

# **Bursting the Information Bubble: Identifying Opportunities for Pediatric Patient-Centered Technology**

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## **Abstract**

*Although hospital care is carefully documented and that information is electronically available to clinicians, few information systems exist for patients and their families to use while they are in the hospital. Information often appears trapped within the hospital room. In this paper, we present findings from three participatory design sessions that we conducted with former patients, their parents, and clinicians from a large children's hospital. Participants discussed challenges they faced getting information while in the hospital, and then designed possible technological solutions. Participants designed technologies aimed at extending parents' access to and involvement in patients' care. Their designs showed opportunities for health informatics within and beyond the children's hospital room: to allow parents and children to disseminate information from within, access information from the hospital room remotely, establish pervasive and collaborative communication with the clinical care team, and learn about their child's care throughout the hospital stay.*

## **Introduction**

The hospital presents a challenging information environment for patients and their caregivers. When patients are active participants in information about their care, readmission rates are lower and errors are less likely to occur (1). Close family members, such as parents, can be essential to patients' information management practices, helping patients get the information they need and participating in medical decision-making (2). However, getting the latest information about a patient's condition and care usually requires physical presence in the hospital room waiting for often unpredictable clinical encounters.

Hospitals now have sophisticated information systems that document details of patient care. Yet, few hospitals have systems that provide patients or caregivers with electronic access to that valuable information (3). Electronic medical records (EMRs) are created primarily for clinician documentation, organizing care, and billing, and patient portals are optimized for outpatient needs. Although much information flows to and from patients and their caregivers, hospitals are set up for all that information transfer to occur verbally, within a patient's room. For example, the primary time for communicating with physicians occurs during the daily rounds, which take place in each patient's room. Otherwise, patients must rely on sporadic in-person clinician encounters or updates from their bedside nurse. From the patients' and caregivers' perspective, information often appears trapped within the hospital room.

In this paper, we present findings from three participatory design sessions that we conducted with former patients, their parents, and clinicians from a large children's hospital. Participants discussed challenges they faced getting information while in the hospital, and then designed possible technological solutions. Participants designed technologies aimed at extending parents' access to and involvement in patients' care, providing more connection between parents, children, and clinicians, and helping parents and children learn throughout their hospital stay. We describe participants' designs, show how these designs represent their desires for improving patient-centered information systems in the hospital, and explain how those desires translate into opportunities for future design and research.

## **Related work**

Our study builds on related work in the HCI and Health Informatics communities in three areas: inpatient information technologies in the hospital room, technology designs for patients and families, and participatory design as a technique for health and health technology research.

### *Patient information technologies in the hospital room*

In recent years, researchers have designed and evaluated technologies to improve hospital patients' access to information and enhance their ability to participate in decisions about their care (3). These technologies have the potential to improve upon existing whiteboard and call button-based systems, which while simple to operate can often frustrate patients and easily get out of sync (3,4).

One particular area of focus has been digital displays within the hospital room, such as large wall-mounted digital whiteboards, bedside tablet-based interfaces, or mobile phone apps (5). These technologies have predominantly focused on improving patients' ability to see information about their care. For example, Wilcox et al. developed a patient-centered large display that could be better kept up to date than manual technologies (6). Dykes et al. built a patient-centered bedside communication center (7) that provides information such as a schedule, test results, and discharge education, and have involved patient preferences in the design of their systems (8). Vawdrey et al. provided a tablet to patients that allowed them to track their progress (9), care plan, and clinical team, and Greysen et al. provided similar information in a mobile phone form factor (10). Kendall et al. show the potential for making background work—"hidden" tasks often performed by patients and their caregivers—more visible in the inpatient setting (11). These and other studies have shown the promise for patient-centered technology to improve access to information. However, there is still much untapped potential of information technologies to empower patients as participants and information providers.

### *Designs for pediatric patients and families*

The pediatric hospital presents unique design challenges for patient-centered information systems. Patients in this setting have diverse developmental abilities and care decisions are made by or at least in collaboration with their parents or guardians. The primary caregiver (often referred to as informal or family caregiver) (12) often takes an active role in information about the child patient's care, and in these settings 'patient-centered' designs often address parents directly. Chen et al. argue that 'informal' caregivers, such as parents, are key stakeholders in decisions about health care and therefore essential users of pediatric health information systems (12). Others have called for the importance of looking at patients and families as whole people, especially in the pediatric setting. Kaziunas et al. studied parent-caregivers of child bone marrow transplant recipients, showing the connections between caregivers' emotion intertwined with information work and arguing for a focus on 'transforming lives' rather than 'transferring information' (13). Miller et al. showed the potential for information technology to support caregivers and patients in the inpatient setting, and identified design implications for future patient and parent-centered technologies (14).

Other researchers have worked on designing parent-focused information systems, with most of these studies based in the neonatal intensive care unit (NICU). This setting often requires both intensive parent involvement in care decisions and physical separation from their child (15). As a result, proposed technologies for the NICU involve parents as active participants, both generating information and communicating with health providers through the tools. Safran et al.'s *BabyCareLink*, for example, allows parents to access information about their child from home or work (16). Liu et al. designed a prototype system for parents of high-risk infants that integrated social network features (17). Yet outside of this specialized context, little is known about parents' and children's desires and values with respect to information systems that involve them as true participants.

### *Participatory design for health*

Participatory design (PD), a technique in which the eventual users of a system co-create ideas and requirements, has been widely used in a variety of settings (18). Using PD, researchers and project leaders can understand the values and priorities of often marginalized or under-represented groups, and the resulting systems better reflect their experiences (18). Health informatics researchers have found PD to be especially useful as a technique for involving patients in the design of hospital technologies. PD has been used in traditional healthcare contexts, such as the design of operating theaters (19). It has also been used to surface the values and priorities of minority populations, such as women from the Caribbean diaspora living with chronic conditions (20) and as part of everyday life (21,22).

Participatory design is particularly useful when designing with and for children (23), and especially when designing health systems. Health-focused human-computer interaction researchers have extended PD techniques for the particular needs of children. Miller et al. worked with young adolescents to design fitness-related games, engaging participants in skits and storytelling (24). Lindberg designed with and for children with cancer (25), finding that designing in pairs was useful, and taking a comics-based approach to help focus on the positive. Others have reflected on the challenges for PD in pediatric healthcare settings, especially for inpatients. Robertson and Balaam questioned the ethics of involving current patients, and suggested working with proxies, such as former patients (26). Researchers have also demonstrated the benefits of involving other representatives, such as family members and clinicians. Bonner et al. co-designed with Child Life Specialists (27). Insights from these projects inspired the design of our study.

## Methods

We conducted our study at Seattle Children's Hospital, a pediatric care hospital in a large urban area in the US, serving patients from a multi-state region. The hospital admits over 15,000 inpatients each year, about half of whom are insured privately. Seattle Children's Hospital is also a teaching hospital.

### *Design sessions*

We held three participatory design sessions with former patients, parents of former patients, and clinicians at Seattle Children's Hospital. Sessions were held in meeting rooms at the hospital and lasted between 90 and 120 minutes. The authors' institutional review board and the hospital approved this work. In Session 1, we recruited only parents and children. In Session 2 and Session 3, both parents and clinicians participated. The same people participated in sessions 2 and 3, which were held one week apart. All sessions were video and audio-recorded; we also took photographs throughout.



**Figure 1.** Two parents design during Session 1.

In Session 1, parents and children identified barriers to information access in the hospital and worked in pairs to design potential solutions to those problems. The session lasted two hours. We first handed out index cards and asked participants to spend five to ten minutes writing down responses to the prompt "What are some big problems in getting information during a hospital stay?" We then invited participants to share their responses with the group, and summarized these responses on an easel. Participants worked in pairs to pick one of the problems discussed and design a solution for it. We invited participants to make use of a variety of craft supplies in their designs. During this design phase, facilitators circulated to both observe participants' progress and help them if they were stuck. We then reconvened and each pair shared their design with the group.

Sessions 2 and 3 followed a similar protocol to Session 1, but broken into two 90-minute sessions one week apart, and had both parents and clinicians participating. We were cognizant of the power imbalance between clinicians, parents, and children, and we chose this different format to give parents and clinicians more time to get acquainted, build trust, and discuss issues in depth. In Session 2, we first asked participants to respond to the question "What are some big problems for patients and families in getting information during a hospital stay?" We then held an extended discussion about these challenges.

In Session 3, held one week after Session 2, we began by asking participants to share any relevant issues or thoughts that had occurred to them during the previous week. We then led a discussion of these topics and a review of the issues raised the previous week. We then divided participants into two groups: the two parents worked together, and the three clinicians worked together. We asked participants to pick one problem identified in the discussion and design a technological solution. The groups presented their designs to each other. We then assigned participants to new groups. One parent worked with the physician, and the other parent worked with the nurses. During this second design phase, we invited the new groups to 'remix' one of their previous designs, or to work on something new.

### *Analysis*

Our research team met after each session to discuss the sessions and identify potential emergent themes. Once all three sessions were complete, we reviewed the transcripts and design artifacts and iteratively identified themes in the design, checking them against the discussions and making sure the themes were present across both participant groups.

## Participants

Thirteen people participated in our sessions: eight parents, two children, and three clinicians. We collaborated with the hospital's Patient Relations office to recruit parents and children, and recruited clinicians through word of mouth. Parent and child participants were eligible to participate if they had spent at least two days in the hospital within the last two years, felt comfortable engaging in a group discussion in English, and were between the ages of 7 and 75.

Clinicians were eligible if they were currently engaged in full-time patient care within the hospital. Two of the clinicians were nurses, and one was a physician.

### Summary of designs

Participants in our study created 9 designs, each focusing on a problem identified during the brainstorming discussion. In this section, we provide a summary of each design. In the section that follows, we extract and describe themes across the designs. Designs 1 through 4 were created by parents and children in our first session, without clinicians present. Designs 5 through 9 were created by parents and clinicians during our third session; designs 8 and 9 from this session were inspired by designs 5, 6, and 7. We have given each design a descriptive label (with the exception of design 6, which the participants named themselves).

#### 1. About me (2 parents)

These parents sought to address the burden of parents and children repeatedly providing the same information to clinicians and the corresponding danger of forgetting something important in the retelling. They designed a patient-centered website where children and parents can provide information in a centralized manner (see figure 2).

#### 2. Knowing me, knowing you (2 parents)

These parents also focused on intake, when parents repeatedly answer similar questions. Their design is a tablet-based interface for capturing patient-generated data, including preferences. This design also includes a list of who has entered the hospital room, including name, photo and role.

#### 3. Parent-clinician watch (2 children)

These two former patients focused on the challenge their parents had getting questions answered and connecting with specific clinicians. To solve this problem, they designed a smart watch, which would allow parents to quickly place a video call to a clinician. We asked them why they designed something for their parents and not for themselves. They responded that their parents were the ones who really needed to be active on their behalf, and they worried about children being overwhelmed.

#### 4. Asking and answering (2 parents)

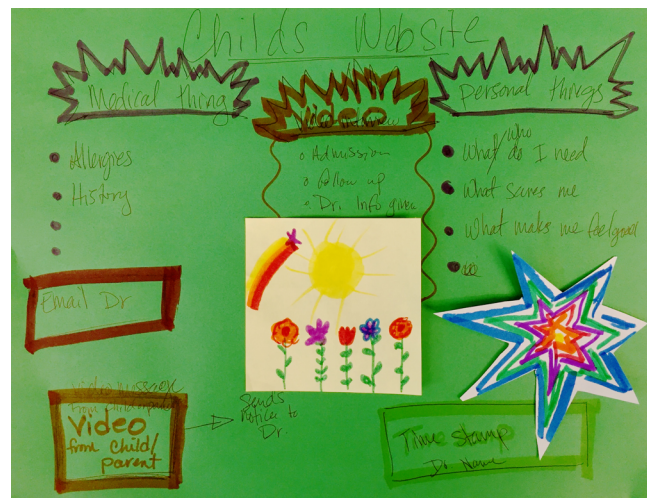
These parents focused on challenges parents face both gathering and providing information. Their solution, also tablet-based, allows parents and children to record their answers to common questions, and those answers would travel with the patient when he or she switched services within the hospital. The system would also allow parents to ask questions before or after daily rounds, and promote various ‘hidden’ services overlooked by parents unfamiliar with the hospital, such as volunteers who can look after children while the parent takes a break.

#### 5. Family-centered portal & communicator (3 clinicians)

The three clinician participants designed a multi-platform system with three main components: an overview of the care team and the hospital, a patient-focused portal with up-to-date information in a way parents can easily understand, and a communication feature so parents can ask questions and have them answered during clinical team meetings.

**Table 1.** Participant demographics

Session	Status	Age	Gender	Ethnicity
1	Parent	40-49	F	White
1	Parent	40-49	F	White
1	Child	13-17	M	White
1	Child	13-17	M	Asian/White
1	Parent	40-49	F	White
1	Parent	40-49	F	White
1	Parent	40-49	F	White
1	Parent	40-49	F	White
2,3	Parent	30-39	F	White
2,3	Parent	50-59	M	White
2,3	Physician	30-39	M	Asian
2,3	Nurse	18-29	F	White
2,3	Nurse	30-39	F	White



**Figure 2.** About me, featuring patient-provided video, and medical as well as personal information.



The hospital overview portion gives parents information about amenities, and the name, photo, and role of clinicians who care for their child. The system's patient-focused portal provides access to the official medical record but in a more interpretable and family-friendly way. This will also include an estimated schedule for the next day, so parents and children can plan ahead. The communication feature seeks to answer the question "what keeps me up at night?" Parents can submit questions 24 hours a day, in the hospital or from home or work, which will be answered by the clinical team and incorporated into the daily rounding activities of the team.

#### 6. OneDocAway (2 parents)

The two parents who participated in the second and third workshops designed two systems. The first of these emerged during a discussion in the second workshop, in which the parents expressed their frustration at feeling 'trapped' in the hospital room waiting for clinicians to come by. This system gives an estimated arrival time of the rounding team, showing their progress from patient to patient. They called their solution *OneDocAway*, based on the transit app *OneBusAway*, which provides real-time estimates of public transit departure and arrival times.

#### 7. Lab investigator (2 parents)

The parents' second design addresses challenges understanding lab results and how those results change over time. The system functions as a sort of super-powered patient portal, with results for a particular lab graphed over time, with a high and low marker so parents could know when levels fall outside of normal ranges. Parents could also click on terms for detailed explanations backed by trusted sources vetted by the hospital.

#### 8. Shared calendar (parent & doctor)

In this 'remixed' team, one parent and one clinician (a physician) collaborated on a system to improve coordination and collaboration through a parent-focused shared calendar. This system collects events from the medical record, such as medications, labs, rounding times, and specialist visits, and presents a month, week, or day view.

#### 9. Hospital buddy (parent & 2 nurses)

In this second 'remixed' team, one parent and two clinicians (both nurses) extended Design 5 to encompass a child and family's whole experience with the children's hospital, across inpatient stays and outpatient interactions. The system works on a phone, computer, or hospital-provided tablet. The additions to the system focus on tracking patient/family-clinician communications, with an emphasis on patient and parent-provided information. Parents can also provide information that would persist across shifts and across hospital stays, such as preferences, habits or personality.

### Bursting the bubble: opportunities from participants' designs

Participants' designs involved parents and children as active participants in the patient's care—as producers, aggregators, communicators, and learners. They showed how information technology can burst the information bubble of the hospital room, using information and communication technology to move beyond the constraints of the physical room. In doing so, participants designed technologies that allow parents and children to disseminate information to

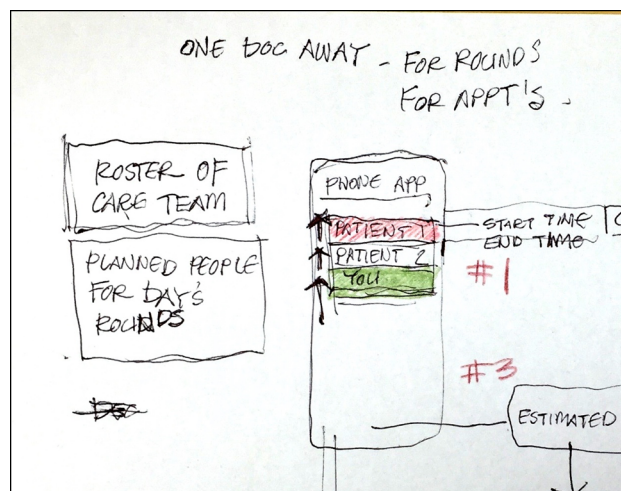


Figure 3. A detail of the *OneDocAway* design.

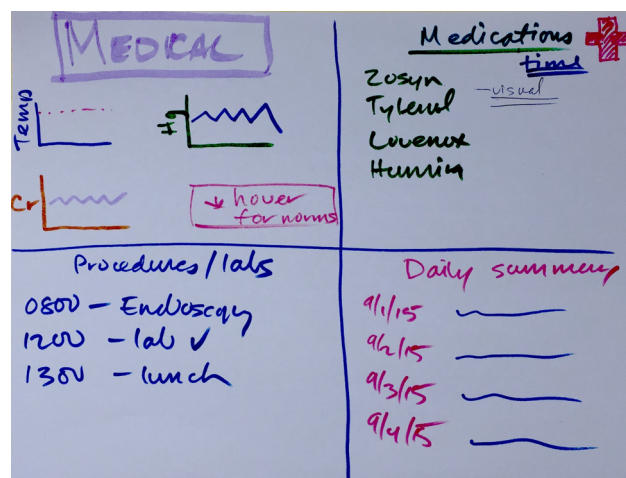


Figure 4. Part of the *Shared calendar* design.

the care team from within the room, share and receive information while outside the room, stay in persistent contact with their care team, and learn about their condition and care throughout the hospital stay.

#### *Sharing out: parent-initiated dissemination*

All participants in our study were adamant in their support of parents and children as participants in their care, and several of the designs encouraged parents and children to take an active role in providing information to clinicians. These designs focused on giving parents and children the ability to pre-emptively share information, so clinicians arrive in the hospital room with a sense of the patient's expertise, priorities, and values.

Many participants spoke about this challenge of sharing out the same information with many clinicians. As one parent put it: *"One of the big things...is that that 50 first dates thing that they do, where I think the shortest ER visit we ever had was nine hours. You have just this constant cavalcade of people that come in and ask you the exact same questions."* Clinician participants also recognized this issue; one of the nurses reported it as a very common concern, but said some overlap was inevitable as patients were transferred between specialties. Four of the designs tackle this theme directly, addressing parents' concerns at being asked the same questions over and over again by allowing them to proactively tell their stories in a way that clinicians would all be able to see. *About Me* even includes 'read receipts' so that parents will know that their messages and updates have been received by specific clinicians. The parents who designed *Knowing me, knowing you* and *Asking and answering* both specified that clinicians would ideally view patients' answers before entering the hospital room, thus arriving informed and ready to ask the important questions. *Hospital buddy* allows parents to proactively share information such as their child's personality or routines.

Clinicians in our study were receptive to this kind of approach, although with some caveats. As the doctor in our study put it: *"If it's something critical and important I want to hear it firsthand from the parent. I don't want to depend on documentation; there's room for error there. For other things, like, I think family history, social history, other things are important but I'd love if that kind of stuff was better automated and documented and I could say 'hey I see this' just run it real quick by the family and not waste as much time on certain things that potentially are very easy to transfer."*

Designs for 'sharing out' also encourage clinicians to regard the patient as a whole person, allowing parents and children to share information that would not be included in standard clinical questions, to share information in a way that makes sense to them but may cut across medical boundaries, and to emphasize certain preferences. For example, *About Me* includes questions such as "what makes me feel better," and *Knowing Me, Knowing You* allows patients to specify preferences, such as an aversion to certain flavors. Those systems also both incorporate parent and child-generated video responses, which add a personal touch by recording information literally in the patient's own words.

#### *Looking in: accessing the hospital room remotely*

Parents, children, and clinicians all designed technologies aimed at extending parents' access to and involvement in patients' care, allowing them to keep up to date without trapping them in the patient's room. Some designs allow parents to virtually peek into the hospital room from afar. In both *Knowing me, knowing you* and *Asking and answering*, parents can see a list of who visited the hospital room while they were away. In *Family-centered portal & communicator* (the clinicians' design), parents can see a calendar view of visits to the hospital room, as well as a tentative schedule for the upcoming day. The clinicians' design also incorporates a parent-focused summary of each day, so even remote parents can keep up to date more easily.

Several designs focus on allowing parents to contribute to discussions and care decisions that take place in the hospital room. For example, the *Family-centered portal & communicator* design allows parents to asynchronously send updates to the clinical care team during clinical rounding. At Seattle Children's Hospital these rounds are done in or just outside of the hospital room and typically include parents or caregivers who are present at the time of rounding. The *Family-centered portal & communicator* extends this participation to include parents who cannot be physically present. Clinicians also felt this type of design would help them do their job more effectively. As one nurse put it: *"If a parent can't make rounds then it's my responsibility as a bedside nurse to relay all that information that happened and I could be prioritizing something different than the parents wanted to hear. And then one provider relaying to another, another nurse relaying something, is difficult."* A technology and ritual in which parents can 'look in' to daily rounding even from afar would allow this nurse to focus on other aspects of the patient's care, secure in the knowledge that the families were well informed and able to provide important information. She would also be able to get a better understanding of how parents were making sense of the information surrounding their child's care, and the kinds of input they valued.

Other designs focus on giving parents more freedom within the hospital. Several parents spoke about these issues. As one parent put it: *“There are many times where I’m like sitting in the hospital room for like hours, like waiting for rounds, although you do kind of know – there is like a four hour time period generally, but that’s a long time, right? And they’re not in your room for very long, so 5-10 minutes, that’s the time that you rush down to grab something to eat because you couldn’t wait any longer.”* Another put it more succinctly: *“You’re basically held captive in your room unnecessarily.”* *OneDocAway*, which helps estimate the timing of upcoming clinician visits to the hospital room, allows parents to feel confident that they can leave the hospital room and not miss an important conversation with a clinician who stops by the room while they are out.

#### *Connecting across the hospital*

Information technology can also improve communication and coordination among parents, children, and clinicians throughout the hospital. Several of the designs enable such pervasive contact throughout the day, allowing parents and clinicians to communicate when they have time, even if both parties cannot meet in the hospital room itself. Parents, children, and clinicians all mentioned the value of transparency and coordinated communication, and several of their designs incorporated ‘anytime’ contact options.

For example, the two child participants in our study designed a smart watch (*Parent-clinician watch*) for their parents to wear that would support video calls to clinicians, allowing parents to get answers from clinicians without requiring the parents or clinicians to be physically present in the hospital room.

Several participants designed pervasive contact features to ensure their peace of mind at times when clinician encounters were unlikely, especially late at night. Parents in our study seemed keenly aware of the design tension between providing parents with pervasive access to clinicians and overwhelming those clinicians. In the design sessions, parents and clinicians discussed this issue directly:

*Parent: “One of the things we started realizing was that you think of something at 11 o’clock at night and you send an email off and then at 11:15 you’re getting an answer back...I learned that I write the email and I save it and I give myself a little reminder that like at eight in the morning or 8:30 I send it to her, because I know she’s going to look at it and I don’t want to disturb her when I shouldn’t be disturbing her.”*

*Doctor: “That’s very considerate of you to do that.”*

*Parent: “She’s so amazing.”*

The designers of *Knowing me, knowing you* added an ‘email a clinician’ button. *“There’d be a way to email your doctor in the middle of the night (laughs), whether or not they check it. Just sometimes you need to do that, to sleep.”*

Other designs focused on another aspect of pervasive contact: proactive awareness. *Shared calendar*, designed collaboratively by a parent and clinician, allows parents to see a timeline view of their previous and upcoming procedures, labs, and clinician visits, but it also allows parents to add their own schedules to the calendar, which would then be visible by everyone on their clinical team. As the doctor on this team described it, *“the parent/caregiver schedule...could automatically go through to the medical team, so the parent just has to say all right, mom’s leaving here, dad’s coming here, then it would automatically be sent over.”*

#### *Promoting learning for partnership*

Parents can become more effective partners in care as they gain expertise in the medical issues related to their child’s care. Several of the designs reflect this theme by improving parents’ understanding of terminology and helping them interpret test results, so they can better understand and participate in decisions around care.

Parents and clinicians saw the potential of clinical information tools to promote greater understanding. For example, the *Lab investigator* design allows parents to learn not only whether their child’s values are in the expected range, but lets them drill down into more detailed explanations whenever they wish. As the doctor in our study put it: *“It would be nice if the medical records system was built for families and patients to understand as well too. A lot of times we’re saying let me print out the labs for you, explain to you what the labs or the radiology shows but if those labs and the radiology results were written in a way that could be easily understandable and interpretable that’d be nice to have a point of reference for families and patients.”*

These tools are especially necessary after an initial diagnosis, when information is flying at parents at high speed while they are trying to cope with the emotional aspects of their child’s condition. As one parent put it: *“Education is a very*

*good point, because we all come in knowing nothing, and we leave with more knowledge than we ever wanted to have but getting from point A to point B can be a long process, a painful process. It would be good to facilitate the learning curve on the early part of it so you're more participatory. Then you have a certain base level of knowledge that you're applying to all these results."*

Others specifically noted the potential for technology to help them record clinical information and process it later when they had more time and were better able to cope. *"I imagine had there been some sort of video recording or something of some key meetings or things of that sort, where it's like okay, then I could go back and play what was said by the doctor, that sort of thing, not just relying on my memory, my husband's memory of what they were saying as I'm sobbing."*

Participants also began to explore the potential for child patients as learners about their own bodies and the teams that care for them. *Hospital buddy* becomes a totem carried by the child and is used by both the child and parent throughout the hospital experience. The design involves children as participants and learners about their own care, within the inpatient setting and beyond.

### **Lessons learned from participatory design with children, parents, and clinicians**

#### *Parents and clinicians designing together*

When it comes to caring for children, parents and clinicians do not always see eye to eye. In the hospital, parents cede a certain level of control over their child and rely on clinicians' knowledge and ability. Likewise, clinicians sometimes see parents' advocacy for their child as a barrier to providing the most effective care. With these issues in mind, we carefully considered the flow and approach of our parent/clinician design sessions. In the end, parents and clinicians worked together quite well. Both sets of participants were accommodating, and frequently expressed their willingness to see things from each others' perspective. In several exchanges, the two parents in these sessions discussed their worry about overburdening clinicians. Likewise, clinicians frequently expressed their desire for transparency and involving parents actively in decisions about their child's care.

Much of this considerate attitude is attributable to the participants themselves; both parents and clinicians clearly came to the design sessions ready to collaborate. In addition, we carefully crafted our approach to foster collaboration and a democratic attitude. We began with an icebreaker exercise in which everyone—participants and facilitators alike—created a simple design and shared it with the rest of the group. We did not ask participants to design until the following session, giving them time to build trust and mutual understanding through discussion in their first session together. Only after participants had discussed problems and designed solutions to those problems did we ask parents and clinicians to collaborate. The resulting designs truly were cooperatively designed; parents and clinicians took turns designing and sharing their designs.

Based on our experiences, we are optimistic about the potential for collaborative patient/provider design for the hospital. Through their discussions and designs, parents and clinicians brought out design tensions and learned more about each others' perspectives, and the designs are all the richer for doing so.

#### *Sharing video with clinicians*

All the designs created during Session 1 allow parents and/or children to communicate with clinicians via video. In particular, the parents' designs from this session intend for clinicians to watch the videos before entering the hospital room. As one of the parents who designed *About me* put it, a clinician enters the hospital room *"and asks you 25 questions, it gets videotaped and then everyone can watch them before they come in and ask you the same 25 questions!"* However, clinical members of our research team quickly pointed out the pragmatic challenges to such an



**Figure 4.** A child participant demonstrates the *Parent-clinician watch* design.



approach. Clinicians operate in a highly text and graph-driven information workflow with little room to add additional tasks, and the idea of a clinician watching even a brief video before entering each hospital room seems impractical.

What, then, are we to make of parents' and children's use of video in their designs? Video-recorded information has definite advantages from a patient's perspective. Participants felt it would be easier for parents and children to record information by just speaking, which seems like a natural response given that clinicians often ask them to verbally recount medical issues or histories. Low-literacy patients and young children would undoubtedly benefit from a verbal communication tool. Second, allowing patients and their caregivers to share information with clinicians in a naturalistic manner also frees them to express themselves as whole people and communicate across and beyond clinical information categories. Finally, in analyzing the data from our design sessions, we came to understand that parents and children believed because *they* find video easier to create and consume, that clinicians would also find it easier. These considerations will be crucial to keep in mind in designing interfaces that allow patients to easily express information but also support clinicians' workflow and need to quickly review text-based information sources.

### **Limitations and future work**

In this study, we worked with parents, children, and clinicians to identify design opportunities for patient-centered information systems in the hospital. However, our study has several limitations. We worked primarily with 'expert' parents and children who had extensive experience in the hospital. Despite extensive outreach and recruitment effort, only two children participated in our study. Participants were not demographically representative of the hospital's patient pool, and Seattle Children's Hospital is not necessarily representative of all pediatric hospitals. In the future, we hope to verify and extend these findings in other contexts and with different participant groups. Furthermore, participants' designs significantly extend the 'status quo' and challenge existing modes of patient-provider interaction, which may inhibit the successful introduction of such technologies into hospital care. To address this, we plan to design and deploy technology probes based on participants' designs. Many of the designs are technically feasible, and mainly require canny interaction design and institutional buy-in to be tested in realistic settings.

### **Conclusion**

In this study, we asked participants to answer a simple question: how can technology alleviate big problems patients face in getting information about their care? Through their designs and discussions, participants showed the potential for information technology to allow parents and children to share information to clinicians from within the hospital room; for parents and other loved ones to look in on the hospital room from afar; for parents, children, and clinicians to stay in touch throughout a hospital stay; and for parents and children to learn within the hospital room and beyond. The designs show that patients and their caregivers can be more than recipients of information about their care; they can produce, aggregate, and learn information throughout a hospital stay. The values expressed in these designs will be important to explore in other contexts, such as adult hospitals and chronic condition management as well. While the hospital room will remain the hub for information about a patient's care, it doesn't have to be a bubble.

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