
</tr>
<tr>
<td>computerized tablet is not a problem.</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Description</td>
<td>Rating Scores</td>
<td></td>
<td></td>
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<td>-----------------------------------------------------------------------------</td>
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<td>---</td>
</tr>
<tr>
<td>21</td>
<td>The computerized tablet is a convenient way to deliver my health information to me.</td>
<td>4 5 5 5 N/A</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Using the computerized tablet saves me time.</td>
<td>4 5 4 N/A N/A</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>Using the computerized tablet makes it easier for me to contact my health care team</td>
<td>4 5 4 4 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>My medication information</td>
<td>4 5 5 5 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>Name of my health care team members</td>
<td>4 5 5 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>Pictures of my health care team members</td>
<td>4 5 4 5 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abbreviation</td>
<td>English</td>
<td>Examples</td>
<td></td>
<td></td>
<td></td>
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<td>--------------</td>
<td>---------</td>
<td>----------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>qnh</td>
<td>Every n hours</td>
<td>“q12h” - (9,21)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Every 12 hours, at 9am and 9pm</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>“/^[0-9]<em>$/&quot;, &quot;/^[0-9]</em>$/&quot;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>(then check for hours, minutes, or weeks)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>qn min</td>
<td>Every n minutes</td>
<td>“q15 min”</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Every 15 minutes</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>“/^[0-9]<em>$/&quot;, &quot;/^[0-9]</em>$/&quot;</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>(then check for hours, minutes, or weeks)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>bid</td>
<td>Twice a day</td>
<td>“bid” - (9,17)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Twice daily: 9am and 5pm</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>“/^[0-9]<em>$/&quot;, &quot;/^[0-9]</em>$/&quot;</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>(then check for hours, minutes, or weeks)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>bedtime</td>
<td>At bedtime</td>
<td>Bedtime (Adults) 9pm</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>At bedtime, around 9pm</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>“/[^bedtime*]/&quot;, /[^Bedtime*]/”</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>(then check if time present)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>qam</td>
<td>Every morning</td>
<td>qam 6am</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Every morning at 6am</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>“/^[0-9]<em>$/&quot;, &quot;/^[0-9]</em>$/&quot;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>(then check if time present)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>qpm</td>
<td>Every evening</td>
<td>qpm 6pm</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Every evening at 6pm</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>“/^[0-9]<em>$/&quot;, &quot;/^[0-9]</em>$/&quot;</td>
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<tr>
<td></td>
<td></td>
<td>(then check if time present)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>qid</td>
<td>Three times a day</td>
<td>qid q6h</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Four times daily, 6 hours apart</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td>“/^[0-9]<em>$/&quot;, &quot;/^[0-9]</em>$/&quot;</td>
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<td></td>
<td></td>
<td>(then check times)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>qod</td>
<td>Every other day</td>
<td>“qod”</td>
<td></td>
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<td></td>
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<tr>
<td></td>
<td></td>
<td>Every other day</td>
<td></td>
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<td></td>
<td></td>
<td>“/^[0-9]<em>$/&quot;, &quot;/^[0-9]</em>$/”</td>
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<td></td>
<td>(then check if time present)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ac</td>
<td>Before meals</td>
<td>“ac” - (8,12,17)</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Before meals, around 8am, 12pm, and 5pm</td>
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<td></td>
<td></td>
<td>“/^[0-9]<em>$/&quot;, &quot;/^[0-9]</em>$/&quot;</td>
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<td></td>
<td>(then check times)</td>
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</tr>
<tr>
<td>pc</td>
<td>After meals</td>
<td>“pc” - (9,13,18)</td>
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<td></td>
<td></td>
<td>After meals, around 9am, 1pm, and 6pm</td>
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<td></td>
<td>“/^[0-9]<em>$/&quot;, &quot;/^[0-9]</em>$/&quot;</td>
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<td></td>
<td></td>
<td>(then check times)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>prn, ad lib</td>
<td>As needed</td>
<td>“prn”</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>As needed</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>“/^[0-9]<em>$/&quot;, &quot;/^[0-9]</em>$/”</td>
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<td></td>
<td></td>
<td>(then check times)</td>
<td></td>
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<tr>
<td>Continuous</td>
<td>Continuous drip</td>
<td>Continuous drip</td>
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<tr>
<td></td>
<td></td>
<td>Continuous drip</td>
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<td>“/^[0-9]<em>$/&quot;, &quot;/^[0-9]</em>$/”</td>
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<td></td>
<td>(then check times)</td>
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</tbody>
</table>
C.3. Thematic Coding of Patient Interview Responses

Information Needs
• Restrictions on Info (end of life)
• Understandability/Health Literacy considerations
• Progress (of care)
• Discharge instructions
• Medications- generic/brand names
• Labs
• Care Team (doctor, PA, nurse)
• Insurance info (cost)
• Procedure/operation details
• Appointments
• Condition explanation
• Nutrition
• Medical History
• How to use instruments (e.g., spirometer)
• What to expect
• Location (map)

Usability (Ease of Use)
• Incomplete information/functionality (e.g., staff names, photos)
• Wi-fi difficulties
• Navigation and discoverability of information
• Confirmation of input
• Correctness of data/accuracy
• Help finding terms (e.g., locations of body)
• Device ergonomics
• Simplicity of language (layman’s terms)
• When to check for a response or new information

Communication of Patient-Documented Information
• Temporal
• Form (face-to-face versus electronic)
• Response and confirmation
• Clinician burden
• Scope (sharing with individuals vs. care team)
• Post-discharge communication

Engagement (in health)
• Keeps an electronic personal health record
• Medical Record file at home
• Looks-up health information online
• Knows health conditions
• Knows medications and medication purpose
• Who manages the patient's care
• Preferences for inpatient awareness
• Asks questions of care team

Use
• Frequency of use
• Duration of use
• Other (non myNYP activities)
• Planned use
• Situational use
• User (patient vs. family)

Access (Availability)
• Privacy
• Where
• When/how long
• Print it out
• Access to whole record

Usefulness (Value)
• Is it helpful?
• Awareness
• Communication benefit
• Information benefit
• Pain score
• Learning
• Patient Satisfaction
• Saves time
• Conditional usefulness (to some people & circumstances)
• Not useful

Suggestions
• Reviews / Favorites
• Way-finding/mapping
• Complaint Feedback
• 'What's normal'/What to expect
• Entertainment (movies, games)
• Progress reports (test feedback like x-rays and INR)
• Plan of Care
• Medical History

C.4. Observation and Interview Guide

Observe how patients use myNYP Inpatient for 5 minutes and take notes. Look out for:
• How they navigate through the application
• How they interact with each page
  o What do they tap on?
  o Do they stay on one page longer than another?
• Note any questions they have while using the application.
• Any areas of confusion
  o Do they have trouble getting back to the home screen?
  o Do they try to tap on things that aren’t links?
  o Do they miss key parts of the application?

*If necessary guide them through parts of the application, but make note of this and ask them if they find it confusing.

Interview Questions

User Background:

1. What is your age? Record sex as well.

2. What is your profession? Level of education?

3. Do you know your medical conditions? Do you know your medications and what they do? How knowledgeable would you say you are about your health?

4. Do you have a smartphone? How much time do you spend each day using the internet or apps on your smartphone on average?

5. Do you have a desktop or laptop computer? Do you have internet on your computer? How much time do you spend each day on your computer on average?

6. Do you have a tablet computer? How much time do you spend each day on your tablet on average?

7. Do you have a personal health record? Who do you use it for (self, children, parents)? How frequently do you use it?

8. Do you look up information about your health online? What websites do you use?

General Inpatient PHR Questions:

1. What do you think about patients receiving an inpatient personal health record like the one you used?

2. What information do you think patients would like to see while they are in the hospital?

3. What information should patients not have access to?

4. What questions have you asked your doctors while in the hospital? What do you think about patients being able to ask questions or make comments to their care team in the application? Is this useful?
5. Should this be one-way or two-way communication? (ie should the patient send messages in which a member of the care team responds in person, or should patients and the care team communicate electronically through the application).

6. What do you think about patients entering their own pain scores? Could this replace the scores recorded by nursing?

7. Patient’s will still have access to their records when they leave, but how long should patients have access to the special features of the inpatient PHR, such as staff profiles or ability message with your team, after the hospital stay?

Questions about myNYP Inpatient:

1. What do you think about the myNYP Inpatient application?

2. What was most useful about the application? What was least useful?

3. What do you think if anything is missing from the application? What do you wish we had included?

4. Was it easy to find what you needed? Did you find navigating through the application confusing?

5. Was the information accurate?

6. What did you think about x (care team, hospital medications, allergies, home medications, notepad, pain)? What would you add or change to them? *(If they did not use it, show it to them and ask for their opinion)*

7. Was the text the right size? How was it entering notes on the iPad?

8. How much time would you say you spent looking at the application? What else did you use the iPad while you had it? *(We want to get a sense of what patients might use iPad for apart from our application)*
D. Micro-Explanations

D.1. Patient Survey

Feedback About Lab Test Explanations for Patients

Introduction

Thank you for participating in our study. This study will help us develop a system that can provide explanations of lab tests to patients while they are receiving care in a hospital. In order to develop such a system, we need insights about what you think makes a good, patient-friendly explanation.

In this study, you will be asked to read background information about two patients who visited an Emergency Department (for privacy, these patients are not real individuals, but are based on real populations). After each patient’s information summary, you will see a list of lab tests ordered for the patient. For each lab test, you will see a list of several possible explanations that might be provided to the patient to help him or her understand why this test was ordered.

After reading each explanation, you will be asked to rate the quality of the explanation, based on how helpful you would find the information, if you received it during care in a hospital. We ask that you try to imagine that you are the patient described in each profile, and draw on your experiences receiving care in rating the helpfulness of each explanation. You will be asked to comment on your reasons for the rating that you give to each explanation.
Using the survey software

This survey is expected to take about an hour to complete. If you’d like to take a break from the survey, you may close the page and revisit the survey at a later time. Your progress is saved automatically whenever you click the "next" button, so if you need to take a break, be sure to finish the page you're on before stopping. Compensation will be offered only to those who complete the survey. You must also be a U.S. Citizen or Permanent Resident to receive compensation.

D.2. Instructions for Non-Physicians

Please read the following background information on Patient 1, which is followed by a list of lab tests ordered for this patient. The list does not represent the entire set of lab tests and procedures ordered, but reflects the set of lab tests that you will be commenting on.

You are not expected to be familiar with these lab tests. In fact, we're trying to understand how to best explain lab tests to patients who might not be familiar with medical terminology, so it's just fine if you've never seen these terms before.

Below this list of lab tests (starting on the next page), each lab test will be given again, with a list of explanations pertaining to the purpose of the lab test for each. Please rate, on a scale of 1-5, the quality of the explanation based on its appropriateness for the patient. Please also provide the reason for your rating.

(Half of the non-physician study participants were shown Form A, the other half saw Form B. Each form shows a unique patient profile, list of labs, and corresponding explanations. All other instructions were the same).

Form A
Patient 1
A 53-year-old male presents with chest pain, shortness of breath, and tingling in both hands. He has a history of anemia (a condition in which the blood lacks enough healthy red blood cells, causing fatigue). He has also undergone successful treatment of cancer, originating in his right colon.

Treatment included surgery and chemotherapy, and the patient is currently in remission. He denies taking medication at home, and he is allergic to sulfa drugs. His blood pressure (184/108) and heart rate (113) are elevated. Other vital signs are within normal range. A physical exam was conducted and nothing unusual was found, so blood labs were ordered to give his physicians more information.

Please review the following 4 lab tests ordered for the patient.
1. Complete Blood Count with Differential
2. Prothrombin Time
3. Troponin
4. D-dimer

Patient 2
(shown after survey questions for Patient 1 are complete)
A 65-year-old male presents with nausea and abdominal pain. He had a colonoscopy 2 days ago (a test that allows a doctor to look at the inner lining of the large intestine, rectum, and colon to help screen for problems). Since the colonoscopy, he has experienced sharp, cramping abdominal pain, nausea, and vomiting. He has had a bowel movement since the colonoscopy, and he denies bloody or dark stool. The patient has a history of diverticulosis (inflammation or infection of the digestive tract), and he takes Atenolol for hypertension (high blood pressure). His blood pressure is on the low end of the normal range, at 94/76. His other vital signs are normal.

Please review the following 4 lab tests ordered for the patient.
1. Urinalysis
2. Lipase Level
3. Liver Panel
4. Complete Blood Count with Differential

Form B
**Patient 1**
A 55-year-old female presents with difficulty breathing, swelling in both legs, confusion, and disorientation. She has a history of seizure disorder and congestive heart failure. She arrives via ambulance. No medication or allergy information is available.

**Please review the following 4 lab tests ordered for the patient:**
1. Bedside Glucose
2. ABG
3. BMP
4. Brain Natriuretic Peptide

**Patient 2**
(shown after survey questions for Patient 1 are complete)
57-year-old male presents with high blood pressure and reports two days of decreasing urinary output. He has a history of diabetes.

**Please review the following 4 lab tests ordered for the patient:**
1. Urinalysis
2. Lipase Level
3. Liver Panel
4. Complete Blood Count with Differential

The survey asks questions about Patient 1 first. The participant completes a similar survey for Patient 2 afterward, rating and commenting on explanations of Patient 2’s labs.

For each lab test listed above, please rate the explanations that follow, each of which describes (in different words) why the lab test was ordered. To rate the appropriateness of the explanation, please draw on your experiences receiving medical information. How helpful would each explanation be to you, if you were to receive it during your care? You will be asked to comment on your reasons for the rating that you give to each explanation.

The rating scale follows. A rating of 1 or 2 means that you did not find the explanation helpful. A rating of 1 means that the explanation confused you a lot more than it helped you, and that you would rather no explanation be provided than that explanation. A rating of 2 means that you think the explanation is poor, and might not be worth viewing. A rating of 3 or higher means that you consider the explanation of enough benefit to display, although the benefit may vary.

1 – The explanation is unacceptable. I would rather no explanation be provided than this one.

2 – The explanation is poor. I have serious concerns about it.

3 – The explanation is acceptable. I have some concerns, but it is more helpful to read it than not have an explanation.
4 – The explanation is pretty good, but could be better.
5 – The explanation is excellent.

You will also be asked to provide a "reason" for each of your ratings, which should be a short (several words up to one sentence) summary of why you liked or disliked that explanation. Please be sure to fill in the "reason" box for each rating.

(Below, an excerpt from the survey questions in Form A is shown).

Form A

Complete Blood Count with Differential

1. “To determine general health status and to screen for and monitor a variety of disorders, such as anemia.”

<table>
<thead>
<tr>
<th>1 Unacceptable</th>
<th>2</th>
<th>3 Acceptable</th>
<th>4</th>
<th>5 Excellent</th>
</tr>
</thead>
</table>

   Reason: 

2. “As part of a routine medical exam or as determined by your doctor.”

<table>
<thead>
<tr>
<th>1 Unacceptable</th>
<th>2</th>
<th>3 Acceptable</th>
<th>4</th>
<th>5 Excellent</th>
</tr>
</thead>
</table>

   Reason: 

3. “The CBC is used as a broad screening test to check for such disorders as anemia, infection, and many other diseases.”

<table>
<thead>
<tr>
<th>1 Unacceptable</th>
<th>2</th>
<th>3 Acceptable</th>
<th>4</th>
<th>5 Excellent</th>
</tr>
</thead>
</table>

   Reason: 

4. “If a patient is having symptoms such as fatigue or weakness or has an infection, inflammation, bruising, or bleeding, then the doctor may order a CBC to help diagnose the cause.”

<table>
<thead>
<tr>
<th>1 Unacceptable</th>
<th>2</th>
<th>3 Acceptable</th>
<th>4</th>
<th>5 Excellent</th>
</tr>
</thead>
</table>

Reason:

5. “Many patients will have baseline CBC tests to help determine their general health status.”

<table>
<thead>
<tr>
<th>1 Unacceptable</th>
<th>2</th>
<th>3 Acceptable</th>
<th>4</th>
<th>5 Excellent</th>
</tr>
</thead>
</table>

Reason:

6. “Panels may be performed for routine health screenings or if a disease or toxicity is suspected.”

<table>
<thead>
<tr>
<th>1 Unacceptable</th>
<th>2</th>
<th>3 Acceptable</th>
<th>4</th>
<th>5 Excellent</th>
</tr>
</thead>
</table>

Reason:

7. “Panels may be used to determine if a medical condition is improving or worsening.”

<table>
<thead>
<tr>
<th>1 Unacceptable</th>
<th>2</th>
<th>3 Acceptable</th>
<th>4</th>
<th>5 Excellent</th>
</tr>
</thead>
</table>

Reason:

8. “The CBC test may be performed under many different conditions and to assess many different symptoms or diseases.”

<table>
<thead>
<tr>
<th>1 Unacceptable</th>
<th>2</th>
<th>3 Acceptable</th>
<th>4</th>
<th>5 Excellent</th>
</tr>
</thead>
</table>

Reason:
9. “The test can reveal problems with RBC production and destruction, or help diagnose infection, allergies, and problems with blood clotting.”

<table>
<thead>
<tr>
<th></th>
<th>Unacceptable</th>
<th>Acceptable</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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<td>5</td>
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</table>

Reason:

* Which explanation, of the given explanations, is your preferred one for this patient? Please enter the number of your favorite explanation, from 1-9.

(Survey includes three more sets of nine web-extracted explanations for Prothrombin Time, Troponin, and D-dimer, the other lab tests ordered for Patient 1 in Form A. After concluding the survey for Patient 1, the participant completes a similar survey for Patient 2.)

(Below, an excerpt from the survey questions in Form B is shown).

Form B

ABG

1. “To determine if your lungs are functioning well enough to exchange oxygen and carbon dioxide if you are having symptoms of a respiratory problem.”

<table>
<thead>
<tr>
<th></th>
<th>Unacceptable</th>
<th>Acceptable</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Reason:
2. “Blood gas measurements are used to evaluate your oxygenation and acid/base status.”

<table>
<thead>
<tr>
<th>1 Unacceptable</th>
<th>2</th>
<th>3 Acceptable</th>
<th>4</th>
<th>5 Excellent</th>
</tr>
</thead>
</table>

Reason: 

3. “Blood gas tests are ordered when you have symptoms of an oxygen/carbon dioxide or pH imbalance, such as difficulty breathing, shortness of breath, nausea or vomiting.”

<table>
<thead>
<tr>
<th>1 Unacceptable</th>
<th>2</th>
<th>3 Acceptable</th>
<th>4</th>
<th>5 Excellent</th>
</tr>
</thead>
</table>

Reason: 

4. “Blood gas measurements may be ordered when you are known to have a respiratory, metabolic, or kidney disease and are experiencing respiratory distress.”

<table>
<thead>
<tr>
<th>1 Unacceptable</th>
<th>2</th>
<th>3 Acceptable</th>
<th>4</th>
<th>5 Excellent</th>
</tr>
</thead>
</table>

Reason: 

5. “Abnormal results of any of the blood gas components may mean that you are not getting enough oxygen, you are not getting rid of enough carbon dioxide, or there is a problem with kidney function.”

<table>
<thead>
<tr>
<th>1 Unacceptable</th>
<th>2</th>
<th>3 Acceptable</th>
<th>4</th>
<th>5 Excellent</th>
</tr>
</thead>
</table>

Reason: 

6. “An arterial blood gas (ABG) test measures the acidity (pH) and the levels of oxygen and carbon dioxide in the blood from an artery.”

<table>
<thead>
<tr>
<th>1 Unacceptable</th>
<th>2</th>
<th>3 Acceptable</th>
<th>4</th>
<th>5 Excellent</th>
</tr>
</thead>
</table>

Reason:
Reason:

7. "This test is used to check how well your lungs are able to move oxygen into the blood and remove carbon dioxide from the blood.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unacceptable</td>
<td>Acceptable</td>
<td>Excellent</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Reason:

8. "To check for severe breathing problems and lung diseases, such as asthma, cystic fibrosis, or chronic obstructive pulmonary disease (COPD)."

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unacceptable</td>
<td>Acceptable</td>
<td>Excellent</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Reason:

9. "To find out if you need extra oxygen or help with breathing (mechanical ventilation)."

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unacceptable</td>
<td>Acceptable</td>
<td>Excellent</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Reason:

Which explanation, of the given explanations, is your preferred one for this patient? 
Please enter the number of your favorite explanation, from 1-9.

(Survey includes three more sets of nine web-extracted explanations for Bedside Glucose, BMP and Brain Natriuretic Peptide, the other lab tests ordered for Patient 1 in Form B. After concluding the survey for Patient 1, the participant completes a similar survey for Patient 2.)
D.3. Physician Survey

Form A

Patient 1
A 53-year-old male presents with chest pain, shortness of breath, and tingling in both hands. He has a history of anemia. He has also undergone successful treatment of malignant neoplasm, originating in his right colon. Treatment included surgery and chemotherapy, and the patient is currently in remission. He denies taking medication at home, and he is allergic to sulfa drugs. His blood pressure (184/108) and heart rate (113) are elevated. Other vital signs are within normal range. A physical exam revealed non-tender chest wall, clear lungs, and no murmurs.

Patient 2
A 65-year-old male presents with nausea and abdominal pain. He had a colonoscopy 2 days ago. Since the colonoscopy, he has experienced sharp, cramping abdominal pain, nausea, and vomiting. He has had a bowel movement since the colonoscopy, and he denies bloody or dark stool. The patient has a history of diverticulosis and takes Atenolol for hypertension. His blood pressure is 94/69. His other vital signs are normal.

Please review the following 4 lab tests ordered for the patient.

1. Complete Blood Count with Differential
2. Prothrombin Time
3. Troponin
4. D-dimer

Please review the following 4 lab tests ordered for the patient:

1. Urinalysis
2. Lipase Level
3. Liver Panel
4. Complete Blood Count with Differential

(Survey includes four sets of nine web-extracted explanations for CBC with Differential, Prothrombin Time, Troponin and D-Dimer, the lab tests ordered for Patient 1 in Form A. After concluding the survey for Patient 1, the participant completes a similar survey for Patient 2, rating and commenting on explanations for Patient 2’s labs).
D.4. Results

Top and bottom explanations overall among physicians, non-physicians, and all participants.

**Top 5 Explanations Overall:**

<table>
<thead>
<tr>
<th>Rank</th>
<th>Mean</th>
<th>Explanation and features</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4.53, +/-.052</td>
<td>The troponin test is used to help diagnose a heart attack, to detect and evaluate mild to severe heart injury, and to separate it from chest pain that may be due to other causes. Verb phrases: 3 - help diagnose, detect and evaluate, separate Symptoms: 1 - chest pain Organs: 1 - heart Problems: 2 - heart attack, heart injury Length: 34</td>
</tr>
<tr>
<td>2</td>
<td>4.27, +/-.096</td>
<td>The troponin test is used to help diagnose a heart attack, to detect and evaluate mild to severe heart injury, and to distinguish chest pain that may be due to other causes. Verb phrases: 3 - help diagnose, detect and evaluate, distinguish Symptoms: 1 - chest pain Organs: 1 - heart Problems: 2 - heart attack, heart injury Length: 32</td>
</tr>
<tr>
<td>3</td>
<td>4.00, +/-.085</td>
<td>The Basic Metabolic Panel (BMP) is a frequently ordered panel of tests that gives your doctor important information about the current status of your kidneys, blood sugar, and electrolyte and acid/base balance. Verb phrases: 1 - gives information about… Organs: 2 - kidneys, blood Length: 32 Medical terms: 1 - acid/base Narrative: 2</td>
</tr>
<tr>
<td>4</td>
<td>4.00, +/-.107</td>
<td>Blood glucose testing is done in emergency settings to determine if low or high glucose is contributing to symptoms such as fainting and unconsciousness. Verb phrases: 1 - determine Symptoms: 2 - fainting, unconsciousness Organs: 1 - blood Length: 24 Activity: 1 - emergency settings</td>
</tr>
<tr>
<td>5</td>
<td>3.93, +/-.088</td>
<td>This test is used to check how well your lungs are able to move oxygen into the blood and remove carbon dioxide from the blood. Verb phrases: 1 - check how well Organs: 2 - lungs, blood Length: 25 Narrative: 2</td>
</tr>
</tbody>
</table>

**Bottom 5 Explanations Overall:**
<table>
<thead>
<tr>
<th>Rank</th>
<th>Mean</th>
<th>Explanation and features</th>
<th>Verb phrases</th>
<th>Length</th>
<th>Medical terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1.47,</td>
<td>This test can also be useful when monitoring certain conditions over time.</td>
<td>1 - monitor</td>
<td>12</td>
<td>coagulation factors, extrinsic and common pathways, coagulation cascade, factors I (fibrinogen), II (Prothrombin), V, VII and X</td>
</tr>
<tr>
<td></td>
<td>+/- 0.74</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>1.60,</td>
<td>It is ordered widely and routinely to detect any abnormalities that require follow up.</td>
<td>1 - detect</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td></td>
<td>+/- 0.91</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>1.67,</td>
<td>D-dimer levels may be used to monitor the effectiveness of DIC treatment.</td>
<td>1 - monitor</td>
<td>12</td>
<td>vitamin K</td>
</tr>
<tr>
<td></td>
<td>+/- 0.90</td>
<td></td>
<td>1 - DIC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>1.80,</td>
<td>The PT test evaluates the integrated function of the coagulation factors that comprise the extrinsic and common pathways of the coagulation cascade, including factors I (fibrinogen), II (Prothrombin), V, VII and X.</td>
<td>1 - evaluates</td>
<td>32</td>
<td>coagulation factors, extrinsic and common pathways, coagulation cascade, factors I (fibrinogen), II (Prothrombin), V, VII and X</td>
</tr>
<tr>
<td></td>
<td>+/- 0.86</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>1.80,</td>
<td>To check for a low level of vitamin K.</td>
<td>1 - check for</td>
<td>9</td>
<td>vitamin K</td>
</tr>
<tr>
<td></td>
<td>+/- 1.15</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

**Physicians' Top 5 Explanations:**

<table>
<thead>
<tr>
<th>Rank</th>
<th>Mean</th>
<th>Explanation and features</th>
<th>Verb phrases</th>
<th>Length</th>
<th>Medical terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4.57,</td>
<td>The troponin test is used to help diagnose a heart attack, to detect and evaluate mild to severe heart injury, and to separate it from chest pain that may be due to other causes.</td>
<td>3 - help diagnose, detect and evaluate, separate</td>
<td>34</td>
<td>heart injury, chest pain</td>
</tr>
<tr>
<td></td>
<td>+/- 0.53</td>
<td></td>
<td>Symptoms: 1 - chest pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Organs: 1 - heart</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Problems: 2 - heart attack, heart injury</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>4.00,</td>
<td>To diagnose and monitor pancreatitis or other pancreatic diseases.</td>
<td>2 - diagnose, monitor</td>
<td>9</td>
<td>pancreas, other pancreatic diseases</td>
</tr>
<tr>
<td></td>
<td>+/- 0.58</td>
<td></td>
<td>Organs: 1 - pancreas</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Problems: 2 - pancreatitis, other pancreatic diseases</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Troponin tests are primarily ordered for people who have chest pain to see if they have had a heart attack or other damage to their heart.

- **Symptoms:** 1 - chest pain
- **Organs:** 1 - heart
- **Problems:** 2 - heart attack, damage to heart
- **Length:** 26
- **Activity:** 1 - people with chest pain
- **Narrative:** 3

To check for pancreatitis and other diseases of the pancreas.

- **Verb phrases:** 1 - check
- **Organs:** 1 - pancreas
- **Problems:** 2 - pancreatitis, other pancreatic diseases
- **Length:** 10

The blood test for lipase is ordered, often along with an amylase test, to help diagnose and monitor acute pancreatitis (inflammation of the pancreas), chronic pancreatitis, and other disorders that involve the pancreas.

- **Verb phrases:** 2 - diagnose, monitor
- **Organs:** 1 - pancreas
- **Problems:** 2 - acute pancreatitis, chronic pancreatitis
- **Length:** 33
- **Medical terms:** 1 - amylase
- **Med terms explained:** 1

**Physicians' Bottom 5 Explanations (?):**

<table>
<thead>
<tr>
<th>Rank</th>
<th>Mean</th>
<th>Explanation and features</th>
</tr>
</thead>
</table>
| 1    | 1.29, +0.76 | This test can also be useful when monitoring certain conditions over time.  
  Verb phrases: 1 - monitor  
  Length: 12 |
| 2    | 1.43, +0.79 | The urinalysis is a set of screening tests that can provide a general overview of a person's health.  
  Verb phrases: 2 - screen, provide overview  
  Length: 18  
  Narrative: 3 |
| 3    | 1.50, +0.65 | Panels may be performed for routine health screenings or if a disease or toxicity is suspected.  
  Problems: 1 - disease or toxicity  
  Length: 16  
  Activity: 1 - routine health screening |
### Non-Physicians' Top 5 Explanations:

<table>
<thead>
<tr>
<th>Rank</th>
<th>Mean</th>
<th>Explanation and features</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4.63, +0.52</td>
<td>The troponin test is used to help diagnose a heart attack, to detect and evaluate mild to severe heart injury, and to distinguish chest pain that may be due to other causes.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Verb phrases: 3 - help diagnose, detect and evaluate, distinguish</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Symptoms: 1 - chest pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Organs: 1 - heart</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Problems: 1 - heart attack, heart injury</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Length: 32</td>
</tr>
<tr>
<td>2</td>
<td>4.50, +0.53</td>
<td>The troponin test is used to help diagnose a heart attack, to detect and evaluate mild to severe heart injury, and to separate it from chest pain that may be due to other causes.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Verb phrases: 3 - help diagnose, detect and evaluate, separate</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Symptoms: 1 - chest pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Organs: 1 - heart</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Problems: 2 - heart attack, heart injury</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Length: 34</td>
</tr>
<tr>
<td>3</td>
<td>4.13, +0.99</td>
<td>A liver panel or one or more of its component tests may be used to help detect liver disease if a person has symptoms that indicate possible liver dysfunction or if a person is being monitored or treated for a known condition or liver disease.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Verb phrases: 2 - help detect, monitor</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Symptoms: 1 - mention of 'symptoms that indicate…'</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Organs: 1 - 1. liver</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Problems: 1 - liver disease</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Length: 45</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Activity: 1 - if a person has symptoms…., if a person being monitored or treated for known condition</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Narrative: 3</td>
</tr>
<tr>
<td>4</td>
<td>1.57, +0.98</td>
<td>Check to see if the body is using up its clotting factors so quickly that the blood cannot clot and bleeding does not stop.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Verb phrases: 1 - check to see</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Organs: 1 - blood</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Problems: 1 - blood cannot clot</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Length: 24</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Medical terms: 1 - clotting factors</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Narrative: 3</td>
</tr>
<tr>
<td>5</td>
<td>1.57, +1.13</td>
<td>D-dimer levels may be used to monitor the effectiveness of DIC treatment.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Verb phrases: 1 - monitor</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Problems: 1 - DIC</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Length: 12</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Acronyms: 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Meds: 1 - DIC treatment</td>
</tr>
<tr>
<td>Rank</td>
<td>Mean</td>
<td>Explanation and features</td>
</tr>
<tr>
<td>------</td>
<td>------</td>
<td>--------------------------</td>
</tr>
<tr>
<td>4</td>
<td>4.13, +0.83</td>
<td>The lipase test is most often used in evaluating inflammation of the pancreas (pancreatitis), but it is also useful in diagnosing kidney failure, intestinal obstruction, mumps, and peptic ulcers.</td>
</tr>
</tbody>
</table>
|      |       | Verb phrases: 2 - evaluate, diagnose  
|      |       | Organs: 3 - pancreas, kidney intestines  
|      |       | Problems: 5 - pancreatitis, kidney failure, intestinal obstruction, mumps, peptic ulcers  
|      |       | Length: 29  |
| 5    | 4.00, +0.85 | The Basic Metabolic Panel (BMP) is a frequently ordered panel of tests that gives your doctor important information about the current status of your kidneys, blood sugar, and electrolyte and acid/base balance. |
|      |       | Verb phrases: 1 - gives information about…  
|      |       | Organs: 2 - kidneys, blood  
|      |       | Length: 32  
|      |       | Medical terms: 1 - acid/base  
|      |       | Narrative: 2  |

Non-Physicians’ Bottom 5 Explanations:

<table>
<thead>
<tr>
<th>Rank</th>
<th>Mean</th>
<th>Explanation and features</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1.50, +-0.76</td>
<td>The PT test evaluates the integrated function of the coagulation factors that comprise the extrinsic and common pathways of the coagulation cascade, including factors I (fibrinogen), II (Prothrombin), V, VII and X.</td>
</tr>
</tbody>
</table>
|      |       | Verb phrases: 1 - evaluates  
|      |       | Length: 32  
|      |       | Medical terms: 9 - coagulation factors, extrinsic and common pathways, coagulation cascade, factors I (fibrinogen), II (Prothrombin), V, VII and X  |
| 2    | 1.63, +-0.74 | Measurements of D-dimer may also be ordered, along with other tests, to help diagnose DIC (Disseminated Intravascular Coagulation). |
|      |       | Verb phrases: 1 - help diagnose  
|      |       | Problems: 1 - DIC  
|      |       | Length: 18  
|      |       | Acronyms: 1  
|      |       | Med terms explained: 1  |
| 3    | 1.63, +-0.74 | It is ordered widely and routinely to detect any abnormalities that require follow up. |
|      |       | Verb phrases: 1 - detect  
|      |       | Length: 14  |
| 4    | 1.63, +-0.74 | This test can also be useful when monitoring certain conditions over time. |
|      |       | Verb phrases: 1 - monitor  
<p>|      |       | Length: 12  |</p>
<table>
<thead>
<tr>
<th>Rank</th>
<th>Mean</th>
<th>Explanation and features</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>1.75, + 0.71</td>
<td><strong>D-dimer levels may be used to monitor the effectiveness of DIC treatment.</strong> Verb phrases: 1 - monitor Problems: 1 - DIC Length: 12 Acronyms: 1 Meds: 1 - DIC treatment</td>
</tr>
</tbody>
</table>

Bottom 5 Overall explanations: mean length 15.80 (std 9.23)
Top 5 Overall explanations: mean length 30.00 (std 8.00)

Bottom 5 physician explanations: mean length 17.60 (std 8.41)
Top 5 physician explanations: mean length 32.80 (std 7.79)

Bottom 5 physician explanations: mean length 16.40 (std 4.98)
Top 5 physician explanations: mean length 22.40 (std 12.18)

**What Makes a “Good” Explanation? Reflections:**

**Physicians (Form A):**

P0: Needs to be brief and comprehensible but detail exactly what the test encompasses and why it is being ordered.

P1: An explanation for a lab test should be specific, but not too specific and should avoid letting the patient over interpret the results. For example, pt shouldn't assume that their liver is completely normal if their liver panel comes back normal, as a liver panel can be normal in cirrhosis.

P2: Any explaination should be patient specific and easily understood. It should not create confusion, uncertainty or unnecessary fear in pts mind

P3: Not too basic, but clearly defines what the test is for - without making it seem like a medical school lecture (too specific).

P4: A explanation does not have to be comprehensive, it should be simply worded and precise. It should list common reasons for a test. It should be reassuring, e.g. low hemoglobin does not always mean that there is a problem. It should also avoid scaring a patient, e.g. mentioning rare things like needing a biopsy or diagnosing cancer.

P5: A lab test explaination should be factual, easy to understand and should be directed towards patients problems. A generic statement can create confusion in patient and caregivers mind.

P6: I think that a good explanation needs to be specific to the patient's situation. It should tell the patient what diagnoses it will help to identify and how the value might be used in the future. Too much information is not helpful, however, because it may just serve to confuse a patient.
Non-physicians (form A):

P7: I think it is important to know what exactly the lab test checks for. Then it should state a brief explanation of what it checks for and what the diseases it checks for might be. It should also state any side effects that might come from one's medications and such.

P8: I think it is dangerous to give too much information. I didn't like the overly technical definitions, those can be reserved for the doctors. I didn't like the ones that listed the possible reasons why a doctor would order (symptom based) because I think doctors would sometimes order the test for other reasons and may not order all of the associated tests that are mentioned. It seems to give the patient a reason to question the doctor's judgment. I really like the simple explanations about what the test was screening for and what the doctor might be looking for in the results. I would rather have the information about what conditions we are ruling out than wonder why I am taking the tests in the first place.

P9: Tell the patient what the test is, why it's needed and explain the results without too much terminology.

P10: I want to be informed using laymen terms. Most patients are not familiar with medical jargon.

P11: a short but concise explanation that doesn't use technical words and directly relates to at least some of my symptoms so I can understand why it is being ordered

P12: A good explanation for a medical lab test clearly explains what conditions/issues the test is purposed for. It should contain a minimal amount of medical techno-jargon. This jargon should only be used sparingly to help explain the test for a general patient.

P13: A good explanation would contain a pretext of what the disease or case was. Also it would contain a definition of what the acronyms mean such as CBC. Finally a good explanation would have definition of what some of the difficult words were in parenthesis.

P14: A good explanation to me, is one that tells me a) why the test was ordered for me b) what the test hopes to diagnose and c) what other uses the test has or what other problems may be diagnosed by the test

Non-physicians (form B):

P15: I believe that understanding what it is that the test is designed to measure, along with what this means to me are both integral to understanding the importance and impact of lab tests.

P16: I think that there can be many different reasons for a medical lab test and what it could be testing for. It should tell me what the test does and why it is important. It may include what it does specifically but I should know why it is important to me.

P17: I think a good explanation for a medical lab test is one expressed in simple, easy to understand terms, that directly relate to the specific condition and situation of the patient at the time of the test. I also think it is important to keep it short and not too clinical.
P18: I want to know what the lab is exactly for, what it means, what it can show. And how it can help me find out what's wrong.

P19: I like to keep things simple! I do not like too many medical terms, just the basic facts and a general explanation of what the test will do.

P20: Tells me in plain English what the test tells you and how it applies to what I think is wrong. It doesn't talk down to me, but doesn't over-use polysyllabic words to confuse me and assert your superiority.

P21: Telling my why the lab test are ordered, what exactly they are looking for, and should I be worried for the ordering of the lab test.

P22: I need to know what the test is, what it measures, why it is important, and how does it relate to my possible condition? I need more than basic information, but I do not want medical jargon either.

P23: Simplicity. I would prefer 5 words that say why and what instead of 20

P24: What is the test looking for in clear, simple terms, and why are you testing me?

P25: I want to know what the test measures, and how it will help diagnose my problem. I want enough detail to understand, but in layman's terms.

P26: 1) Tells what the test measures in simple language, 2) Contains enough info but doesn't overwhelm, 3) Doesn't use scary language, 4) Gives some insight into what could be causing abnormal readings, 5) Gives some understanding about the ramifications of the test results

P27: I want something that is simple. I want to understand it and I don't want it to scare me. I don't need to know all the technical details. When I went in for surgery, during the prep they have to tell you all of the things that can go wrong so that you are informed. I think that was worse than the actual surgery. Don't scare me unless you have to. Tell me why you are going to run the test and keep it simple, especially if it is an emergency situation.

P28: Simple explanation with as few technical terms for the majority of people. Nothing to excite them further like this is for cancer screening when either they know they have cancer or are in there for something totally different. Keeping the patient calm helps and simple explanations are best, just what it is for and if they ask then maybe further explanations.

P29: 1 that breaks down the acronyms and offers explanations in laymans terms so that the patient can understand what's going on. A lab report that gives full explanations of the tests being performed as to what is expected. What was being sought from the test and was the test revealed. What the level ranges are and where the patient's level was and whether or not that was considered good, bad or indifferent for THAT patient NOT in general
### E. Topic Modeling Medication Information Resources for Consumers

#### E.1. Medications Selected for Modeling

<table>
<thead>
<tr>
<th>Medication</th>
<th>Formulation</th>
<th>Medication</th>
<th>Formulation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abciximab</td>
<td></td>
<td>Diazepam Inj</td>
<td>Oseltamivir Oral</td>
</tr>
<tr>
<td>Acetaminophen Codeine Oral</td>
<td></td>
<td>Diazepam Oral</td>
<td>Oxycodeone Acetaminophen</td>
</tr>
<tr>
<td>Acetaminophen Oral</td>
<td></td>
<td>Digoxin Inj</td>
<td>Paroxetine Oral</td>
</tr>
<tr>
<td>Acetazolamide Inj</td>
<td></td>
<td>Digoxin Oral</td>
<td>Polyethylene Glycol Oral</td>
</tr>
<tr>
<td>Acetazolamide Oral</td>
<td></td>
<td>Diltiazem Cd Oral</td>
<td>Polymyxin Bacitracin Oint Opth</td>
</tr>
<tr>
<td>Acetylcysteine 20 Inh Soln</td>
<td></td>
<td>Diltiazem Hcl Oral</td>
<td>Potassium Chloride Inj</td>
</tr>
<tr>
<td>Acetylcysteine 20 Oral</td>
<td></td>
<td>Epinephrine Iv</td>
<td>Potassium Chloride Oral</td>
</tr>
<tr>
<td>Acyclovir Oral</td>
<td></td>
<td>Enoxaparin Inj</td>
<td>Potassium Phosphate Inj</td>
</tr>
<tr>
<td>Albendazole Oral</td>
<td></td>
<td>Eptifibatide Iv</td>
<td>Prasugrel Oral</td>
</tr>
<tr>
<td>Albumin Human 25 Inj</td>
<td></td>
<td>Escitalopram Oral</td>
<td>Pravastatin Tab</td>
</tr>
<tr>
<td>Albumin Human 5 Inj</td>
<td></td>
<td>Esmolol Iv</td>
<td>Prednisone Oral</td>
</tr>
<tr>
<td>Albuterol Inh Soln</td>
<td></td>
<td>Fentanyl Citrate Inj</td>
<td>Propranolol Oral</td>
</tr>
<tr>
<td>Albuterol MDI</td>
<td></td>
<td>Fentanyl IV</td>
<td>Pyrazinamide Oral</td>
</tr>
<tr>
<td>Alendronate Oral</td>
<td></td>
<td>Fentanyl Patch</td>
<td>Quinapril Oral</td>
</tr>
<tr>
<td>Aliskiren Oral</td>
<td></td>
<td>Fluconazole Oral</td>
<td>Ramipril Oral</td>
</tr>
<tr>
<td>Allopurinol Oral</td>
<td></td>
<td>Furosemide Inj</td>
<td>Ribavirin Oral</td>
</tr>
<tr>
<td>Alprazolam Oral</td>
<td></td>
<td>Furosemide Oral</td>
<td>Ritonavir Oral</td>
</tr>
<tr>
<td>Alteplase Inj</td>
<td></td>
<td>Heparin Inj</td>
<td>Rosuvastatin Tab</td>
</tr>
<tr>
<td>Amiodarone IV</td>
<td></td>
<td>Hydralazine Hcl Inj</td>
<td>Sertraline Oral</td>
</tr>
<tr>
<td>Amiodarone Inj</td>
<td></td>
<td>Hydralazine Hcl Oral</td>
<td>Simvastatin Tab</td>
</tr>
<tr>
<td>Amiodarone Oral</td>
<td></td>
<td>Isosorbide Dinitrate Oral</td>
<td>Sodium Bicarbonate Inj</td>
</tr>
<tr>
<td>Amlodipine Oral</td>
<td></td>
<td>Isosorbide Mononitrate Er Oral</td>
<td>Spironolactone Oral</td>
</tr>
<tr>
<td>Amphotericin B (Abelcet) Lipid Inj</td>
<td></td>
<td>Lorazepam Inj</td>
<td>Temazepam Oral</td>
</tr>
<tr>
<td>Argatroban IV</td>
<td></td>
<td>Lorazepam Oral</td>
<td>Tramadol Hcl Oral</td>
</tr>
<tr>
<td>Aspirin Oral</td>
<td></td>
<td>Losartan Oral</td>
<td>Valsartan Oral</td>
</tr>
<tr>
<td>Atorvastatin Tab</td>
<td></td>
<td>Magnesium Oxide Oral</td>
<td>Vancomycin Inj</td>
</tr>
<tr>
<td>Bacitracin Oint</td>
<td></td>
<td>Metolazone Oral</td>
<td>Vancomycin Oral</td>
</tr>
<tr>
<td>Barium Sulfate 2.1 Oral Susp</td>
<td></td>
<td>Metoprolol Tartrate Inj</td>
<td>Vasopressin Iv</td>
</tr>
<tr>
<td>Basiliximab Inj</td>
<td></td>
<td>Metoprolol Tartrate Oral</td>
<td>Warfarin Sodium Oral</td>
</tr>
<tr>
<td>Buspirone Oral</td>
<td></td>
<td>Metronidazole Oral</td>
<td>Oxycodeone Oral</td>
</tr>
<tr>
<td>Cardizem IV</td>
<td></td>
<td>Morphine Sulfate Inj</td>
<td>Dopamine Iv</td>
</tr>
<tr>
<td>Carvedilol Oral</td>
<td></td>
<td>Nitroglycerin Iv</td>
<td></td>
</tr>
<tr>
<td>Citalopram Oral</td>
<td></td>
<td>Nitroglycerin Oint 2</td>
<td></td>
</tr>
<tr>
<td>Clopidogrel Bisulfate Oral</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
E.2. Filter Categories Applied to Content in Strong Topic Categories

1. Numerical sentence undetected by structural analysis
2. Multi-Media undetected by structural analysis
3. Subscription and social networking links
4. Navigation
5. Advertisements not detected by structural analysis
6. Incomplete sentences
7. Professional reference (e.g., “your patients”)

E.3. Topic Cluster Labels

Uses
Contraindications
Dose
Interactions
Mechanism of Action
Metabolism
Overdose
Precautions
Pregnancy and Breast Feeding
Side Effects
Clinical Studies
How to Use
Patient Monitoring
E.4. Medications Selected for Remedy

<table>
<thead>
<tr>
<th>Medication</th>
<th>Formulation</th>
</tr>
</thead>
<tbody>
<tr>
<td>AliskirenOral</td>
<td>AmiodaroneIV</td>
</tr>
<tr>
<td>AmiodaroneInj</td>
<td>AmiodaroneOral</td>
</tr>
<tr>
<td>AspirinOral</td>
<td>ClopidogrelBisulfateOral</td>
</tr>
<tr>
<td>FurosemideInj</td>
<td>FurosemideOral</td>
</tr>
<tr>
<td>HeparinInj</td>
<td>MetoprololTartrateInj</td>
</tr>
<tr>
<td>MetoprololTartrateOral</td>
<td>MorphineSulfateInj</td>
</tr>
</tbody>
</table>

Represent seven classes common to cardiac surgery:

Beta-blockers, ACE Inhibitors, Statins, Anti-Arrhythmia, Anti-Coagulants, Diuretics, Anti-Platelet
### E.5. Pharmacists Auditing/Review Instrument

**Table E.5.1: Excerpt of physicians’ instrument to audit and review clustered excerpts. The first three entries (of 475) in the “Side Effects” cluster are shown.**

<table>
<thead>
<tr>
<th>Art. Sent.</th>
<th>Incorrect High Quality</th>
<th>Incorrect High Quality</th>
<th>Incorrect High Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mediation Name</td>
<td>Page Excerpt</td>
<td>Art. Sent.</td>
<td>Incorrect High Quality</td>
</tr>
<tr>
<td>Mediation Name</td>
<td>Page Excerpt</td>
<td>Art. Sent.</td>
<td>Incorrect High Quality</td>
</tr>
<tr>
<td>Mediation Name</td>
<td>Page Excerpt</td>
<td>Art. Sent.</td>
<td>Incorrect High Quality</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Medication Name</th>
<th>Page Excerpt</th>
<th>Art. Sent.</th>
<th>Incorrect High Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>AmiodaroneInj</td>
<td>Incorrect High Quality</td>
<td>Art. Sent.</td>
<td>Incorrect High Quality</td>
</tr>
<tr>
<td>RamiprilOral</td>
<td>Incorrect High Quality</td>
<td>Art. Sent.</td>
<td>Incorrect High Quality</td>
</tr>
<tr>
<td>Morphine</td>
<td>Incorrect High Quality</td>
<td>Art. Sent.</td>
<td>Incorrect High Quality</td>
</tr>
</tbody>
</table>
### E.6. Inpatient Study Data

**Active Medication Orders**

<table>
<thead>
<tr>
<th>Class</th>
<th>Name</th>
<th>Dose</th>
<th>Frequency</th>
<th>Method</th>
<th>Users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adrenergic bronchodilators</td>
<td>Albuterol Inh Soln</td>
<td>3 ml</td>
<td>Take every 6 hours</td>
<td>IN</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Aspirin Ec Tab</td>
<td>325 mg</td>
<td>Take at 9:00 am</td>
<td>PILL</td>
<td>No description</td>
</tr>
<tr>
<td>Statins (HMG CoA reductase inhibitors)</td>
<td>Atorvastatin Tab ++</td>
<td>40 mg</td>
<td>Take at bedtime</td>
<td>PILL</td>
<td>Used to reduce the production of certain fatty substances in the body</td>
</tr>
<tr>
<td>Cardiac stress agents</td>
<td>Dipyridamole Oral</td>
<td>75 mg</td>
<td>Take every 4 hours</td>
<td>PILL</td>
<td>Used to prevent blood clots</td>
</tr>
<tr>
<td>Proton pump inhibitors</td>
<td>Esomeprazole Oral</td>
<td>40 mg</td>
<td>Take once daily</td>
<td>PILL</td>
<td>Used to control rapid heartbeats or abnormal heart rhythms</td>
</tr>
<tr>
<td>Anticholinergic bronchodilators</td>
<td>Ipratropium Bromide Inh Soln</td>
<td>3 ml</td>
<td>Take every 6 hours</td>
<td>IN</td>
<td>No description</td>
</tr>
<tr>
<td></td>
<td>Metoprolol Tartrate Tab</td>
<td>13 mg</td>
<td>Take every 12 hours</td>
<td>PILL</td>
<td>No description</td>
</tr>
<tr>
<td>Narcotic analgesic combinations</td>
<td>Oxycodone/acetaminophen 5/325 Mg Tab (persocet)</td>
<td>2 tab</td>
<td>Take every 4 hours</td>
<td>PILL</td>
<td>Used to relieve pain</td>
</tr>
</tbody>
</table>

**Medications Ordered Today**

**Completed or Discontinued Medications**

**Active Medication Orders**

<table>
<thead>
<tr>
<th>Class</th>
<th>Name</th>
<th>Dose</th>
<th>Frequency</th>
<th>Method</th>
<th>Users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loop diuretics</td>
<td>Furosemide In</td>
<td>20 mg</td>
<td>Take once daily</td>
<td>IN</td>
<td>A diuretic (water pill) used to reduce build-up fluids</td>
</tr>
<tr>
<td>Anticholinergic bronchodilators</td>
<td>Ipratropium Bromide Inh Soln</td>
<td>3 ml</td>
<td>Take every 6 hours</td>
<td>IN</td>
<td>No description</td>
</tr>
</tbody>
</table>
Figure E.6.1. Screenshots of a participating patient’s inpatient medication lists.

Table E.6.1. Inpatient participant preferences for features and tools in Remedy.
<table>
<thead>
<tr>
<th>Pt</th>
<th>Task Med</th>
<th>Remedy</th>
<th>Gen-purpose</th>
<th>Errors</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Simvastatin</td>
<td>40</td>
<td>33</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Heparin*</td>
<td>75</td>
<td>90</td>
<td>1 (GP)</td>
</tr>
<tr>
<td>3</td>
<td>Amiodarone</td>
<td>25</td>
<td>75</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Plavix</td>
<td>41</td>
<td>85</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Metoprolol</td>
<td>46</td>
<td>46</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Metoprolol</td>
<td>40</td>
<td>83</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Lasix</td>
<td>42</td>
<td>51</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Plavix*</td>
<td>75</td>
<td>136</td>
<td>1 (GP)</td>
</tr>
<tr>
<td>9</td>
<td>Metoprolol</td>
<td>45</td>
<td>60</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Heparin*</td>
<td>30</td>
<td>72</td>
<td>1 (GP)</td>
</tr>
<tr>
<td>11</td>
<td>Amiodarone</td>
<td>16</td>
<td>72</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Vancomycin</td>
<td>36</td>
<td>61</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Mean</strong></td>
<td><strong>42.58</strong></td>
<td><strong>72</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>StdDev</td>
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</tr>
<tr>
<td></td>
<td>StdErr</td>
<td>5.04</td>
<td>7.59</td>
<td></td>
</tr>
</tbody>
</table>

Table E.6.2. Inpatient participant search task completion times and occurrences of errors.