

Designing Patient-Centric Information Displays for Hospitals

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ABSTRACT

Electronic medical records are increasingly comprehensive, and this vast repository of information has already contributed to medical efficiency and hospital procedure. However, this information is not typically accessible to patients, who are frequently under-informed and unclear about their own hospital courses. In this paper, we propose a design for in-room, patient-centric information displays, based on iterative design with physicians. We use this as the basis for a Wizard-of-Oz study in an emergency department, to assess patient and provider responses to in-room information displays. 18 patients were presented with real-time information displays based on their medical records. Semi-structured interviews with patients, family members, and hospital staff reveal that subjective response to in-room displays was overwhelmingly positive, and through these interviews we elicited guidelines regarding specific information types, privacy, use cases, and information presentation techniques. We describe these findings, and we discuss the feasibility of a fully-automatic implementation of our design.

Author Keywords

Patient Awareness, Electronic Medical Records

ACM Classification Keywords

J.3 [Computer Applications] Life and Medical Sciences – Health.

General Terms

Human Factors

INTRODUCTION

Visiting a hospital Emergency Department (ED) is a disorienting and often scary experience for patients and their loved ones. Studies have shown that most patients in the ED are extremely anxious about all the uncertainties associated with a hospital stay. This includes fear of feeling pain, having to undergo uncomfortable procedures, not being able to carry out their usual activities, and not knowing what is wrong or what will happen to them in the hospital [5]. In fact, findings indicate that patients tend to be as concerned with psychological and social aspects of their stay as

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CHI 2010, April 10–15, 2010, Atlanta, Georgia, USA.

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they are about physical factors. Unfortunately, this anxiety has been shown to be correlated to negative clinical outcomes in both chronic and emergency treatment [6].

We believe that a reasonable amount of this uncertainty and anxiety can be alleviated by better communication that provides the patient with relevant information throughout the care process. Researchers have shown, for example, that patients who were given more information during a visit to an emergency room, particularly information about what to expect next, rated their hospital experience significantly more positively than those who did not have access to this information while receiving care [3]. Fortunately, the recent push towards using electronic medical records (EMRs) for providing, tracking, and documenting care provides us with a rapidly evolving infrastructure from which to retrieve much of this information.

In this work, we explore 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 study in which we manually compiled information extracted from the patient medical record and constructed posters that mimicked a potential digital display (Figures 1 and 3). 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.

The primary contributions of this paper are:

1. A preliminary design for an in-room patient information display, representing the endpoint of an iterative process involving patients, providers, and designers.

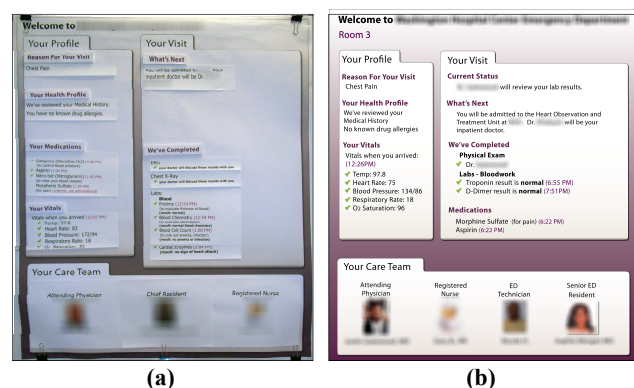


Figure 1. Prototype information displays presented to patients in (a) 3'x4' poster and (b) letter-sized format.

2. Findings from the study detailing 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 Emergency Department.
3. Identification of challenges and opportunities that exist in leveraging the EMR and automating the information extraction and construction process used in our study.

RELATED WORK

Research has shown that memory of medical information presented to patients during hospital visits is poor [14,15,16]. This limited recall is the result of both clinician-related factors, such as use of difficult terminology and information mode (spoken vs. written); and patient-related factors such as low education level, or inappropriately specific expectations [15]. Studies have also shown that written information documenting the medical consultation is better remembered and more likely to result in care adherence [4].

Communication has been particularly well studied at the point of patient discharge. Research indicates that patients lack comprehension of their care and discharge instructions, and worse yet, patients and care providers are often unaware of these gaps in comprehension [8,20]. Since comprehension is crucial to continuity of care and adherence to a treatment plan, leaving the hospital without appropriate understanding of critical information has been correlated with poor health outcomes and repeat visits [19,20].

Fortunately, written medical information has historically played a prominent role in patient discharge, in addition to oral briefings. This is important as patients experience an abrupt transition from passive involvement in the ED to absolute responsibility of their care upon discharge [2,8,19].

Furthermore, to assist in continuity of care and patient education, researchers have developed technologies to help patients browse health information via information kiosks in waiting areas [10,13,17], or post-visit via Internet-based Personal Health Record (PHR) systems [11]. In fact, the recent trend toward adoption of PHRs has raised several questions related to information sharing between patients and care providers. Several helpful case studies have outlined challenges involved in showing patients their clinical information [11], and additional research explored patient responses to viewing their medical information online [22].

However, these technologies do not address the informational needs of patients during the hospital visit itself. In fact, few technological interventions have been designed specifically to support patient awareness of the procedures, activities, medications, and people involved in their care, and the results of events in their hospital course throughout a visit. As noted by [2], little research has explored the design of systems which provide a patient with information throughout the patient's stay and are viewable from their bed. This is the problem we tackle in the present work.

There has been a plethora of relevant work on designing

technology to support various other aspects of hospital care. For example, [9] focuses on the design of portable digital artifacts to facilitate collection of medical information by pregnant women. Also, recent HCI research has focused on the design of large displays for coordination and information sharing [7,12,21,23]. Research detailing the role of the large display in clinical settings [1] has offered several insights into the benefits of such displays for awareness and coordination among care providers. However, studies investigating the role that a large information display can play in coordination and communication between patients and their care team in the hospital are limited. Other work has looked at specialized interventions such as the use of interactive tabletops to facilitate medical conversations between deaf and hearing individuals [18].

ITERATIVE DESIGN PROCESS

Our display prototypes were designed to support an exploratory study around in-room information presentation, so we sought to reduce pragmatic constraints and maximize flexibility. 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, the author with domain expertise 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 1 and 3).

STUDY METHODOLOGY

We conducted our study in the Emergency Department (ED) at 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 supports 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.

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.

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.

Procedure

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 2 and 3), and 5 were prepared as letter-sized handouts (Figure 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.



Figure 2. Staged illustration of patient discussing poster with physician, in actual deployment site.

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.

RESULTS AND DISCUSSION

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."

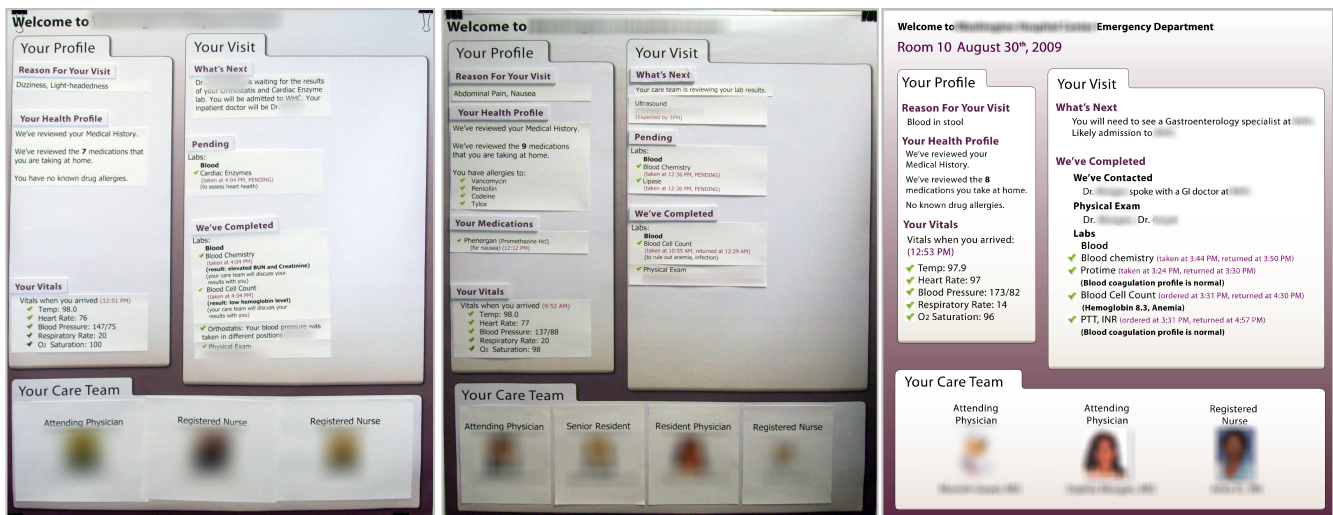


Figure 3: Three prototype information displays deployed during our study (anonymized). Left, center: posters. Right: handout.

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 con-

firmed 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 “What’s 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 “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, so 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. Similar sentiments were expressed by P9 (“*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.

P13 was asked whether she would have concerns with visitors seeing the information on the prototype, 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 emergency department, 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 critical windows 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, and particularly to our prototype designs. This section explores the responses of providers (doctors and nurses) to our prototypes.

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 [11]. 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 phy-

sician 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 both hospital staff for interpretation, and one physician suggested specifically that “*sometimes [a] blood pressure [reading] escalates concern*”.

4. “Medications”

The “medications” section of the prototype was viewed as uniformly positive by providers. 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 informa-

tion 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 among 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.”

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, 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 was also immediately 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 EMR 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.

CONCLUSION AND FUTURE WORK

We have 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. Patient and provider response was very positive, suggesting that this space merits further work, particularly in specific problems – at the intersection of HCI, medical informatics, and machine learning – that will better enable digital, automated versions of this concept. Our results also suggested significant value in this design for post-visit review and archive, motivating an adapted design and an additional study centered around automatic generation of patient-centric discharge summaries. We hope to study our design in other hospital wards, to assess the generalizability of our design and our findings outside of the ED. Similarly, we hope to study how information needs change throughout an entire inpatient hospital stay.

SUPPLEMENTARY MATERIAL

Anonymized versions of all of the posters and handouts prepared during our study are available at:

<http://research.microsoft.com/cue/patientdisplays>

ACKNOWLEDGEMENTS

We thank Bill Frohna, Michael Gillam, Eric Horvitz, Liz Tondreau, PD Singh, Meredith Skeels, Mark Smith, Ann Paradiso, Jim St. George, our participants, and the ED staff.

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