Sharing by Design: Understanding and supporting personal health information sharing and collaboration within social networks

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Abstract

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Friends, family, and community provide important support and help to patients who face an illness. Unfortunately, keeping a social network informed about a patient's health status and needs takes effort, making it difficult for people who are sick and exhausted from illness. Members of a patient's social network are often eager to help, but can be unsure of what to do; they must balance their desire to help with trying not to bother a sick friend. In this dissertation, I describe research on how people share health information within their existing social networks and present technology to create informed, helpful networks. I used a mixed methods approach of interviews and an online questionnaire to provide a detailed analysis of what health information people share, who they share with, mode of transmission, and why people share personal health information.

My research culminates in the design of new technology that enables patients to create an informed network and catalyzes helping activities within that network. I used participatory design methods with breast cancer patients and survivors to ensure that the design is based on a firm understanding of users' goals, priorities, constraints, and current sharing practices. Together, we designed a technology that allows a patient to keep their social network up to date, solicit help from their network, field offers of help, and collaborate through discussions. The design is motivated by the insight that a more informed social network is better able to provide needed help and support. Advocating that patient-centered technology should allow users to share personal health information with others comes with the responsibility to contribute to the effort to create

usable privacy interfaces. I present a method for evaluating the transparency of privacy controls and use this method to identify a transparent icon that can be embedded within interfaces to show how information is being shared.

Embracing the complex picture of how patients manage and share personal health information with others will ultimately improve the technology available to support patients. I contribute a better understanding of current sharing practices and technology to enable patients to create informed, helpful social networks.

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This is to certify that I have examined this copy of a doctoral dissertation by

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and have found that it is complete and satisfactory in all respects,
and that any and all revisions required by the final
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The iMed research group has been a wonderful place to incubate ideas about how to change the playing field for patients and generally make the world a better place. Past and current members have all contributed to making this dissertation possible. Thank you to the whole team for your support, encouragement, and lively discussions. Special thanks to Andrea Civan for her involvement in the questionnaire study and transparency study; to Christopher Powell for his help with the first design group and for implementing the technology we designed; to Kenton Unruh for his early work with breast cancer patients and his involvement in the second design group; and to Marlee Mukai for her involvement in the transparency study.

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DEDICATION

To the people who made this possible.

"I think, with never-ending gratitude, that the young women of today do not and can never know at what price their right to free speech and to speak at all in public has been earned."

–Lucy Stone, from her 1893 speech *The Progress of Fifty Years*

Chapter 1

Introduction

Ellen got the news that she had breast cancer on a Tuesday. She had to pull the car over twice on the way home because she couldn't stop crying. In one afternoon, her life was overturned and the pieces seemed to be spilling everywhere. Her perspective on what was important changed. Her daily activities changed. Her understanding of what it means to have cancer changed. Her self-image changed. Her relationships with her friends and family changed.

In 2009, over 190,000 people were diagnosed with invasive breast cancer in the United States (an additional 62,000 were diagnosed with in situ breast cancer) (American Cancer Society, 2010). The statistics for all forms of cancer are sobering: approximately 1.5 million new cancer diagnoses in 2009 (American Cancer Society, 2009). Cancer has become a survivable disease for many people, but a cancer diagnosis is still serious. 98 percent of women diagnosed with localized breast cancer survive at least 5 years; 83 percent of women diagnosed with regional disease survive at least 5 years; 23 percent survive at least 5 years after a distant-stage diagnosis (American Cancer Society, 2010). For all the wonderful advances in medicine, cancer remains deadly and it requires swift action. Many cancer patients begin treatment within just a few weeks of their diagnosis.

After a cancer diagnosis, patients often scramble to learn about the disease and to make room in their lives for this new, potentially all-consuming, problem. They often have a substantial amount to learn about their diagnosis and upcoming treatments. They must decide how much information to share with friends and family and must find ways to handle everyone else's reactions to their disease.

Social networks can play a large role in a cancer patient's experience. Loved ones' presence, absence, helpfulness, or inability to cope can have a big impact on a patient who is busy trying to survive cancer. However, many people do not have extensive experience with cancer; they are not sure how to be helpful and do not know much about what the patient is experiencing. Even the best intentioned friend or family member can fail to be helpful or, worse, unintentionally make life more difficult for a cancer patient. In this dissertation, I explore how patients share health information with their social networks and describe technology to promote collaboration between patients and their social networks.

Simple actions on the part of the social network can add up to improve the cancer experience. Providing rides, running errands, doing chores, and generally being present to show they care are some of the many ways members of a social network can help. Social networks that are armed with information about what the cancer patient is up against and what they are experiencing are in a much better position to provide help and support than networks that are kept in the dark. Further, networks can use information about what has helped other cancer patients to help their own loved one. Presently, people have this information only if they have been through cancer treatment themselves or with a close family member. I present research and a new technology designed to make this information available to social networks without the benefit of personal experience with cancer. The technology I designed in collaboration with cancer patients allows an individual to share health information with their social network –creating an informed network – and share information about how to help –positioning the network to take helpful actions.

1.1 The Patient Experience

Fully understanding the patient experience requires a look at the environment in which patients in the United States operate. A paradigm shift in health care has occurred over the last several decades. In the past, doctors made most health care decisions for patients. Patients took a passive role and did not expect that the doctor would include them in making decisions about their treatment. The antiquated term "patient" personifies the general attitude towards the role of the patient.

As medical care has advanced we have shifted to a more shared and collaborative relationship between clinicians and patients. More diseases can now be effectively treated with substantially more treatment options now. Doctors no longer expect to make all health decisions for a patient; a doctor partners with a patient to help them make their own informed decisions. This shift has happened slowly, and patients and doctors continue to negotiate their roles in health care. This renegotiation process has been studied from the clinical perspective, and a focus has emerged in the literature on ways for clinicians to allow patients to be more active in their care (Charles, Whelan, Gafni, Willan, & Farrell, 2003; Charles, Gafni, & Whelan, 2004). Kaplan et al. say, "The changing roles of both providers and patients point to a need for patient-centered systems" (Kaplan, Brennan, Dowling, Friedman, & Peel, 2001).

A literature review paper found that "the informed activated patient is associated in research studies with improved health-related behaviors and better clinical outcomes" (Bodenheimer, 2005). The paper explains that, "Patient activation refers to patients being active participants in their care. Pre-activation describes a process of assisting patients to be more assertive during the medical visit," and suggests that patient activation and pre-activation will be key to improving outcomes. One study shows that patients who play a more active role in their care had favorable health outcomes and also consumed fewer services (Laine & Davidoff, 1996). A paper titled "The patient: our teacher and friend" describes how patient experiences and expertise should be respected and utilized by clinicians (Wiederholt & Wiederholt, 1997). The author gained this insight after undergoing treatment for cancer. We are moving towards a situation in which patients are truly empowered in the healthcare environment and are viewed as partners by the clinicians they consult, but we have a ways to go.

One barrier to patient empowerment is that being an active partner involves a substantial amount of work. Besides the physical work of healing and recovery, patients also need to gather, read, and understand information relevant to their diagnosis, make decisions, and attempt to navigate the health care delivery system. Patients often need help with all of these activities. Social networks, friends and family members, can be involved in most aspects of a patient's experience. Unfortunately, very few tools have been created to support the work that patients do, and even fewer tools support the role the social network plays in this work.

1.2 Guide for the Reader

My research builds on previous efforts to describe the patient experience and design technology to support the work it takes to be a patient. I begin Chapter 2 with a description of this research. Research on personal health information management and on the role social networks play in the patient experience should inform the development of technology to improve the patient experience. Although the published research about personal health information management is new, and somewhat limited in scope, there have been some tools created to support patients. Before describing my own research to create technology for patients, I describe the existing technology to support personal health information management and the extent to which these tools support the role of the social network. I also describe technology specifically designed to support the information exchange between patients and their social networks. My research also draws upon work in the field of human-computer interaction where researchers have studied sharing non-health information within social network and within the workplace. Finally, a discussion of using technology to share personal health information would not be complete without investigating and finding ways to ameliorate the potential risks. As a starting place, I describe recent human-computer interaction research on developing interfaces for displaying sharing settings in usable and understandable ways outside the health domain.

Chapter 2. Related Work

- Review of research on Personal Health Information Management and sharing
- Review of research on the importance of social support
- Discussion of existing technology for personal health information sharing
- Review of research on information sharing in the human-computer interaction domain
- Description of Usable Privacy domain as it relates to personal health information sharing technology

Designing technology to support information exchange and collaboration between patients and their social networks requires a mixed-methods approach. Before jumping into drawing interfaces and talking about databases, it is important to understand who will use the technology and what problems the technology should address. I began my inquiry into how people share personal health information and collaborate with their social networks with interviews. These semi-structured interviews provided a deep understanding of a small number of people's experiences. Based on my findings, I designed an online questionnaire to capture the experiences of a larger number of people. Questionnaire results are more limited in their depth and do not provide the opportunity for follow-up questions, but these results provide a much larger sample and provide qualitative data about how people currently share and collaborate with their social networks. I describe my findings about people's current practices in Chapter 3.

Chapter 3. Understand personal health information sharing in a general population

- What personal health information people share with their social network.
- Who people share personal health information with.
- Why people share personal health information within their social networks.
- How people decide what information to share and who to share it with.
- What means people use to share personal health information within their social networks.

After building a deep understanding of why people share information within their social network, I was in a better position to see where technology could be useful and what types of functionality might be useful in consumer health technology. During the design process I collaborated with two groups of breast cancer patients and survivors. I used participatory design methods to bring the voices of potential users into the design process. The participatory design process both generated a design based on their needs and experiences and provided me with still more information about the experiences of cancer patients and their social networks. Chapter 4 describes the relevant participatory design literature, the design process, insights into the problems we designed for, and design ideas generated by the groups.

Chapter 4. Design technology with health consumers to support sharing and collaboration

- Review of participatory design literature as it relates to designing with health consumers
- Insights into sharing and collaborating within social networks and how technology can help
- Design ideas for technology that facilitates sharing and collaboration within the social networks of cancer patients

Chapter 4 ends with design ideas generated by the two design groups. I integrated those designs, and some of my own ideas based on my previous research, into a cohesive system design in Chapter 5. Through a series of screenshots and wireframes, I describe technology that will facilitate sharing within social networks to create informed helpful networks and will catalyze helping activities to support cancer patients.

Chapter 5. Technology to support sharing and collaboration within social networks

- Functionality to create an informed social network
- Functionality to catalyze help within a social network
- Ways to use existing technology to disseminate information

Chapter 4 and Chapter 5 present technology to facilitate sharing personal health information within social networks. Further, the research presented in Chapter 3 also implies that controlled sharing of information should be part of the future development of personal health records (PHRs). Suggesting that people should use technology to share personal health information with others brings up a host of privacy concerns. Security will certainly need to be carefully designed for any such technology. However, even the most secure systems cannot prevent unintended sharing. Transparent interfaces that make sharing features abundantly clear to uses will help ensure that information sharing is always intentional. In Chapter 6, I describe a study of multiple sharing interfaces to determine the most transparent design. The laboratory-style study described in Chapter 6 measured users' abilities to infer sharing settings from multiple interfaces and to change sharing settings. I also report user preferences and qualitative observations of breakdown in usability and transparency.

Chapter 6. Identify transparent interfaces for sharing health information

- Comparison of interfaces for showing who can see a piece of information
- Usability of interfaces for showing who can see a piece of information
- Comparison of icons providing an overview of the sharing settings for a piece of information

Chapter 7 wraps up the design discussion with my reflection on bringing patients into the design process. The health domain holds some challenges for traditional participatory design methods and I describe the ways that I adapted the methodology to meet those challenges. I also describe techniques I developed over 5 different design groups for helping patients become active partners in the design process.

Chapter 7. Bring health consumers' voices into the design process

- Methods for overcoming challenges to traditional participatory design methods
- Practical advice for helping health consumers become active partners in the design process

In Chapter 8, I describe the implications of my research for the larger design space –technology for health consumers. I also describe some of the limitations of this work and opportunities for future work.

1.3 Conclusion

In the following pages you will read about a set of studies that contribute to our understanding of how people share personal health information and collaborate with their social networks and also how new technology can support these needs. I describe a mixed-methods approach, pulled from multiple domains, to triangulate and improve our understanding both of what people do now and what they would like to be able to do in the future. I present the design of new technology to support individuals creating an informed social network and catalyzing helping activity within their network. As technology in medicine improves, it is spreading to the patient population as well. My findings and the technology I present further our understanding of what patients do and need and have implications for the design of future technology for patients.

Chapter 2
Related Work

The research in this dissertation draws substantially from both the health informatics and the human-computer interaction (HCI) literature. There are also related products available to the public that are relevant to the technology I designed in collaboration with patients. I begin my review of related work by summarizing the health informatics research on how individuals manage their own personal health information and how individuals share personal health information within their social networks. Related to this, is research in social work, psychology, and medicine on the role that social support plays during cancer care. After describing what we know about how people operate without technology, I describe technology that has been designed to enable patients to share personal health information within their social networks. Although they are not based on research, and papers are not published about their use, these systems are directly related to the technology I propose.

Sharing personal health information has not been widely studied, but there could be similarities between sharing health information and sharing other types of information. Within the domain of human-computer interaction, technology for sharing information at work and in personal contexts has existed, and been studied, for decades. It is hard to imagine information more personal than health information, but calendars and photographs might come close. I review select HCI literature on how people make decisions about what information to share and how systems can support comfortable sharing. I also draw on the usable privacy literature to further examine how technology can support intentional sharing, and eliminate unintended disclosure.

2.1 Personal Health Information Management and Sharing

As the patient's role in the clinical relationship shifts, research has investigated how to help people gather health information and better understand the decisions they are now involved in making (Degner et al., 1997). However, the research on the information needs of patients (Hinds, Streater, & Mood, 1995; Mills & Sullivan, 1999; Rees & Bath, 2000) is just the tip of the iceberg of all the work health consumers do to understand their health condition, make decisions, manage their treatments, and navigate the healthcare delivery system. Personal health information management (PHIM) involves getting, keeping, using, and sharing personal health information and more research is needed to understand the full scope of the work that health consumers do (Pratt, Unruh, Civan, & Skeels, 2006). The most thorough research in this area focused on understanding the work breast cancer patients do and was conducted by Kenton Unruh for his dissertation (Unruh, 2007). He describes three kinds of work his participants engaged in: the work required to be a patient, the work required to maintain their personal life, and distributed work done with others including clinicians and members of their social network. He says, "Patient work is real work in the sense that it is necessary to achieve positive health outcomes but much of the work is largely invisible because it remains hidden amidst activities that span multiple clinicians and extend beyond the treatment center" (Unruh, 2007). During this research, he also found that the work patients do enabled them to help "identify, prevent, and recover from medical errors" (Unruh & Pratt, 2007). A study of a more general health consumer population focused on the ways people manage personal health information in their homes (Brennan & Kwiatkowski, 2003; Moen & Brennan, 2005). This study documented people managing a wide range of health information including medical records as well as outside health information sources, prescription information, and artifacts of their own creation. One of the important findings from this work was that information was collocated based on anticipated use. Personal Health Information Management (PHIM) work takes time and effort, yet it is necessary for any patient who wants to be actively involved in their care. More research on the work people do to manage their health information, maintain their personal lives, and navigate the health care environment will add depth to our understanding of what can be done to support health consumers.

The third category of work that Unruh identified, "distributed work," is most relevant for this dissertation; this is the work breast cancer patients do with others (Unruh, 2007). He found that, "patients involve a wide range of people from their social networks in their patient and personal work. Despite the prevalence of such multi-actor work patients receive little support from information systems to facilitate their work with others in a distributed context." Some of this work is with and in the midst of clinicians, but other work takes place with the social network. Participants sometimes shared their workload with others by getting help with tasks or simply asking others to complete tasks for them. Patients also received other forms of support from their networks throughout the cancer process.

Within the larger domain of personal health information management and the work it takes to be a consumer, my focus is on the roles others play in the work it takes to be a patient. Much exploration was needed in this area before I could begin to build technology to support the sharing and collaboration people do with their social networks. Some early work has shown that social networks can play an important role in helping health consumers. A study with prostate cancer patients and "informal care givers" revealed several kinds of relationships patients had with others, including explicit supportive relationships and implicit supportive relationships (Weiss & Lorenzi, 2005). They highlight the difference between designing systems that are information-centric and systems that are relationship-centric. Relationship-centric systems would allow individuals to define roles and privacy within their community of friends and family. Relationship-centric systems would also provide forms of implicit feedback, which are important for maintaining relationships. The researchers conclude that "Developers of cancer communication systems, and perhaps developers of all patient communication systems, should attempt to address more of the patients' outside relationships that might influence or be affected by the online clinical communication with the health care team." This research with prostate cancer patients confirms that personal health information is not collected and used by a single individual –others are involved too. The two studies presented in Chapter 3 add substantially to this area of research by presenting a detailed look at the information people share, who they share information with, and how they make decisions about what to share and what to keep private.

2.1.1 Helping within Existing Social Networks

Social support is a critical ingredient to physical and mental health during cancer treatment (Hewitt, Herdman, & Holland, 2004; Manne, 2003; Roberts, Cox, Shannon, & Wells, 1994). The term "social support" describes the extent to which an individual feels supported by their social network; it is measured subjectively by an individual and can be high or low regardless of the amount of people in the individual's network or the number of interactions within a network. While high levels of social support are correlated with better physical and mental health during cancer treatment, social support is not something every cancer patient experiences. People are often reluctant to ask for help—even when they need it, and social networks do not always know what type of support to provide. Ironically, social networks are often ready and willing to provide help. Psychology research shows that people significantly underestimate the willingness of others to help (Flynn & Lake, 2008). One reason for this underestimation is that people, including patients, over-weight the burden their request for help will place on a potential helper (Depaulo & Fisher, 1980; Flynn & Lake, 2008; Lee, 1997). These weightings often occur without explicit information from the social network. Thus, we are faced with a situation where patients who need help don't ask, and a network who wants to help is never provided with the opportunity. Through the participatory design process, described in Chapter 4, I identified barriers that patients and members of the social network face that inhibit helping. The design groups and I focused on developing technology to overcome these barriers and span the gap between networks who want to help and patients who need help.

2.2 Existing Information Sharing Technology for Health Consumers

A limited number of systems have been created for health consumers that include some type of sharing features. One relatively large sector of technology for health consumers is the Personal Health Record (PHR). These systems are designed to facilitate gathering and using a personal collection of health information –largely pulled from medical records. Some of these systems now include features to support sharing portions of a personal health record with others. In a different vein of technology, several websites have been developed for the purpose of facilitating sharing updates about a patient's health within their social networks. The latter technology has grown up mostly outside of the medical community, whereas many, though not all, PHRs have grown as off-shoots of Electronic Medical Records (EMRs). Table 2-1 shows these two types of technology in terms of their sharing features. The first two columns (highlighted in blue) are two

	HealthVault	Google Health	theStatus	CarePages	Caring Bridge	Lotsa Helping Hands
Keep and manage health Information	Yes	Yes				
Share information (all or none)	Yes	Yes	Yes	Yes	Yes	Yes
Share information selectively	Yes					
Give selective write access of health information	Yes					
Collaborate through discussions						Yes
Share health related & helping calendar						Yes
Share caregiving information	Some					Yes
Post updates to your network			Yes	Yes	Yes	Yes
Ask for help						Yes
Sharing photo albums			Yes	Yes	Yes	Yes
Share background information & resources			Yes	Text	Text	Links
Well wishes from social network			Yes	Yes	Yes	Yes
Favorite things (food, flowers, activities, etc.)						Yes

Table 2-1: Functionality of existing information sharing technology for health consumers.

PHRs that have sharing features (Google Health and HealthVault). The right four columns (highlighted in purple) are four websites for sharing health information within a social network.

2.2.1 Personal Health Records

Some technology has been created to help health consumers manage personal health information on an individual basis (managing their own information for their own personal use). These tools are often associated with clinical information systems and have traditionally involved little input from health consumers. However understanding these tools and the current health care information systems environment is important for developing future technology for health consumers. Although many clinical medical records are still in paper form, a transition is being made to electronic systems that house medical records (Berner, Detmer, & Simborg, 2005). Tools to allow consumers access to their records through personal health records (PHRs) are becoming increasingly popular. These tools are often simply portals into the electronic medical record. There are, however, a limited number of PHRs where patients are allowed to add to the health record. The My Health*e*Vet system implemented in the Veterans Affairs hospitals is one such system (Veterans Affairs Hospitals, 2010). This tool enables patients to see the clinician's version of the record and to add their own information in a different part of the record. A PHR with much more consumer control is Capmed, which is designed to import medical information into an application controlled by the patient (CapMed, 2010). Progress towards PHRs has been aided by a strong push towards electronic health records (EHRs, or EMRs) throughout the healthcare system in the United States, which can be attributed in part to federal mandates for interoperable EHRs by 2014 and for PHRs because "Consumers are increasingly seeking information about their care as a means of getting better control over their health care experience" (Office of the National Health Information Technology Coordinator, 2004). The National Health Information Network (NHIN, previously known as NHII) is in the process of promoting electronic medical records and encouraging the creation of information exchanges in which several care organizations come together to exchange medical records (Altarum Institute, 2007; Stead, Kelly, & Kolodner, 2005; Yasnoff et al., 2004). The vision is that these PHRs would allow patients to easily integrate their medical records from multiple institutions with other health information, thereby creating a complete repository of their personal health information.

In addition to supporting PHRs for individual use, NHIN also promote the creation of personal health records with consumer privacy controls allowing individuals to control who sees and uses their information (Altarum Institute, 2007; Lafky, 2008; Stead, Kelly, & Kolodner, 2005; Yasnoff et al., 2004). The Healthcare Information and Management Systems Society (HIMSS) has also come out in favor of PHRs that allow individuals control over who accesses their health information. One of their reports reads, "HIMSS champions the development of a universally-accepted ePHR model that would allow patients to: ... Designate read access to the ePHR (either by portion or in its entirety); ... Provide [a] log of both information shared and information recorded (or entered into the ePHR), including an audit trail of who has entered, accessed, or modified the information" (HIMSS Board of Directors, 2007). The PHR systems are intended to help health consumers by giving them access to their medical information, but existing tools are often built on the model of having just one user –the patient. At this time, they do not allow for the possibility that other people in a social network may interact with someone's personal health information or that others may play an important role in managing the information. Although sharing functionality has been suggested, our community needs to know more about what kinds of sharing functionality would be useful.

A slightly different sort of PHR has emerged within the last couple years –PHRs that did not emerge from close ties to a medical records system. Microsoft's HealthVault (Microsoft, 2010a) and Google's Google Health are both examples of stand-along PHRs. Google Health is an online personal health record where people can enter their own health information and can import medical records from a small number of medical record systems (this functionality is limited by a lack of standards in electronic medical records) (Google, 2010). Google Health records can also be shared with other individuals. Users can select any number of people to be able to view all of their record. Taking a slightly different approach, HealthVault is designed to be an online platform that others can use to build personal health record applications on top of. HealthVault can be used to create a personal health record, but their focus has been on creating a platform. For example, there are third party applications to help individuals track their exercise and promote an active lifestyle (Microsoft, 2010b). The HealthVault platform allows users to share their information with trusted applications, developed by third parties. In the example of the exercise tracker, a user's exercise data is kept in their HealthVault account, but is accessed through the customized application. In addition to sharing health information with selected applications, users can also giving individuals read and/or write privileges on their record. HealthVault has a sophisticated permissions system where users can select all or only portions of their record to be available to others. Users can also see who has accessed the information they have chosen to share. This type of sharing supports a simple sharing model of passing the information on to others, but does not support the more complex two-way communication and collaboration that I found during the interview study described in Chapter 3. In my concluding chapter, I describe the implications my findings have for PHR design.

2.2.2 Websites for sharing health information within a social network

Another domain of technology is health-related, but does not focus on traditional medical record-style personal health information. Instead these websites are designed to facilitate keeping a social network informed about a patient's condition and progress. This class of websites has the common functionality of supporting blog-style updates to a controlled network. CarePages (CarePages, 2010), theStatus (theStatus, 2010a), CaringBridge (CaringBridge, 2010a), and Lotsa Helping Hands (Lotsa Helping Hands, 2010a) are all examples of this type of technology and their functionality is described in Table 2-1. These systems are all free for patients and their networks. In all of these systems, a patient can post updates to their network, can share photos with their network, can receive messages and well wishes from their network, and can share background information about their health condition and health history (via text in some systems and links to resources in others).

In addition to the functionality available in the other three systems, Lotsa Helping Hands also facilitates helping within a network. A "coordinator" can ask the social network for help, on behalf of the patient. That help, and other events, can be seen on the patient's calendar. Community members can also participate in discussions. There are several categories of caregiving information that can be entered and made available to the social network (e.g. medications, emergency contact information, etc.). The social network can also see a list of a patient's favorite things to help them tailor the help they offer. For example, a patient or "coordinator" can enter favorite foods, movies, flowers, or activities.

The way that these systems emerged makes them especially interesting as related work. CarePages, for example, was created by a family who found the need for such technology when their young son was diagnosed with a congenital heart defect (CarePages, 2010). CaringBridge's creator began the website when a friend experienced a life-threatening pregnancy. Unfortunately, the baby girl, named Brighid, died just a few days after birth. A memorial fun in her name enabled CaringBridge to become available to others at St. Paul's Children's Hospital and it grew from there (CaringBridge, 2010b). The creator of theStatus began the website when his sister-in-law was hospitalized and needed a way to keep in touch with her social network "without burdening herself or her close family" (theStatus, 2010b). Lotsa Helping Hands' creators share a similar story of developing the technology in response to a family need, "Seeing how earnestly friends wanted to help, and juggling the difficulty of organizing their assistance, we designed Lotsa Helping Hands with the understanding of how to bring together a variety of social circles and what a resulting community would need" (Lotsa Helping Hands, 2010b). Every single one of these systems emerged because the creators personally experienced a need for this type of technology. These are born out of necessity and reflect an intimate knowledge of what users will need. I view these systems, and the functionality they provide, as additional data points about what technology should do for patients and their social networks. In Chapter 4 and Chapter 5, I describe the technology I designed with participants and in the concluding chapter I describe how the technology we designed relates to these existing systems.

2.2.3 Websites for peer-to-peer information sharing and discussion

A related domain of technology is designed to enable patients to communicate with other patients in similar situations. Discussion boards and forums can be a wonderful place for people to share their own experiences, learn from others, and find support from people who have been in similar situations. One study of breast cancer message boards found that people received a significant amount of informational support as well as the previously acknowledged emotional support (Civan & Pratt, 2007). Other work has been done on the potential online support groups hold (Høybye, Johansen, & Tjørnhøj-Thomsen, 2005; Winefield, 2006) and the positive outcomes that can result from participating in online support groups (Winzelberg et al., 2003). A systematic look at existing social networking software (e.g. MySpace, Facebook) revealed that patients are also using this technology to find and form groups of people with similar health conditions (Farmer, Bruckner Holt, Cook, & Hearing, 2009). Some of these groups were exclusively for patients, while others included people close to patients, and some focused on fund raising for a cause.

PatientsLikeMe is a website that goes a step farther and enables both discussion and structured information sharing among patients with similar conditions. An individual user creates a health profile and their information and experiences can be aggregated so the community gets a larger perspective of what others are doing. Individuals can also share their experiences with others through their health profile and through participating in discussions. One focus of PatientsLikeMe is supporting communities of users with rare conditions; this provides isolated patients to learn from one another and sometimes innovate on their treatments based on what they learn from others (Frost, Massagli, Wicks, & Heywood, 2008). These technologies hold promise for improving the patient experience and certainly deserve future research, but they are outside the scope of the research in this dissertation. Instead of focusing on the potential of creating networks of patients, my focus is on patients' interactions and collaborations with their existing social networks.

2.3 Sharing Information Outside the Health Domain

I have reviewed the limited literature on technology for sharing personal health information within social networks, but there is a larger literature on technology for sharing other types of information in other settings. Previous models of privacy and sharing might prove useful in understanding the views of health consumers. For example, other researchers, in multiple domains, have found the line between what is and is not private is fluid and negotiable rather than a hard boundary (Adams, Cunningham, & Masoodian, 2007; Iachello & Hong, 2007). This fluidity has also been seen in the health domain; the amount of information breast cancer patients share with others changes as situations and relationships evolve (Unruh, 2007).

Much of the privacy and information sharing research in computer supported cooperative work (CSCW) and HCI is focused on the workplace. This work brings up issues of trade-offs between the benefits and potential vulnerabilities of sharing as well as the importance of reciprocity (Allen, 1993; Jarvenpaa & Staples, 2000; Kolekofski & Heminger, 2003; Palen, 1999; Raban & Rafaeli, 2007). Although the need for reciprocity and the trade-offs impacting privacy decisions in the workplace might transfer to health consumers, many of the findings from the workplace seem inappropriate to generalize to the health domain. Theories of information sharing based on workplace practices are based on different assumptions about motivations for sharing. For example, through experimentation, Constant et al. found that "greater self interest reduces support for sharing" (Constant, Kiesler, & Sproull, 1994). Although it might be true that in the workforce there is a disincentive to help other people through information sharing, that disincentive to help is not apparent in any previous work with health consumers.

However, workplace research on sharing personal information within the workplace does seem more relevant to the personal health information sharing domain. Work calendars, for example, have work content and might also reveal personal information such as doctors appointments or important family events. For all the positive benefits of shared calendars (improved coordination and awareness) a study of a calendar system in a large workplace identified several difficult issues regarding privacy and sharing decisions (Palen, 1999). Under the category "interpersonal communication" researchers identified "peer judgment & influence" as an important issue; workers can use open calendars to make judgments about how others use their time or how much work others are doing. To maintain personal boundaries, workers disguised calendar appointments using cryptic and context-sensitive entries that others would not be able to decipher. In a health context, it is not a large stretch to see how these results could apply to a patient's calendar being shared within their social network. There might be certain activities or events that they would be less comfortable with everyone in their network seeing, or asking them about. If the system did not allow patients to have fine-grain access controls, patients might employ similar tactics to hide information in plain sight through obfuscation.

Shared calendar systems have also been studied within social networks. Plaisant et al. conducted a field study with a multi-generation multi-household family using a shared calendar system (Plaisant, Clamage, Hutchinson, Bederson, & Druin, 2006). One of the most important findings from the study was the value of reciprocity. Past studies have focused on making the older generation's activities visible to adult children, but in this study the older generation was equally interested in having access to their children's schedule. It is unknown how this will play out for a cancer patient sharing their information with friends and family. The importance of reciprocity is identified in many studies of group information management systems (Erickson & Kellogg, 2000; Palen, 1999; Raento & Oulasvirta, 2005), but it is not clear how this concept will play-out in the health domain. One possibility is that patients are so consumed with their own challenges that they have less interest than usual in having equal access to others' data. However, this interpretation strays from years of HCI research indicating that the amount of information one person is comfortable sharing with a second person is related to the amount of information the second person shares with the first.

Reciprocity is just one attribute human-computer interaction researchers have found important in successful systems for sharing information. Individual control over the type and amount of information shared and the ability to hold someone accountable for a sharing action are important attributes of a successful system (Raento & Oulasvirta, 2005). It is also important to design for plausible deniability; an individual should be able to plausibly claim that they did not hide the information intentionally or plausibly deny that the information exists at all.

The Adams Privacy Model provides a way to break apart a sharing decision that might transfer to health consumers' views of sharing health information (Adams, Cunningham, & Masoodian, 2007). This model is based on personal information, such as photo collections, instead of on work-related information. The model says that privacy is impacted by three factors: (1) "information sensitivity" (i.e. how personal or sensitive the owner feels the information is), (2) the "information receiver" and the relationship between the owner and the receiver, and (3) "information usage" (i.e. how the owner believes the information will be used and kept). Although created outside the health domain, the factors in the Adams' model provide a way to break down the factors involved in deciding whether to share any type of personal information, including health information.

One study of how people share personal health information in general focused on what Adams Privacy Model considers the "information receiver" and "information sensitivity." Olson et al. administered a questionnaire through which they examined workers' comfort with sharing various types of personal information with various types of people. Participants in the study used a large grid to select with whom they would be comfortable sharing each type of information (Olson, Grudin, & Horvitz, 2005). Examples of types of information included "location," "specific calendar entries," "your health status" and "salary". They used the resulting data to create groups of people who would receive similar information. For example, a manager and a trusted colleague received similar types of information. They also used the data to create clusters of information that were shared similarly. For example, pregnancy status, health status, and preferences (politics, religion, associates, etc.) were all shared with similar people. Their findings were intended to help identify default sharing settings that can be customized by users, but their approach is more generalizable and I replicated their study design in research presented in Chapter 3.

2.4 Usable privacy

As with other forms of personal information, sharing personal health information brings up privacy concerns that should not be ignored. When studying sharing we are also studying privacy; these are simply two different perspectives on the same issue. Privacy is focused on what is important to keep private; sharing is focused on what is useful to show others. In my work, I am most interested in why sharing is useful and how to facilitate sharing. However, it is also important to understand why people choose to keep information private and to help people maintain as much privacy as they want. An exhaustive review of the privacy literature, as it relates to technology, describes both the philosophical and legal positions on privacy as well as the relationship between privacy and human-computer interaction (HCI) (Iachello & Hong, 2007). In this dissertation research, I take the philosophical perspective that privacy is a right. Each person should be able to make decisions about who they share information with and how much information they share. I take this position as a given and from that standpoint have studied the situations in which sharing information is useful.

One important distinction is between privacy and security. A secure system is one that does not leak information in ways that the system developers did not intend. Encryption, passwords, and physical locks all help keep data secure. Security will certainly be an important part of any personal health information sharing system, but it is an entire field unto itself and is beyond the scope of this dissertation work. Privacy depends on having secure systems, but it introduces user intention into the equation. Good privacy settings allow just the information that users want to share to be accessible to others. Even secure systems can lead to privacy breaches, via unintentional disclosure, when users do not configure sharing settings the way they intended. These mistakes might be caused by difficult interfaces and misunderstandings about how privacy settings work. They could also be caused by simple slips, when the user meant to carry out one action, but accidently did something else.

Even setting security concerns aside, unintended disclosure still poses a substantial risk in the domain of personal health information sharing. The field of Usable Privacy has worked to improve the human-computer interaction side of access controls (i.e. privacy settings or sharing settings), but there is still substantial work to be done (Beznosov, Inglesant, Lobo, Reeder, & Zurko, 2009). The regularity with which users, including well-trained system administrators, make mistakes setting up access control lists (ACLs) is quite troubling and suggests that better interfaces to these controls are necessary (Bauer, Cranor, Reeder, Reiter, & Vaniea, 2008; Maxion & Reeder, 2005; Smetters & Good, 2009). To that end, several approaches have been tried to improve ACL interfaces. Natural language rules that are then converted into privacy settings have been designed and evaluated (Brodie, Karat, Karat, & Feng, 2005; Karat, Brodie, & Karat, 2006). Decision-support style interfaces (Cao & Iverson, 2006), rule visualizing (Montemayor, Freeman, Gersh, Llanso, & Patrone, 2006), and rule manipulation interfaces (Ueno, Hashimoto, Shimomura, & Takahashi, 2009) have all been proposed in place of traditional ACL interfaces. Two different, but related, interfaces to replace the Windows XP file system ACL proved more usable than the existing system (Maxion & Reeder, 2005; Reeder et al., 2008). These research efforts all show that there is hope for improving the existing ACL interfaces. However, the whole model of creating large, complicated, interfaces so users can interact with ACLs has also been called into question.

In the health domain, we know that the amount of information people share and who they share with changes over time (Unruh, 2007). In this setting, and in others, perhaps privacy settings should not be designed with the model that users will set them once and then rarely touch them. In a thoughtful paper on the intersection of technology and privacy as a social phenomenon, Dourish and Anderson write,

> *"The focus on practice has two major implications. The first is that privacy and security are continual, ongoing accomplishments; they are constantly being produced and reproduced. This is a significant departure from technical models that suggest that your security or privacy needs can be "set up" through a control panel and then left alone; instead, it posits privacy and security as ongoing features of activity, which must always be done security or in ways that are accountably private and so forth. The second is that they are pervasive elements of everyday settings, which extend beyond the boundaries of any or all computer systems and incorporate organizational arrangements and practices, the physical environment, and so on"* (Dourish & Anderson, 2006).

We should also not view this problem as merely an interface design or usability problem (Balfanz, Durfee, Grinter, & Smetters, 2004). The model of a mammoth ACL interface might simply be the wrong way to interact with underlying permissions regardless of how artfully the interface is designed. Instead, in Chapter 6, I propose a model of interaction where users are aware of their settings and are able to quickly make changes to these settings within the interfaces where they create and view content. As their relationships with people and their needs change, their privacy settings can be maintained and updated as part of an ongoing negotiation related to factors spanning the boundaries of the system.

Chapter 3
Sharing Personal Health Information

3.1 Introduction

Before we can begin to design technology to support sharing personal health information and collaboration within social networks, we need to first understand what information people currently share and what they are trying to accomplish by sharing personal health information. We need to understand how people make decisions about what to share and what means they employ for actually sharing their information.

The objective of this aim is to understand current personal health information sharing practices so we can design technology for health consumers that appropriately supports sharing, while also preserving privacy. Our research questions are listed below.

Research Questions:

- What personal health information do people share with their social network?
- Who do people share personal health information with?
- Why do people share personal health information?
- How do people decide what information to share and who to share it with?
- What means do people use to share personal health information?

3.2 Methods

I have selected both qualitative and quantitative research methods to answer these questions. My research began with semi-structured interviews to gain a deep understanding of current practices (n=13). Based on my findings, I designed and released an online questionnaire to gain a broad understanding of sharing practices (n=51). Pairing these methodologies allowed me to start with exploratory questions and then narrow my investigation based on data from the interviews to a set of questions I could ask a larger sample of health consumers through an online questionnaire.

3.2.1 Interviews

For my semi-structured interviews, I recruited 13 participants in a convenience sample through flyers and email. My participants included people with a serious or ongoing health situation as well as people close to someone with a serious or ongoing health situation. Although I recruited individuals based on whether they belonged to one of these two categories, I later discovered that the distinction between these two groups was mostly irrelevant; each of my participants described experiences from both roles. For example, one participant, who identified himself as someone with a health situation (from joint replacement surgeries), also described his experiences being close to someone (his first wife) who had a serious health condition (Alzheimer's).

I interviewed each participant once, in a setting of his/her choice, ranging from their kitchen table to a café. Interviews ranged in duration from 30 to 120 minutes. Each session began with informed consent and a demographic questionnaire. I used semi-structured interview guides that outlined topics to cover during the interview (see Appendix A for interview guides). Using interview guides instead of a set script allowed me both to investigate issues raised by participants that I had not anticipated and to ask probing questions. I asked participants questions about what personal health information they share or receive, who they share with or get information from, and why they share health information. I asked participants how they decide with whom to share information and how much information to share. I also asked participants how they currently share information (over the phone, in email, etc.) and how well those modes of sharing worked for them.

Interviews were audio recorded and transcribed; transcripts were de-identified by removing names of people, places, and organizations. I did not begin my analysis of the transcripts with a list of themes, but instead engaged in an open coding to let themes emerge from the data. My first pass through the data identified broad themes that appeared in the transcripts, resulting in a paper list of themes. I then made subsequent passes through the data coding quotations with themes using the ATLAS.ti software. Iteratively, during this process, I identified and grouped similar themes and created higher level categories to identify larger themes in the transcripts.

3.2.2 Questionnaire

Following my analysis of the interview transcripts, I designed an online questionnaire to follow-up on the themes I identified (see Appendix B for the online questionnaire). This online questionnaire allowed me to explore these themes with a broader sample of participants. In contrast to the open-ended interviews, this online questionnaire provided an opportunity to ask every participant exactly the same questions about the same issues. I broadened the population of interest to anyone 18 years of age or older because in the interviews with people who had serious health conditions they also discussed sharing health information about less serious conditions, such as food allergies, alongside more serious conditions, like cancer and diabetes. I recruited 51 participants through flyers, emails, and online postings. To get a diverse sample of health consumers, I did not recruit from specific care institutions and instead focused on community centers and other public locations (e.g. libraries, swimming pools, and grocery stores).

The online questionnaire began with informed consent and then demographic and health status questions. Participants filled out a grid asking what health information they possessed and with whom they shared each type of information. I also asked participants about their motivations for sharing information and the factors that affected their sharing decisions. The questionnaire ended with a question about what methods they currently employ for sharing information.

What information is shared and who receives it

Based on previous work (Civan, Skeels, Stolyar, & Pratt, 2006) and my interview results, I created a list of people who might receive health information and a list of types of health information people might have and share. Based on a methodology used in a survey of general personal information management (Olson, Grudin, & Horvitz, 2005), I created a table asking about what health information participants had, what they share, and who they share with (see Table 3-1 in Results). Instead of asking participants to speculate about how comfortable they would be sharing certain information, I used a critical incident approach. Before filling in the table, I asked participants to think of the most serious health condition they have had and to think about that situation while they fill in the table. I also asked them to think of a person for each category that fits into just that category. I then asked them to fill out the table based on what information about their most serious health condition they shared with each person. I chose to anchor the survey in an actual event and encourage participants to think of specific people because people would likely provide a more accurate depiction of existing health information sharing practices than I would have found by asking more hypothetical or abstract questions.

Motivations for sharing and factors that influence sharing

Through my analysis of the interviews, I identified several motivations for sharing information or not sharing information. I also identified factors that encourage or discourage sharing, such as characteristics of the person who is receiving information or the location of an interaction. To further my understanding of how people make sharing decisions and why they choose to share or not share information, I designed survey questions based on these motivations and factors. Participants were asked if a list of possible motivations ever influenced their decision to share information. I also gave them a list of factors that could influence their likelihood to share information and asked what effect, if any, those factors had on sharing decisions. The factors fall into four categories: factors about themselves, factors about the other person, context, and factors about the condition. Participants were asked to answer these questions about all of their health information sharing experiences, not just for their most serious health condition.

Methods for sharing

To get a better idea of how people currently share health information, I asked what methods people currently use to share health information (e.g. talking in person, email, etc.).

3.3 Results

I begin this section by describing participants from the semi-structured interviews and from the online questionnaire. I then present the results of the interviews and questionnaire together, organized by my research questions, because the data provided by each method is

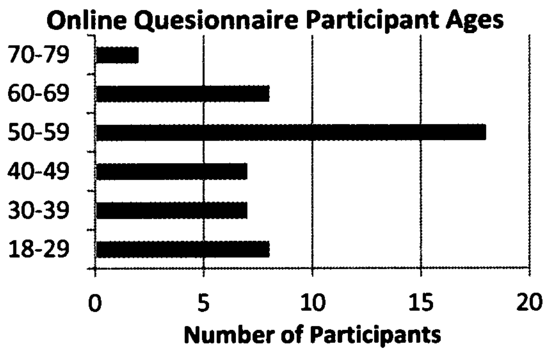


Figure 3-1: Age distribution of questionnaire participants

complementary. The interview results focus on rich, detailed description, while the questionnaire results provide frequency counts from a larger sample of a broad range of health consumers.

3.3.1 Interview Participants

My convenience sample of thirteen interview participants had a wide range of health issues. Some of these issues included colon cancer, osteoporosis, heart disease, thyroid cancer, Alzheimer's disease, diabetes, prostate cancer, joint replacement, pain, and bacterial infection. Ten participants were female, three were male, and participants' ranged in age from 36 to over 75 years. Most participants were frequent computer users, with eleven participants reporting having a computer in their home. Participants' occupations included teacher, retired, florist, nurse practitioner, housewife, secretary, medical technologist, management, and disabled.

3.3.2 Online Questionnaire Participants

Fifty one people completed my online questionnaire. The age distribution of participants is depicted in Figure 3-1 and the gender distribution was 36 women (71%) and 15 men (29%). Participants' occupations included nanny, writer, sales, student, attorney, homemaker, and retired. Notably, 5 of the 51 participants worked in the health care field including nurses, a medical social worker, and a physician's assistant. Participants reported the wide range of health conditions one would expect from 51 health consumers. For the set of questions about what information they shared and with whom, I used a critical incident methodology by asking for them to think of the most serious health condition they had faced. Figure 3-2 lists some of these conditions, grouped by whether participants self-identified as ever having a life threatening injury or illness.

Participant-reported categorization	*Examples of most serious condition or injury*
29% reported experiencing a life threatening illness or injury	Asthma, cancer (breast, prostate, and others), septicemia, traumatic injury, staph infection, pancreatitis, etc.
71% reported never experiencing a life threatening illness or injury	Broken bones, celiac disease, skin cancer, depression, diabetes, pneumonia, arthritis, hernia, spinal meningitis, PTSD, cardiac arrhythmia, drug addiction, appendicitis, dislocation, etc.

Figure 3-2: Conditions and injuries reported by questionnaire participants, grouped by self-reported life threatening status

3.3.3 Types of Personal Health Information people share and who receives it

Interview participants described sharing personal health information with a range of people, from close family to new acquaintances. All interview participants described sharing health information with their family, especially siblings, children, and parents. Some also shared information with friends, neighbors, and co-workers. On one extreme end, a participant described sharing his prostate-specific antigen (PSA) test score with two women he met in a store while telling them about his cancer treatment experience. On the other end of the spectrum, one woman said, *"I'm not one to talk about my health a lot because I'm usually fairly healthy and I don't want to be one of these women that all they do is talk about how sick they are."(P46)*

Interview participants shared details about a wide range of health information with others, including diagnosis, treatments, treatment decisions, symptoms, clinicians, clinics, and outcomes of treatments. For example, one participant said he talked to his friends, who had similar health problems, about *"...what they're taking, how they manage the pain or whatever it is. How to get supplies, like wheelchair parts..."(P48)* Another participant described the range of questions others have asked him about his experiences with his first wife's Alzheimer's *"'When did you notice?' And 'what was the progression for your wife?' and 'how does this behavior... Does this behavior compare to anything that your wife did?' How, you know, 'what did you do for respite?'"(P51)* Participants described sharing personal health information mostly though sharing personal experiences or telling their stories. Often these experiences included high levels of detail and were quite personal.

Based on previous work and my interview data, I generated a list of types of information people keep about their health (see Table 3-1). The percentage of questionnaire participants who had each type of information is reported on the left side of Table 3-1. For each type of information, the grid in Table 3-1 shows with whom they shared that information. For example, 80% of people had information about the 'likely long term impact of their condition or injury.' Of that 80%, 85% shared that information with close family, 76% shared it with a close friend, and 34% shared it with a co-worker. For all categories, except for 'advice for someone else,' a spouse, partner or close family member were most likely to receive information from my participants.

The questionnaire results indicate that a substantial portion of people's personal health information is shared with others and is sometimes shared with a wide range of people. We can examine what information people shared most and least in the 'Did not share' column of the table (indicating what percentage of people who had the information in that row but did not share it with anyone). Participants most frequently shared information about Treatment (98% shared), Diagnosis (100% shared), Symptoms (98% shared), Likely long term impact (98% shared), and Experiences with doctors or other care providers (100% shared). The information that participants were least likely to have shared was 'kinds of help they would appreciate receiving.' Of the 35 people who had information about the kinds of help they would appreciate receiving (69% of my total sample), 17% of them did not share 'helping' information with anyone.

Table 3-1: The personal health information participants had and who they shared it with

% of participants who reported having each type of information		For people with each type of information, % of those people who shared that information (with each type of person)									
		Did not share	Spouse or Partner	Close family	Distant family	Close friend	Friend	Manager	Co-worker	Acquaintance	Someone you only know online
96% (49)	Diagnosis (what you have or what is wrong)	0% (0)	73% (36)	100% (49)	35% (17)	94% (46)	67% (33)	37% (18)	49% (24)	29% (14)	2% (1)
94% (48)	Treatments (such as prescriptions, procedures, therapies, etc.)	2% (1)	54% (26)	96% (46)	25% (12)	90% (43)	54% (26)	29% (14)	35% (17)	23% (11)	4% (2)
96% (49)	Symptoms you experienced	2% (1)	76% (37)	90% (44)	24% (12)	82% (40)	51% (25)	18% (9)	31% (15)	20% (10)	4% (2)
65% (33)	Side effects from treatments	6% (2)	76% (25)	91% (30)	27% (9)	76% (25)	36% (12)	21% (7)	24% (8)	21% (7)	0% (0)
80% (41)	Likely long term impact(s) of the condition or injury	2% (1)	68% (28)	85% (35)	17% (7)	76% (31)	41% (17)	17% (7)	34% (14)	15% (6)	0% (0)
100% (51)	Your experiences with doctors or other care providers	0% (0)	69% (35)	84% (43)	16% (8)	67% (34)	41% (21)	14% (7)	33% (17)	14% (7)	2% (1)
76% (39)	Information you got from the clinic	10% (4)	79% (31)	79% (31)	13% (5)	62% (24)	28% (11)	8% (3)	18% (7)	10% (4)	0% (0)
41% (21)	Notes you took during a clinic visit	14% (3)	86% (18)	57% (12)	5% (1)	33% (7)	5% (1)	0% (0)	0% (0)	0% (0)	0% (0)
53% (27)	Records you kept about your health	11% (3)	85% (23)	52% (14)	4% (1)	22% (6)	4% (1)	4% (1)	4% (1)	0% (0)	4% (1)
63% (32)	Information you found (such as webpages, books, articles, etc.)	9% (3)	72% (23)	72% (23)	16% (5)	50% (16)	22% (7)	0% (0)	3% (1)	16% (5)	6% (2)
78% (40)	Payments, billing, or insurance information	5% (2)	78% (31)	50% (20)	5% (2)	15% (6)	13% (5)	3% (1)	10% (4)	5% (2)	0% (0)
53% (27)	Advice for someone else	11% (3)	59% (16)	59% (16)	15% (4)	74% (20)	52% (14)	4% (1)	26% (7)	30% (8)	7% (2)
78% (40)	Appointment and scheduling information	10% (4)	75% (30)	53% (21)	3% (1)	28% (11)	10% (4)	18% (7)	20% (8)	0% (0)	0% (0)
69% (35)	Kinds of help you would appreciate receiving	17% (6)	74% (26)	77% (27)	6% (2)	54% (19)	20% (7)	3% (1)	9% (3)	3% (1)	0% (0)
61% (31)	Records from a clinic (such as medical records, x-rays, etc.)	10% (3)	74% (23)	68% (21)	3% (1)	32% (10)	13% (4)	0% (0)	6% (2)	3% (1)	0% (0)

Another way to find out what types of health information people share is to investigate what types of health information people receive from other people. I asked questionnaire participants about the types of information that my interview participants reported receiving (listed in Table 3-2). Table 3-2 describes how many people received different types of information from someone else and, for those who received that type of information, from whom it came. Many participants (73%) received stories about someone else's experiences related to their own, most frequently from close family or close friends. Many participants (61%) also received references to someone who had been through a similar experience.

Table 3-2: The types of information questionnaire participants received and from whom it came

% of participants who received each type of information		For participants who received each type of information, % of those participants who received information from each type of person								
		Spouse or Partner	Close family	Distant family	Close friend	Friend	Manager	Co-worker	Acquaintance	Someone you only know online
75% (38)	Advice	61% (23)	74% (28)	5% (2)	68% (26)	29% (11)	5% (2)	21% (8)	16% (6)	5% (2)
61% (31)	References to information resources	45% (14)	58% (18)	16% (5)	52% (16)	23% (7)	6% (2)	10% (3)	6% (2)	3% (1)
53% (27)	Reference to doctor or clinic	44% (12)	44% (12)	4% (1)	59% (16)	11% (3)	4% (1)	19% (5)	7% (2)	4% (1)
61% (31)	Reference to someone who has been through a similar experience	35% (11)	48% (15)	10% (3)	42% (13)	23% (7)	0% (0)	13% (4)	19% (6)	3% (1)
90% (46)	Encouragement, support, or sympathy	65% (30)	98% (45)	22% (10)	83% (38)	54% (25)	24% (11)	35% (16)	20% (9)	4% (2)
73% (37)	Stories about others' experiences that related to your own	35% (13)	65% (24)	14% (5)	70% (26)	38% (14)	5% (2)	24% (9)	27% (10)	3% (1)
76% (39)	Offers to help (such as rides, prescription refills, housekeeping, etc.)	69% (27)	67% (26)	8% (3)	72% (28)	31% (12)	3% (1)	13% (5)	8% (3)	0% (0)

3.3.4 Reasons people share personal health information

In this section, I provide both detailed descriptions of what reasons my interview participants had for sharing information and how frequently my questionnaire participants reported sharing for these same reasons. I gathered the reasons for sharing from my interview participants based on their answers to direct question about why they share health information and also from the stories they told about with whom they shared information and the outcomes of those conversations.

Sharing to Learn from Others' Experiences

One reason to share information within your social network is to learn from other people's experiences. Sharing often prompts others to share in return, and their experiences can be a useful source of information. Sometimes interview participants described asking direct questions, but even this approach also involved sharing some amount of information with the person who they were asking. The participant who had joint replacement surgery talked to several friends about their experiences and said that he learned from the people he talked to. *"Yeah, 'what can I expect?', you know, 'what is rehab like?' And the most common thing that came out of all of it was 'Do your rehab!' 'Do your rehab!' Everybody has a little bit different experience, not only with surgery and recovery, but also with rehab. But, everybody who has had successful recovery has said the same thing."*(P51) He reiterated this advice based on his own experience and based on a woman he knew who had not done her rehab and who did not have a good outcome. He felt that it was helpful to be able to learn from the experiences of others and shared his experiences freely so others could learn from them.

Another example of learning from others' health experiences came from a woman who described how other people's experiences helped inform her conversations with her doctor. She said, "*Well, yeah I talk to people that I know that have the disease that are being treated to check out symptoms. Then I can go and say, 'I have the very same symptoms that these people have that are being treated for this. Do I or don't I have it?'*"(P53) She felt that if she didn't bring this sort of question to her doctor that she may not get to the underlying reason for her symptoms, so she gathered information from other peoples' experiences and then consulted her doctor.

For some participants, the idea that they learned from other people's experiences seemed obvious. One man said, in response to a question about whether he shares health information, *"Well yeah, that's the way you find out, is you talk to people. I belong to a number of organizations and the* *organizations I belong to are generally the age of me. I mean the people in there are generally old gray haired guys, so that's where I learn. That's where I learn is from my friends, and we talk all the time. Constantly."*(P54) He cited examples of experiences his friends had with prostate cancer that informed his own understanding of prostate cancer and his treatment choices. Another participant also described how she had learned about health problems from other people's experiences, *"And you know over the years you talk to people. You just kind of learn as you go."*(P55) She went on to elaborate, *"And also by talking to other people is how you learn what they know. They sometimes can give you information that you didn't know about. ... And learning, a learning process."*(P55) Specifically she described an instance where she had already known quite a bit about the back and back surgeries based on the experiences of her friend. She said, *"I have a girlfriend who had three back operations and I've been with her since the first of it. And I have learned a lot about that situation with hers."*(P55) When this participant later had back problems and contemplated back surgery it was helpful for her to have the background she gained from her friend's health experiences even though she recognized that they were not exactly the same as her own.

Another participant used his social network of wheel chair bound friends to keep informed, "*About information about different types of medications and all and I have several friends who are in wheel chair also and we share always kind of information, new things on the market or something like that. For handicaps*"(P48). He and his friends learned from one another about medications and about products that could be useful to them. If his wheel chair needed to be fixed he used his social network to find out where to get parts and how to fix it.

Table 3-3: Frequency with which questionnaire participants share personal health information for the following reasons

	Never	Sometimes	Frequently
Get support or sympathy	21% (10)	63% (30)	17% (8)
Getting help (such as rides, help around the house, prescription refills, etc.)	29% (14)	61% (30)	10% (5)
Wanting to hear about someone else's experiences	29% (14)	45% (22)	27% (13)
Helping someone else	2% (1)	57% (28)	41% (20)
Talking through it with someone	2% (1)	66% (33)	32% (16)
Alleviating anxiety	6% (3)	71% (35)	23% (11)
Updating people about what's happening so they'll know	6% (3)	55% (27)	39% (19)

The majority of questionnaire participants reported that "Wanting to hear about someone else's experiences" was a reason they shared health information. For 45% of participants it was sometimes a reason to share information, for 26% it was frequently a reason to share, and for 29% it was never a reason to share information (see Table 3-3). We also know from the questionnaire that73% of participants had heard stories about others' experiences that related to their own and 75% of participants had received advice from someone else about their most serious health condition. I also asked questionnaire participants whether they had "obtained health advice from someone who has been through a similar health experience." The vast majority of participants (94%) had obtained health advice from someone with a similar condition, while only 6% had not. To identify whether this advice was valued, as it was with the interview participants who sought it, I asked questionnaire respondents how valuable "health advice from others who have experienced health situations similar to your own" is. No one reported that it was not valuable, 74% reported that it was somewhat valuable, and 26% reported that it was extremely valuable.

Sharing to Learn from Others Who Have Professional Expertise

In the last section, I discussed how participants learned from and sought out other people's personal experiences. Participants also sometimes sought information from people who they thought had expertise in an area. They shared personal health information with these people to get their advice because they were experts. Sometimes this expertise was related to their profession and sometimes it came from studying an area. A participant described how he went to one friend when he had questions about medications. He said, *"For example like medication. If I have question about some kind of medication I know who to call. He knows everything about medications."*(P48)

Participants also turned to people within their social networks who had expertise because of their professional training. When asked if she talked to anyone about her health one participant said, *"I mean well one of my friends is actually a doctor so I talked to her a lot, but, she's a doctor and she's a friend, but she's not my doctor."*(P47) Another participant described how her mother gave her copies of health information and kept her up to date on what happened at doctor appointments, while her sister received less detailed health information. She said, *"and part of it is you know being in the medical field, even though I don't know what the heck they're talking about, you know I'm the resources person because I guess it's a little closer than anybody else, so I think I get the copies and my sister just gets verbal information."*(P52) Another participant's profession as a school librarian also led people to share health information with her when they came to the library to ask for help finding information on a health condition (P56).

Questionnaire participants reported that "someone being a health professional" did influence their likelihood to share information with that person. For 63% of participants this encouraged sharing, and for 6% it discouraged them from sharing information. A substantial number of respondents, 27% said that this did not affect their decision to share information.

Sharing to Help Others

Just as some participants sought other people's experiences and advice, some interview participants also described sharing their information and experiences to try to help other people. This result is consistent with the responses of my questionnaire participants who reported that "helping someone else" was a reason to share information sometimes for 57% of them, frequently for 41%, and was never a reason to share for just 2% (one person). Most questionnaire participants (94%) also reported giving advice to others based on their own experiences. They felt that offering this advice was somewhat valuable (78%) or extremely valuable (16%) in most cases, while 6% said that it was not valuable. One example of sharing information to try to help others is an interview participant who shared his experiences about caring for a spouse with

Alzheimers. For example, he wants people to know how important respite is for the care givers, *"And you know we talk about it. It's really really tough, it's tough on care givers. The Alzheimer's is. The thing that I tell people who are going through that is make sure that you get yourself respite. Respite is just incredibly important. You tire yourself down and you don't realize that you're tiring yourself down."*(P51) He valued other people sharing their personal health information with him and described sharing his own information as a way of helping other people. Another participant also reported sharing her experiences and what worked for her joint pain with others in the hopes that it might help them. She described a time when she told a friend about a supplement she was taking for her joints, *"And I have also shared that with a friend of mine, and her husband is a veterinarian, and I told them about it, and he says, 'Yes, that's way better than glucosamine.' It helps way more. So she's now taking it and it's helped her and now she's got her son taking it."*(P45)

One participant felt very strongly about the importance of telling other men about his experiences with prostate cancer. After his initial diagnosis, this man benefited from a member of his own social network who strongly advocated that anyone who was diagnosed should come to him for information, *"And he says, [name] if you ever get prostate cancer before you do anything, of course after you're diagnosed, call me. Don't start any treatment until you call me!"*(P54) My participant took a similarly aggressive approach about spreading information within his own network and described sharing information as a way to try to help other men his age. He said, *"Like when I got back from my cancer treatment, the very next club meeting I went to at all these different organizations, that's the first thing I get up and tell everybody. I urge them to contact me if you have any problem. ...then after the meeting when people are on their way home and so forth then they will come and talk. I've tried to help many people."*(P54) He feels strongly that men should openly discuss their experiences with prostate cancer in order to help other men who may need to visit their doctors and have screenings done.

He also wanted his friends to know about the treatment option he chose because some of his friends had not been given treatment options at all by their doctors. He said, *"The only, the worst part... I'll tell you the bad part first. Many times men will come to me and they'll ask about their prostate cancer and they waited too long. They haven't had somebody like me up in front of them telling them, 'hey talk to me' so many, a couple of the men that I've talked to just recently, in fact one just a couple weeks ago, I'm afraid he's waited too long. So some people don't talk freely* *about these things, but if you don't. If you don't want to listen or don't want to talk about it, you just suffer the consequences."*(P54) The same participant described an example of telling people health information that he thinks they need to know. *"November of '05 I'm diagnosed and so I'm sending out Christmas cards now... And some of my Christmas cards I just put a hand written note to some of my old friends, that I felt that they needed to know, I'm thinking about my age and my gender, so I just put a hand written note in there that I'm going to be going to, that I'm trying to go to [treatment center] for cancer treatment. Well just immediately I got an email back from a friend of mine in [another state] and he says, 'guess what?' he says, 'I was diagnosed yesterday and why would you go from [hometown] all the way to [treatment center]?' So then I got on the email and emailed him right back and said, 'because of this!' And I said, '[friend] check out these websites and this...' and you know I had some websites and some phone numbers."*(P54) For this participant this was an example of a great success because he tried to share information he thought would be helpful to other men his age and then was able to correspond with a friend who had just been diagnosed and who could benefit from his experiences and the information he had gathered.

Protocols for Giving Information to Help Others

Interview participants described three different strategies for helping other people by sharing their own personal health information. The first was **identifying that someone needs information and giving them what they need**. This strategy involved identifying that someone was in a situation where they could use a certain type of information. For example, when the participant who talked to people about his first wife's Alzheimer's he described deciding how *"aggressive"* to be with the information he gave them. He said, *"depending on the person, depending on the relationship of the person I'm talking to with the person who has Alzheimer's I will be more or less aggressive."*(P51)

A second approach to giving someone personal health information is **advertising that you have information and then letting people come to you**. The man sharing information about his prostate cancer purposefully carried out this approach by making announcements at meetings and putting notes in his Christmas card so that anyone with questions would seek him out and talk to him. He felt strongly that men could benefit from knowing about his experience with prostate cancer, but he tried not to push it on them. He explained that some men are *"bashful"* and "*So, what we found is if we, if I can get up before the group and just let them know where I've been* *and I'm really happy with this, and then just let them come to me, because you can't force them to talk about it,"*(P54) Although other participants did not articulate this approach as clearly, there were other examples from the receiving side of this approach where participants approached members of their social network who they knew had experienced health situations that might be relevant to their own.

A third protocol for giving personal health information is **giving it in response to questions**. Some participants did not actively attempt to give people information they thought others could benefit from, but were willing to give information in response to questions. One woman explained, *"I don't mind sharing my information and I'd be willing to tell them anything they want to know, and I do most of the time"*(P45). This is similar to the second protocol in that she waits to be approached, but it differs in that she is not advertising that she has information to share. Occasionally this type of giving information was arranged by a third party. For example, one participant with a rare form of cancer had a friend who set up a time for her to talk to another person who had the same type of cancer (P13). The person giving information in this situation had been asked to do so by my participant's friend.

Sharing to Get Help or Support

My interviews showed that one consequence of a health consumer sharing personal health information with other people is that subsequently other people often attempted to provide help to that health consumer. However, participants did not often describe receiving help as a reason to share their personal health information. An interesting case of this is a woman who was less enthusiastic about sharing her personal health information than most other interview participants. She had a neighbor, who she referred to as a *"busybody,"* who tried to give her advice and urged her to get surgery. The participant seemed to feel that the neighbor had been overly involved in her private health situation, then said, *"But then when I got out of the hospital for the surgery she got two other neighbors and they brought me over a bouquet of flowers and stuff, that was kind of nice."*(P47) When other people knew what was happening with a participant's health they were likely to offer help and people showed their support through gestures like flowers or phone calls. Another participant described how she helped her father based on receiving information about his health, *"I would go over there once a week and make up his pill box and I made this little chart, even though he didn't keep it right, but it was sort of to kind of keep him on track. So I did really need to know what was going on, what the prescription was, how much, whatever."*(P52) She needed his personal health information so that she could help him manage his medications. I heard about other participants who had received rides to the store, help around the house, and help getting prescriptions refilled. Even though participants did not frequently articulate getting help from others as a reason to share health information, it is clear that people do receive help and that the helpers are receiving personal health information. The majority of questionnaire participants reported that getting help was a reason to share health information. It was sometimes a reason to share personal health information for 61% of participants and frequently a reason for 10% of participants, while it was never a reason to share information for 29% of participants. Relating to their most serious health condition, 76% of questionnaire participants reported receiving offers to help from others, most frequently from a spouse, close family member, or close friend.

Another reason for sharing health information that interview participants rarely brought up was to get sympathy or support. When asked why she told people about her health situation one participant did respond, *"Why do you tell people? Probably originally to get sympathy."*(P55) and then laughed. She appreciated people letting her know that they were there for her and that they cared. This was not a reason people frequently gave for sharing information, but I suspect that this might be because it is a less socially acceptable answer than the frequently given answer that they shared information to help others. Not wanting to appear selfish might have motivated people to downplay their desire for sympathy and support, so I included this potential reason for sharing in the questionnaire. Most questionnaire participants reported that getting support or sympathy was a reason to share health information, with 62% saying it was sometimes a reason, 17% saying it was frequently a reason, and 21% saying it was never a reason for them to share personal health information. Most questionnaire participants (90%) reported receiving encouragement, support, or sympathy from someone in their social network about their most serious illness.

Sharing Because Other People Make Valuable Observations and Ask Good Questions

Some interview participants described that the benefit of talking through a health problem can go beyond getting information or help. It can be a way to alleviate anxiety, as discussed in the next section, and it can also be a way to get someone else's take on the situation. Several interview participants stated that talking their situation over with someone else was helpful even if they could not always articulate the reasons the conversation helped. One participant described her friends asking good questions that she could then ask the doctor. Another participant described how other people close to him can make relevant observations he might have missed, *"I really think that it's important as folks get older and are retired that as much as possible ... but for support, if nothing else, I think that very often people who are not even in the medical field, like me, like whoever, can see the things and know what's wrong more easily than the doctor. You know, this is what I think is wrong... this is what I think she's having. You know, let's basically focus on that. And I think doctors more and more, especially younger doctors, more appreciate the insights that their patients and their patient's partners have."*(P51) In his experience, he thought that people in his social network could make valuable observations about his health. He also described how people who have been away for a while and come back into the situation can see changes that have happened gradually over time and were not apparent to him. All but one questionnaire participant said that talking through it with someone was a reason for them to share health information. Most participants, 66%, said that it was sometimes a reason to share and 32% said that it was frequently a reason to share.

Sharing to Alleviate Anxiety

Interview participants said that one reason sharing health information or talking about a health situation was helpful was to get reassurance or to alleviate anxiety. The participant who had recently had surgery, but was reluctant to talk about her health in general, said, *"I mean I don't really talk about it anymore."* When asked, *"Oh, why do you think that is?"* she explained, *"Because it's done, and I was freaked out. I was pretty you know apprehensive about having it."*(P47) She elaborated to say that she talked about the surgery to some people, *"Just to feel more... I mean because before surgery you're scared out of your mind you know. So I guess just to feel more at ease with having surgery. I mean that's about, I don't really talk about anything else. Like I got asthma really bad but I don't talk about that or anything."*(P47) The participant had asthma, but she rarely talked about it because it was not new and she was not nervous about it. She later reiterated, *"Yeah, I don't talk about that kind of stuff. I just talked mostly because I was having surgery and I was all, you know, nervous about it."*(P47)

Another participant described asking co-workers if they had experience with the kind of surgery she was contemplating having. She also talked to her sister, who had asked her friends if they had any experience with the surgery. In the end, she said, *"But, honestly I honestly used pretty much what I saw on the Internet and from talking with the doctor. The pros and cons and pretty much* *made my mind up anyway, but it was just kind of like 'ok, now I want some reassurance here.'"*(P52) She felt that her conversations with other people about their experience had been useful to reassure her that this was the right decision and that the *"cons"* she was worried about should not stop her. Sharing personal health information and talking it through with others was a way for some participants to alleviate anxiety or nervousness. They felt that the information they gained, or the experiences others shared with them, had been useful because the process of talking about it had alleviated some of their anxiety. Online survey participants also reported that alleviating anxiety was a reason to share personal health information, with 71% saying it was sometimes a reason, 23% saying it was frequently a reason, and just 6% saying it was never a reason to share personal health information. The factor, 'being stressed out, worried or concerned about a health situation' encouraged 76% of questionnaire participants to share.

Sharing Because Someone Else Should Know What's Happening

The final reason for sharing personal health information that interview participants described was simply because someone else should know what's happening. When I asked participants why they shared information with people, some responded to the question by simply asserting that it is important for someone else to know. One participant said that she wouldn't keep health information from her husband because, *"Well no, because he needs to know."*(P56) Another participant wanted to be sure that her daughter knew what was happening with her health. She asserted that it was important for someone else to know what was happening. After the interviewer pushed further on the topic she said, *"You never know when you're going to lose the ability to talk or write. And if you don't know, just like everybody needs to set up a legal will. So that they know. Then you have to hope that you've built up a big enough trust over the years that they will do what's best for you. Not always what you wish, but what's best for you."*(P53) It turned out she thought it was important that someone else know what was going on with her so that if she became unable to make decisions for herself they would be able to make the right decisions for her. She said this was especially important to her because she had been in that position with her mother and her husband towards the end of their lives. Her husband had not told her everything that was going on with his health and she felt that this was a mistake. These responses indicated that it can be important that other people get updates even if it is not to fulfill an immediate need for help, information, or to alleviate anxiety. Questionnaire participants agreed; 55% said that "Updating people about what's happening so they'll know" was sometimes a reason to share information and 39% saying that it was frequently a reason to share information, while just 6% saying it was never a reason to share information.

3.3.5 Reasons not to share

I have discussed the many reasons participants described for sharing personal health information, but there are also many reasons not to share personal health information. Privacy has been in the forefront of research discussions of personal health records and personal health information. Not surprisingly, privacy was also a concern for my participants. However, they also raised additional reasons to not share information and added nuances to the general privacy concern.

Not Sharing Because it is Personal

Participants had different ideas of what was too personal to share, but the personal nature of a health condition did make some participants not want to tell others about it. One participant explained, *"I mean because this surgery was kind of, you know, personal so, so I went to some kind of party and they said 'what kind of surgery are you having?' and I was just like 'I don't really want to talk about it'"*(P47). Her surgery was related to her colon and she felt that it was too personal to discuss in that setting, although she had talked to a friend and to a neighbor about the surgery. A participant described talking to friends of his who were also in wheel chairs about some aspects of his health, but also said there were some things he did not talk to them about.

> *"Yes, I try to keep, mostly I think I try to keep those private. I think. And my idea is I try to just keep something for myself."*
>
> *Interviewer- "I realize I'm really prying here..."*
>
> *"Well it is, and when you are exposed to anything, things happen to you, then you realize that you really cannot tell everything to a friend. It is just between the doctor and you perhaps."*(P48)

He did not describe exactly what types of information he was reluctant to share with his friends, but he said that, for example, they may talk about an upcoming surgery but not discuss the outcomes of the surgery.

The participant who sought out ways to share information with others about his prostate cancer treatment acknowledged that not everyone wanted to be so open about their prostate. He said, *"Some guys are a little bit bashful about talking, and the ladies, especially if there's a lady present, if it's just the three or four of us guys talking they'll say a lot of things that they won't say if there's a lady there"*(P54). He said that in a setting of all men it was sometimes easier for men to talk about their prostate. He felt that this was due to the fact that it is the prostate and is quite personal. For questionnaire participants, 'the condition affecting a personal area of your body' was a factor that discouraged sharing for 53% of participants and encouraged sharing for only 18%.

Not Sharing Bad News or Making People Worry

Several interview participants talked about being careful with bad news. They were concerned about asking people about their health if it would make them repeat bad news and they seemed more hesitant to share health information if it was bad news. A woman described trying to decide whether to call a neighbor and ask about his lung cancer, *"So it's kind of like you're going ok, should I call? Should I not call? And then you're hesitant to call because you don't want to make them repeat the bad news, if there's bad news."*(P52) A participant explained that someone she knew had used a website to post updates about her son's cancer. She said, *"it was a lot easier to put stuff on the website than to have to deal with the same question over and over and over again. It was just easier to put that and the treatments and explain what was going on because she just did it once and it was done versus every single person."*(P56) This participant suggested that it was emotionally difficult to have to repeat news about his treatment and appreciated being able to know what was going on without having to ask her friend to tell her. The participant who talked to several people about their joint replacement experiences discussed one of his friends who did not want to talk about his experience, *"and he's one who I talked to and he doesn't want to talk about it because he's a tennis player and has been just as active as I have and is much younger, but his rehab was more like nine months and the doctor had him in the hospital for five days and on crutches for a month."*(P51) This hesitancy to talk about bad outcomes is shared by the participant I described in the last section who usually did not talk to his friends about the outcomes of surgeries.

The wheelchair-bound participant who talked extensively to his friends about his health situation and got advice from them shared far less information with his immediate family. He described not sharing bad news with his family because it made them worry. He was very concerned that his family would worry about him if they knew what he was going through and he did not want that.

He said, *"I don't tell them what I'm going through or the risks that I'm taking all the time or something. Especially my Mom. My problem is if I tell my siblings, my siblings are going to tell my Mom and she is going to be even more worried than she already is. I just think, the other things that I told you, that I moved back here alone to lift the burden from anybody there."*(P48) He moved to a different state than his family and he felt that in part he had moved so that he was not a burden to them, *"Also, somehow I didn't, in the back of my mind I think I decided to lift the burden from my family."*(P48) He had a half-brother in his town and several friends who he was close to. The quote from this participant in the last section shows, though, that there were some things he did not share with anyone besides his doctor.

Trying Not to Dwell on Health

A desire to be *"normal"* and to not be someone who dwells or focuses on health was another reason some participants gave for not talking about health too often. One participant explained, *"I'm not one to talk about my health a lot because I'm usually fairly healthy and I don't want to be one of these women that all they do is talk about how sick they are. No way."*(P46) She felt that being a person who talked about their health all the time was a bad thing. This is in stark contrast to a few participants who seemed to talk about their health frequently and with a broad range of people. This participant elaborated, *"No, but everybody is different, it's true. I don't know, but my sister she's the same way as me. She don't talk about her ailments. It's boring. We talk on the phone, but we talk about everything but that you know. We talk on the phone a lot."*(P46) So while some participants felt discussing their health was interesting and was a valuable source of information for others and a good way to gain valuable information, this participant felt that talking about health too much was *"boring."* She characterized herself as a *"fairly healthy"* person and it may be that for her, part of feeling healthy is not discussing her health too often. Another participant also described not wanting to talk about his health too frequently. He said, *"but the point is when your health has been down the drain for three years in a row it's, talking about that often is a little too annoying, because every time you see the person, or people, are you going to be talking about the same thing over and over? It's a little too... not for me. I try to forget as much as I can and try to be as normal as I can. Yeah, the thing of happiness today was yesterday and today is a new day, so to me I try to be normal."*(P48) Both of these participants shared the desire to discuss other things and to not focus entirely on their health. The second participant also said, *"Yeah, I try not to live in the past always, living in the*

Table 3-4: Factors that influence sharing decisions from questionnaire participants

Factors that could influence sharing decisions	Affect factor has on sharing			
	Encourages	Does not influence	Discourages	N/A
Someone having experience with similar health situations	96% (49)	2% (1)	2% (1)	0% (0)
Trusting and being close to someone	96% (48)	2% (1)	2% (1)	0% (0)
Interacting frequently with someone	90% (45)	8% (4)	2% (1)	0% (0)
Being stressed out, worried, or concerned about a health situation	76% (39)	12% (6)	10% (5)	2% (1)
The condition affecting a personal area of your body	18% (9)	16% (8)	54% (27)	12% (6)
A desire to maintain your privacy	14% (7)	16% (8)	69% (35)	2% (1)
Being concerned you may be blamed for the condition	16% (8)	18% (9)	49% (25)	18% (9)
Knowing information about your health may be passed on to others	8% (4)	18% (9)	71% (36)	4% (2)
The condition requiring you to adapt your lifestyle (for example change your schedule, behavior, etc.)	72% (36)	20% (10)	6% (3)	2% (1)
Someone seeming interested in your health	70% (35)	20% (10)	8% (4)	2% (1)
The condition being noticeable by others	59% (30)	25% (13)	6% (3)	10% (5)
Someone being a health professional (but not one treating you)	64% (32)	28% (14)	6% (3)	2% (1)
Interacting in a public location	10% (5)	30% (15)	52% (26)	8% (4)

past brings you too much bitterness."(P48) He felt it was important to live in the moment and look forward; spending time discussing his health felt like living in the past and could make him unhappy.

3.3.6 Other factors that influence sharing decisions

People share health information to get information, to get help, to talk through a health situation, and to keep others up to date. People sometimes choose not to share health information for fear of burdening others, to prevent themselves from dwelling on their health problems, and to preserve their privacy or avoid sharing such personal information. My interviews also revealed that beyond these motivations, other factors influence sharing decisions. I asked participants how they decided how much information they would share with a particular person or in a particular setting. Most people had shared different amounts or types of information with different people and they had a variety of reasons for doing so. I identified several factors that influence participants' decisions, including factors about the person receiving information, the context or environment where the sharing is happening, the condition itself, and the mental state of the person sharing information.

Aspects about the person who would potentially receive information influenced sharing decisions. First, level of experience with the specific condition or with a similar health problem was an important factor for many interview participants. The participant whose first wife had Alzheimer's described how he shared far more details with people who had similar experiences because the details were more meaningful to them and they could relate to his experiences better. In general, people talked about their health more to others with similar health conditions than they talked to people who were not familiar with their condition. For questionnaire participants, 96% reported that 'someone having experience with similar health situations' encouraged sharing information with that person. Second, closeness to the other person was an important factor for many interview participants. They were more willing to share personal information or detailed information with people who were close to them--usually a spouse or close family member. The participant who had the most nuanced working definition of closeness was the person who did not want to burden his family or have his mom worry about him. Instead he shared more information with the people he knew in his town, one of whom he called 'Mom' and was quite close to. He still shared more information with the people he was closest to, but in his case that was not his family. For questionnaire participants, 'trusting and being close to someone' encouraged sharing for 96% of participants (it did not influence 2% and discouraged sharing for 2%). The third factor about the information receiver that people used in deciding how much information to share was 'level of interest'. If a potential information receiver seemed interested in the information, the participant was likely to share details with that person. Someone who seemed less interested heard less of the story. Seventy percent of interview participants reported that 'someone seeming interested in your health' encouraged sharing. The fourth factor about the receiver that people used was 'level of expertise'. The person's academic or professional level of expertise was an important factor in how many details, especially how many medical details, they received. Interview participants said that the technical language they used would vary depending on the person's background and how much they thought the person would understand. The questionnaire participants agreed, and 64% reported that 'someone being a health professional (but not one treating you)' encouraged sharing.

Environmental factors also influenced people's decisions about sharing personal health information. Half of questionnaire participants reported that 'Interacting in a public location" discouraged sharing (51%), although of all the factors in the questionnaire this one was the least likely to influence a sharing decision. Factors about the condition also influenced sharing decisions. For example, a 'condition being noticeable by others' encouraged sharing for 59% of participants and 'the condition requiring you to adapt your lifestyle' encouraged sharing for 71% of participants. Factors about the condition sometimes discouraged sharing. 'The condition affecting a personal area of your body' and 'being concerned you may be blamed for the condition' were both concerns raised in interviews; about half of questionnaire participants said these discouraged sharing (53% and 49% respectively). Lastly, the individual's mental state could also influence sharing decisions. In interviews, some participants described times of vulnerability, which could either increase or decrease sharing. Questionnaire participants reported that 'being stressed out, worried, or concerned about a health situation' largely encouraged sharing (76%) with a few people saying it discouraged sharing (10%).

3.4 How personal information is shared

Technology holds promise for allowing more access to our health information and more freedom to share that information appropriately with clinicians and members of our social network, but this consumer health technology is largely still underdeveloped and is not widely available. In my interviews, participants described mostly talking in person to other people about their health, but they also described communicating by phone, through email, and in mailed letters. One participant who used email to communicate with a sibling about their mother's health noted that email was convenient because it enabled asynchronous communication. Based on these interview results, I provided questionnaire participants with a list of ways they might exchange information and asked them to mark any they have used to share personal health information. The results in Table X show that everyone had shared health information by talking with someone in person and 82% had shared health information over the phone. The third most common way to share health information was by email (61%) and 29% reported giving out links to information online. In the interviews, participants described giving copies of physical documents or printing out documents for others and in the questionnaire 18% of participants reported that they had given health

Table 3-5: Percentage of participants who used each mode to share health information with their social network (anyone besides their health care provider).

		Mode of sharing
100%	(51)	Talking in person
82%	(42)	Talking on the phone
61%	(31)	Emailing
29%	(15)	Giving out links to information online
18%	(9)	Giving others physical documents (photocopies, brochures, etc.)
14%	(7)	Showing others physical documents
12%	(6)	Sending information through the mail
10%	(5)	Instant messaging or chatting online
6%	(3)	Faxing information

information to someone else in the form of a physical document (photocopy, brochures, etc.) and 14% had shown someone else a physical document with personal health information.

3.5 Limitations

I have provided a mixed-methods investigation into health consumers' sharing practices within their existing social networks. The interviews provided detailed descriptions of sharing practices, and the reasoning behind those practices. The online questionnaire enabled me to ask a large sample of participants about the themes that emerged from the interviews. This approach provides rich descriptions of the themes and also provides strong evidence that these themes do exist in a larger population. However, this data should not be used to generalize the exact proportions of people who had these experiences to the general population. The sample for the online questionnaire was a convenience sample and, while we did not intend any systematic bias, the sample would need to be random to have a strong claim on this type of generalizability. One way to assess our sample is to compare the demographics of our participants to the general population. When we do this, two concerning features emerge. First, 71% of our respondents were female, which is not representative of the nearly even gender distribution in the general population. Also, there were roughly twice as many respondents in the 50-59 age category as in any other category, which is not reflected in the general population. The final limitation to consider is the inherent bias introduced by doing an online survey. Although I recruited through paper-based flyers as well as distributing the survey online, the people who took the survey all had access to a computer and the Internet. I believe this bias will be most limiting for the final question about how people share health information. For example, 61% of our respondents used email to send share health information; this number might be inflated if our participants are more likely to have email access than the general population. None of these limitations invalidate my results, but they should make us cautious about drawing conclusions about exact proportions of people and perhaps even relative weight of themes.

3.6 Conclusions

As we design personal health records and other technology for health consumers, we must acknowledge the important role other people in an individual's social network play. Technology that supports controlled sharing of health information could enhance people's ability to keep their social network up to date and get help from their social network. The two studies presented in this chapter contribute primarily to our understanding of what people do now –how people share personal health information and how they make those sharing decisions. However, we can also use this research as we design technology for patients.

Both the interviews and questionnaires show that people do not interact with their personal health information alone. The model of one personal health record being used by one patient simply does not match the ways people actually use their personal health information. My findings also call into question the existing schism between most personal health record systems (emerging from electronic health records and lacking sharing features) and web technology to facilitate sharing within social networks (e.g. CarePages). Even information that most people would view as part of a medical record, for example diagnosis and side effects from treatment, was shared widely within social networks. The data presented in this chapter suggests that for some people there is a substantial overlap between the contents of a personal health record and the information they share with their social network. There is a substantial difference between telling someone about a cancer diagnosis and handing them a copy of a pathology report, but I saw examples of both extremes. This suggests that technology should provide the option of sharing detailed medical information as well as the option of providing less data. Users should have the opportunity to share their primary records (e.g. pathology reports or list of medications) if they choose; based on these findings I expect most people will take the opportunity to share those records within a very small group of close family and friends.

Chapter 4

Designing with Breast Cancer Patients

I have described how general health consumers share personal health information within their social networks and what their motivations for sharing this information were. With this understanding in mind, we now transition to designing technology to support these sharing practices between breast cancer patients and their social networks. Instead of simply taking my empirical data about how people collaborate now and designing a system, I have chosen to involve users in the design process. Using participatory methods brings users' voices into the design process and helps ensure that the design of technology is both driven by a deep understanding of users' needs and values as well as rooted in real experiences.

4.1 Participatory Design

Participatory Design (PD) is more a philosophy about how technology should be designed than a prescriptive methodology of design. PD practitioners share a common belief that users can and should be involved in the design process from the beginning; they seek to promote user empowerment and democracy through user driven design. To these ends, a diverse range of qualitative research methods have been incorporated into participatory design processes, including observations, interviews, and ethnography. PD researchers have also developed their own methods for working with users to create technology, including future workshops, role playing, games, and new ways to prototype. All these methods are incorporated as needed to understand users and engage them in the design process.

Emphasizing the point that PD is not one protocol, Bodker, Gronbaek, and Kyng assert that *"Each application of the techniques... will be different depending on the type of project in which they are applied....This is why we think example driven presentations...are more appropriate than stating general guidelines and methods. Trying to apply techniques that have been described by example will force the reader to consider similarities and differences between the described example and the current situation. This exercise will move the attention towards how to fit the technique to the current setting, rather than just sticking to a guideline that most likely doesn't fit the situation"* (Bødker, Gronbaek, & Kyng, 1993). Within the book Participatory Design: Principles and Practices, for example, cooperative design, contextual design, and PICTIVE (Plastic Interface for Collaborative Technology Initiative through Video Exploration) methods are all described as ways of doing Participatory Design (Schuler & Namioka, 1993). Furthermore, within those methods, a robust toolkit of techniques for interacting with users are described and used as appropriate.

4.1.1 History & Evolution

Understanding the history and evolution of participatory design can help explain what motivates and ties this research community together. Participatory design arose in Scandinavia during the 1970's, a time when work was becoming automated and trade unions were gravely concerned that technology would negatively impact work environments by devaluing skilled work (Bødker, Gronbaek, & Kyng, 1993; Winograd, 1996). In this setting, new legislation in Scandinavia gave unions and workers more influence over their work and their workplace. Increased demand for workers to have an influence in decisions made about technology adoption eventually gave way to a participatory approach that involved workers in the design of new technology (Bødker, Gronbaek, & Kyng, 1993). This environment gave birth to the first participatory design efforts. The goal of this new approach was to incorporate user expertise into the creation of systems that did not devalue worker skill and competency (Greenbaum & Kyng, 1991; Muller & Kuhn, 1993).

As this revolution took place in Europe, researchers and designers in North America were facing their own challenges with emerging technology. Workers in the United States also had little influence over the technology that affected them, and--despite the movement to make software "user friendly,"—software was often designed with very little knowledge of the workers who would use it (Greenbaum, 1993; Grudin, 1993). In response to this problem, researchers and designers began the evolution of making user-centered software instead of merely user-friendly software. During the 1980's and into the 1990's, there was debate about how much involvement from users was necessary to create useful and usable software (Grudin, 1993; Muller, 1993). Moving from user-centered to user-driven technology through the use of participatory methods held great allure, but proved difficult in the North American political climate. Unlike Scandinavia, the importance of democracy in the workplace alone was not an overwhelmingly compelling argument to use participatory methods.

Some researchers and designers in North America did pursue participatory methods; however, they often argued for participatory methods because they would improve the utility and usability of technology, rather than because of the political implications (Spinuzzi, 2002). They did not emphasize the argument that workers have a right to have their voices heard, and instead focused on the pragmatic argument that participatory methods create better technology. Spinuzzi describes these differences and concludes that the Marxist ideals of the Scandinavian approach (namely the UTOPIA project) conflicts with the capitalist ideals of the North American approach (namely Contextual Design). These two philosophies lead both groups to use the term "empowerment" differently and Spinuzzi identifies the Scandinavian approach as seeking democratic empowerment *"in which workers make decisions along with management"*, while the North American approach seeks functional empowerment *"in which workers are better able to perform their jobs."* While these generalizations hold quite a bit of truth, there have been exceptions. For example, Muller developed a method called PICTIVE for prototyping with users (Muller, 1993). Working within a large US corporation, he still cited democracy as one of his motivations for using participatory methods. *"While it may be more convenient in a corporate context to phrase our argument in terms of the first two motivations–expertise and commitment–this appeared to us to be unwise. As Winner notes (1980, 1986), a social or political motivation that is left unsaid may become unsayable and thus be forced further into the closet. We have therefore continued to state the democratic nature of one of the motivations of the approach. In this way, we support the inclusive nature of participatory design through three different but convergent motivations: product quality, product commitment, and democracy."*

The dichotomy between motivations for using PD lingers and is an argument over why users *should* be involved in the design of technology. Beyond believing that users should be involved, participatory design practitioners also believe that participants *can* contribute to technology design. Many specific methods used during PD are explained extensively elsewhere (Bjerknes, Ehn, & Kyng, 1987; Greenbaum & Kyng, 1991; Kyng & Mathiassen, 1997; Muller & Kuhn, 1993; Schuler & Namioka, 1993). These methods are continually adapted and new methods are added to the PD toolkit. Inherent in all of these methods and in PD in general is the important concept that users have something to contribute to the design process.

4.1.2 Mutual Learning

One of the core concepts in participatory design is respect for the user's knowledge and expertise. This respect is embodied in designers not only expecting users to learn from them, but also recognizing users as experts in their own practice and actively trying to learn from users' experiences. This two-way street of learning is referred to as Mutual learning (Ehn, 1993). Within a participatory design group, each person brings their own expertise, and part of the design process is learning from one another. *"Group discussions should lead to a changed perspectives [sic] on the design by each member of the group, and thus for the group as a whole"* (Bratteteig & Stolterman, 1997). One misconception about participatory design is that users are relied upon to create the design themselves. Instead, the design is truly a collaborative process. Bjerknes tells us that although users should design, designers should not necessarily do everything a user suggests every time (Bjerknes, Ehn, & Kyng, 1987). He cautions that designers should use their own experience and expertise to guide the design, just as the participants use their own knowledge about their work and lives to guide the design. An example of the role that mutual learning plays is evident in design work done by anesthesiologists and ergonomics experts (Held, Brüesch, Zollinger, Pasch, & Krueger, 2002). The group re-designed the physical layout of the anesthesiology workspace because tangles of lines and tubes and ill-placed machines were hampering anesthesiologists. The anesthesiologists brought in expertise about the workspace, but were focused on the tangle of lines as the main problem. The ergonomics experts knew little about the workspace, but were able to see a larger view of the problem and see how placement of machines affected the workspace. By working together, they redesigned the workspace and designers concluded that, *"Compared to the traditional consulting process, more time and efforts were necessary but were offset by the users' acceptance of the improvements and the prevention* *of design errors"*. The basis of successful participatory design is active participation of all members of the design team and respect for each individual's expertise.

4.1.3 Power of Prototyping

Many participatory design efforts rely on prototyping as a valuable means of communication. One of the first examples of technology prototyping came from the UTOPIA project, where paper and cardboard boxes were used to make mock-ups of technology (Bødker, Gronbaek, & Kyng, 1993; Ehn & Kyng, 1991). The team promoted the use of mock-ups because they both provide *"hands on experience"* and anchor user involvement in tangible interactions instead of *"detached reflection."* The team also found that mock-ups were more understandable than specifications or other abstractions of technology; thus, they were a better way to communicate design ideas. Finally, mock-ups are also cheap and fun. Low-fidelity prototypes, like the cardboard boxes with paper taped to them, are not costly in terms of time or resources and can be changed quickly.

Subsequent to the UTOPIA project, many methods for creating mock-ups and working with users to create mock-ups have been developed. These non-functional or partially functional representations of technology are now more widely called prototypes and are described on a spectrum from low to high fidelity. Low-fidelity prototypes, such as paper prototyping, are quick and cheap to make and re-make. For example, paper prototyping can be done during a design session with participants. The barrier to entry for paper prototypes is low because the technology required (paper and a writing implement) are familiar and accessible to most people. On the other end of the spectrum, high-fidelity prototypes more closely resemble the end product. High-fidelity prototypes are often electronic mock-ups of partially working technology. These prototypes are more costly, somewhat more difficult to iterate on, and have a higher barrier to entry because they require special skills. However, with higher fidelity prototypes comes more realism and accuracy as a tradeoff for the cost and barrier to entry.

4.2 Participatory Design in Health Settings

"We are repeatedly 'surprised' by computer systems that don't work as intended" (Greenbaum & Kyng, 1991). This statement is as true in medical informatics today as it was in general software development in 1991 (Berger & Kichak, 2004). The Informatics community struggles with adoption issues, which are usually framed as a reluctance of users to take up new technology (Ford, Menachemi, Peterson, & Huerta, 2009). Considering whether the technology is

fundamentally useful to these reluctant users is rarely the focus of concern; rather, developers spend time contemplating ways to incentivize adoption. A pioneer in advocating the importance of understanding users to create useful systems in the health domain was Diana Forsythe, who pointed out that *"the scientists who build these systems tend to blame potential users for their failure to adopt this new technology on a widespread basis"* (Forsythe, 2001). She attributes this failure to the design process and the inherent assumptions designers made about their users. The medical informatics community has begun to recognize that there is a problem and has become interested in improving the usability of technology. Unfortunately, when technology has been developed with little understanding of users, the problems go much deeper than making interfaces more usable. Involving users in the design process long before there are implemented interfaces to do usability evaluations of is vital to creating technology that is helpful to users. I see a parallel between the state of medical informatics now and the state of workplace software when participatory design methods were being developed. The call for more user friendliness (in the 1990's) and today's call for better usability are analogous – both recognize that there is a problem and that technology does not work as well as it should for users, but both fail to recognize that the problem is not skin deep. Making buttons more easily clickable on an interface that fundamentally does the wrong thing is of limited utility. Participatory design is a way to involve users early in the creation of new technology to ensure that the eventually deployed technology fulfills the needs of users and works for them.

Within the larger medical informatics field, health consumers are a largely overlooked stakeholder. Even technology specifically for health consumers (e.g. Personal Health Records) are developed with a very limited understanding of what kinds of information are useful to patients and how patients will want to use medical records. Our field is just beginning to research how people are currently keeping and using medical information (Moen & Brennan, 2005; Unruh, 2007). Before we spend more time and resources developing systems without understanding the needs or values of health consumers, we should begin engaging consumers in the design process. Learning from other fields, we should move from promoting user-friendliness to user-centeredness and should strive further to creating user-driven designs.

Participatory design methods have not been entirely overlooked by researchers and designers working in the health context. In Scandinavian countries, participatory design is used in many disciplines including one of the earliest participatory design efforts was conducted in Norway with nurses (Bjerknes, Ehn, & Kyng, 1987). Advocates for using participatory design in medical informatics published an article in 1998 discussing how participatory design in health care could help *"develop a model of design objectives, processes, and ideologies"* of clinical users (Sjöberg & Timpka, 1998). I fully support bringing participatory design practices into clinical environments and see strong parallels between clinical environments in the United States and the Scandinavian workplace in the 1970's and 1980's. In the Scandinavian workplace, strong unions had the political will and legal backing to force management to involve workers in decisions about technology that influenced their workplace. In the United States today, clinical workers have proven that they too have the power to derail technology they feel is a detriment to their work (Berger & Kichak, 2004). Participatory methods could be used to bring clinicians into the design process instead of designing without them and becoming frustrated at poor adoption rates.

Moving participatory design out of the workplace, be it a factory or a medical center, and into less structured environments has been challenging. Grudin describes the difficulty of involving users in the design of a software product that is intended for a very large audience who do not all work in the same organization (Grudin, 1993). *"In-house projects involve the development of a new system for a specific group of users. Since the system must be accepted by the target group, it makes sense to learn as much as possible about the future users' shared or even individual backgrounds, work practices, and preferences. The product situation is different—the specific users are not known in advance, one is in a sense targeting a 'greatest common denominator.'"* These challenges are also described by researchers conducting early participatory design work with wageless people in Sheffield (Darwin, Fitter, Fryer, & Smith, 1987). The aim of the research was to identify the needs of wageless people and identify ways information technology could benefit them. Similarly to trying to design for office workers everywhere, these researchers sought to design with the wageless, who *"do not form an homogeneous group with uniform needs and interests."* Although workplace participation methods did not fit their situation exactly, they adapted the methods to fit because *"Too often people in a position of lesser power are told what they need for their own good. The needs of the wageless are best understood by the wageless, and one good way to start to discover these needs is to ask them."* Patients, or health consumers, are a similarly diverse group who do not reside within one organization. They also share the property that people in positions of more power, e.g. physicians, tell them *"what they need for their own good."* Unfortunately, this prescriptive approach has made its way into the process of designing technology for patients. PHRs, for example, are largely designed based on medical records alone without regard for, or knowledge about, what information patients value or find useful. A shift needs to be made towards understanding patients' needs, experiences, and values and towards building technology, in partnership with patients, to support their needs, experiences, and values.

Participatory design work with patients has begun in a few places. Kyng, a founder of the PD methodology, has begun working on health-related projects from what his team calls *"the citizen perspective"* (Ballegaard, Hansen, & Kyng, 2008). They affirm that citizens in the patient role develop expertise about their condition and the everyday management of their condition. These researchers have also identified a strong and problematic tension between the clinic view of a "patient" and the reality that all these patients are people with lives outside of their patient role. Based on their research with elders and pregnant women with diabetes, these researchers argue for the importance of involving citizens in the design of health technology. They found that *"the power structure present in healthcare (re)produces many of the problems found in the workplace. First and foremost the group(s) at the top of the hierarchy are used to define the problems and solutions for the people at the bottom.... Thus, specific attention has to be paid to the design of the development process in order for the citizen to be able to influence on the result. Otherwise healthcare professionals, mainly doctors, and technology companies will continue to define the problems and the solutions."* Without participation in the design process, the perspectives of citizens, or patients, will not influence the technology created.

Another example of participatory design involving health consumers bridges the clinical and patient worlds. Designers worked with clinicians, two patients, and one family representative to improve a clinical system for home treatment of diabetic ulcers (Clemensen, Larsen, Kyng, & Kirkevold, 2007). Part way through the design process researchers interviewed participants about the process and found, *"overwhelming satisfaction with being part of the project."* Another example of participatory design work done with health consumers was a project with elderly participants designing door handles that would allow the elderly to age in their homes (Demirbilek & Demirkan, 2004). Encouragingly, researchers reported that the elderly participants *"gained satisfaction by having influenced the decisions."* Their project used brainstorming, idea sketching, and scenario building, as well as unstructured discussion time. Participants were able to both critique designs created by researchers and to sketch their own designs. They found that during design sessions, smaller groups of 3-6 were effective. A partnership between designers and amnesiacs to create an orientation aid is another successful example of health consumers participating in design (Wu, Baecker, & Richards, 2005; Wu, Richards, & Baecker, 2004). As early PD practitioners recommended (Bødker, Gronbaek, & Kyng, 1993), these researchers examined their unique circumstances and users and found ways to adapt PD methods to their participants by developing a note taking system and taking advantage of reminder tools already used by participants. These studies with the elderly and amnesiacs show that it is possible to adapt participatory design methods to be productive with a variety of health consumers.

A final strength of participatory design that makes it particularly appropriate for health consumers is that it is one of the few design methods that incorporates user values into technology (Value Sensitive Design is another method that incorporates values explicitly in the design process) (Davis, 2009). Persuasive technology researchers are striving to find ways to create technology to change people's behavior. These researchers hope technology interventions will be accessible to the masses and enable people to lead healthier lives (Consolvo et al., 2008) and be more environmentally friendly (Froehlich, Findlater, & Landay, 2010). However, as Janet Davis puts it, *"Attempting to change others' behaviors or attitudes seems an ethical minefield"* (Davis, 2009). Bringing users to the design table and engaging with them brings their voices, and their values, into the design process. Davis writes, *"Involving potential users in design helps to avoid potential ethical issues with persuasive technology. Potentially vulnerable stakeholders can be engaged in the design process to ensure they have a say in the form the technology takes."* The importance of creating technology that is consistent with users' values is important for all of health informatics, not just for persuasive technology. Engaging health consumers in a participatory process will help insure that new technology supports users' values as well as their needs and experiences.

4.3 Designing with Breast Cancer Patients

Technology support for the needs of cancer patients is in its infancy and participatory design is the best way to bring the experiences, values, and needs of health consumers directly into the design process. I have worked with breast cancer patients and survivors to design technology to facilitate useful sharing of personal health information and facilitate collaboration within social networks. In this chapter, I describe my use of participatory methods with breast cancer patients and survivors. As part of a larger project to support personal health information management, I created and collaborated with five design groups in succession. In this chapter I present findings from the two participatory design groups that focused their attention on sharing and collaboration within patients' social network. Each of the two group began with future workshops. During the

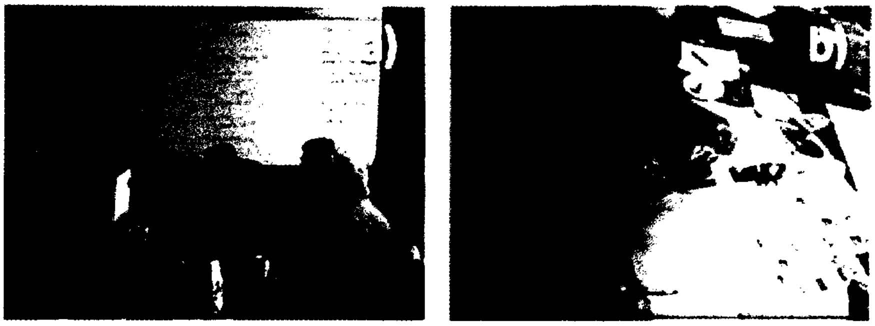


Figure 4-1: a) Group 1 discussing design ideas b) Group 2 creating paper prototypes

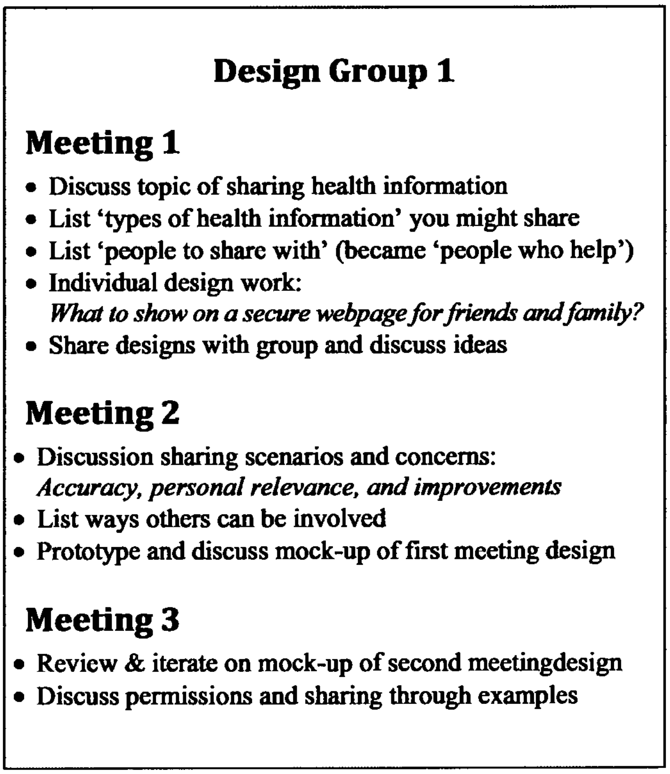
envisioning and designing activities, participants used paper prototyping to describe their design ideas. They created paper prototypes both individually between sessions and as a group (see Figure 4-1). We also used scenarios to gain insight into participants' experiences and to create foundations for scenario-based designs. We conducted brainstorming activities structured around creating lists (e.g. lists of people who help, lists of ways to help, lists of health information to share) and also facilitated more free-form discussions. Between sessions, our research team mocked up the group's ideas and implemented some designs into a Facebook Connect web application. I shared these high fidelity prototypes with the group to further iterate on their ideas.

4.3.1 Participants and Recruiting

During this research, I created and collaborated with two design groups of breast cancer patients and survivors. I recruited participants through flyers, emails, and online postings. The two design groups were separated by approximately two months. Each group met three times, for two-hours each time, with one week between meetings and participants were compensated $110 for attending all three meetings. Participants were also asked to do about an hour of "homework" between sessions and were given a design book (a blank notebook) where they were encouraged to record ideas to discuss at the beginning of the next meeting (see example notebook in Figure 1c). Our inspiration for this approach comes from Muller, who in his early participatory work, also gave homework activities to participants because he found that it made group interactions more productive (Muller, 1993).

4.3.2 Data Collection & Analysis

The design group meetings were videotaped to allow me to concentrate on the discussion and design during the session. Between sessions, I used these videos to synthesize the ideas generated



Design Group 1

Meeting 1

- Discuss topic of sharing health information
- List 'types of health information' you might share
- List 'people to share with' (became 'people who help')
- Individual design work:
  What to show on a secure webpage for friends and family?
- Share designs with group and discuss ideas

Meeting 2

- Discussion sharing scenarios and concerns:
  Accuracy, personal relevance, and improvements
- List ways others can be involved
- Prototype and discuss mock-up of first meeting design

Meeting 3

- Review & iterate on mock-up of second meetingdesign
- Discuss permissions and sharing through examples

Figure 4-2: Meeting agenda of activities for design group 1

and mock-up design ideas in preparation for the next meeting. The video has also been a valuable resource for revisiting discussions of design rational, descriptions of priorities, and developing a deeper understanding of health information sharing.

4.3.3 Design Group 1: Sharing and Collaboration

The first design group included me, one other member of my research group, and four external participants. The external participants included one woman currently being treated for breast cancer and three female breast cancer survivors. Participants ranged in age from 58 to 77. All four were regular computer users. The women in this group had been, or were being, treated for stage 1 or 2 breast cancer. Three participants were college graduates and the other was a high school graduate.

I intended to have the first design group focus on the topic of sharing and collaborating between breast cancer patients and their social networks. The group worked on designing a secure webpage where a cancer patient could post content for their social network. Although existing technology offers similar functionality (Boyd, 2008; CarePages, 2010; Patil & Lai, 2005), the group was not familiar with this technology and started with a blank slate. I chose not to introduce them to the existing technology because we did not want to influence participants' priorities or constrain their ideas. As the group progressed, the priorities of the participants led to a much greater emphasis on how social networks can help breast cancer patients, rather than the planned sharing and collaborating focus. This priority shift influenced the designs created by the group and also the topic and focus of the second design group.

The activities we did during each of the three meetings are described in Figure 2.1. We used group brainstorming and prototyping extensively and provided opportunities for both group collaboration and individual work time. Between meetings, I created paper prototypes of the ideas generated by the group, and then we iterated on those prototypes during the next meeting. Some members of the group worked best by describing how a system should work, while others expressed their ideas in drawings. The prototypes I created incorporated interface elements from both styles of describing the technology.

Scenario Use and Creation

With this group, I used scenarios as a way to stimulate discussion about existing practices and problems and also to begin to shift the group toward thinking of potential solutions (Hewitt, Herdman, & Holland, 2004). The discussion also served as a method for the research team members to verify past research findings and their applicability to these breast cancer patients. Between the first and second meeting, I gave participants five scenarios of breast cancer patients who were sharing and collaborating with their social networks. I based these scenarios on research data to ensure that they reflect realistic situations and needs. The full text of the scenarios used with the design group is available in Appendix C along with annotations describing the important characteristics of the characters in the scenarios and themes described in the scenarios. The five scenarios describe women of different ages, in different phases of treatment, with different work and family situations. The themes depicted in the scenarios came from the interview data described in Chapter 3 as well as from coding field data gathered by two members of my research group (Andrea Hartzler and Kent Unruh). Their data is from a study of Personal Health Information Management with breast cancer patients. They interacted with 15 breast cancer patients over several weeks and their transcripts are a deep look into the information breast cancer patients have and use, the goals they work toward, the challenges they encounter,

Design Group 2

Meeting 1

- Present idea for helping system
- Discuss asking for and offering help:
  Discuss how this could be done through a website
- Expand Group 1 list of ways to help
- Review & Critique asking for help webpage prototype

Meeting 2

- Re-design process for requesting help and review other designs prototyped at home between sessions
- List descriptors about healthy helping community
- Discuss and prototype status indicator idea

Meeting 3

- Deep discussion of barriers to asking for & receiving help
- Specify functionality for proxy and coordinator roles
- Prototype homepage: calendar & people-centric interfaces

Figure 4-3: Meeting agenda of activities for design group 2.

and the other people involved in their lives. Their transcripts also include information on how these breast cancer patients shared health information with others, obtained health information from others, and received help from social networks. This second dataset leant additional support to the coding scheme developed for my data presented in Chapter 3 and also contriubuted relevant examples from the breast cancer domain that I was able to pull into the scenarios.

When I introduced these five scenarios to the participatory design group, I explained that these were fictional stories, and that I wanted their help improving and making them more realistic. I asked them to read the scenarios and think about whether they seemed plausible, they could personally relate to any of the scenarios, and they could improve the scenarios to make them more realistic.

4.3.4 Design Group 2: Helping

The second design group included me, one other member of my research group, and five external participants. The participants included four female breast cancer survivors, and a woman who

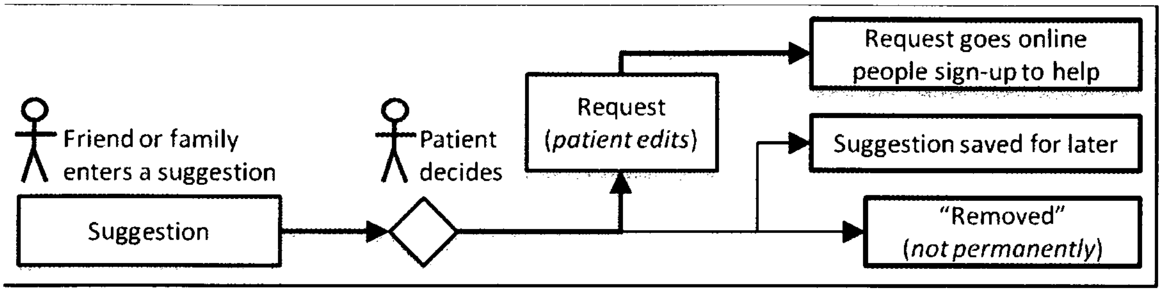


Figure 4-4: System for soliciting help from a social network. The process can begin with a suggestion from someone else or be initiated by a patient asking for help.

was close friends with a breast cancer patient. They were between 47 and 57 years old and used computers regularly. Four participants were single. Three had obtained college degrees. All four of the survivors had been treated for stage 2 or 3 breast cancer.

The second design group was assembled to iterate on and improve design ideas generated by the first group and iterated on by our research team. The group focused primarily on creating a system to support social networks helping patients during breast cancer treatment. Following the future workshop approach, we discussed what was difficult about requesting and receiving the help that participants wanted and progressed to envisioning how a better system could work and finally prototyped parts of the system during the group meetings. Figure 4-2 lists the activities we conducted during the three meetings of Design Group 2.

Design group 2 began with the goal of creating technology to supporting helping and collaboration within the social network. I used artifacts and lists from group 1 to confirm and add to the findings about helping and collaboration within social networks. I also introduced to the group our initial idea of an online system where patients can request help and members of their social networks can sign up to help. The high-level model of requesting and offering help is described in Figure 4-3.

I described the system we envisioned in terms of Sally, a fictitious breast cancer patient who was recently diagnosed and will need help after her upcoming surgery. I described the following situation. Sally creates a profile in the system and sends her friends and family a link to the system, where she will grant them permission to see her content. Sally's surgeon advised her that she would have limited mobility in her right arm for a few weeks after surgery, so Sally enters a help request online asking for someone to vacuum her house once a week for a few weeks. Her friend, Marsha, signs up to do the first week. After considering Sally's surgery, Marsha suggests that Sally might also want to ask for help walking her dog. Having already talked to her husband about being the dog-walker for a few weeks, Sally declines Marsha's suggestion.

4.4 Results

The participatory design sessions yielded two types of results. First, I gained a better understanding of how sharing, collaborating, and helping within social networks presently works, what difficulties are inherent in current practice, and how the situation could be improved. Second, we designed technology to overcome the current difficulties and enable the participants' visions of how social networks could both be kept up to date and provide useful help to a patient. I begin by describing what I learned about sharing, collaboration, and helping between breast cancer patients and their social networks. I follow this with descriptions of designs the two groups created to improve the way breast cancer patients collaborate with their social networks.

4.4.1 Who Helps

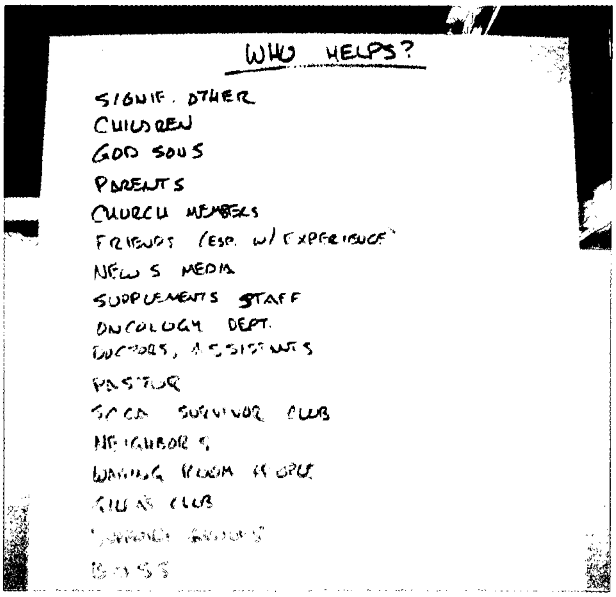
During the first meeting with Design Group 1, we created a list of everyone with whom a cancer patient might share health information. Driven by participants' responses, this activity quickly changed into creating a list of everyone who does helpful or supportive things for a cancer patient. During this design activity, they also began listing things people can do to help a cancer patient. Figure 4-4 shows a picture of the list of people created during the first meeting. The group listed family, friends, professional connections, other patients and survivors, oncology professionals, and many other examples of people who might receive information related to their cancer. Design Group 2 had a similarly broad view of the people who might be involved in helping or in receiving cancer-related information. Each individual shared different amounts and types of information with different people and anticipated the need to continue this pattern with the technology they designed.

4.4.2 Scenarios Describing Sharing and Collaboration

The scenarios (see Appendix C) were well received by Design Group 1. Participants found the scenarios realistic and believable. They provided additional related examples of events in their own lives and identified additional information that could be included in the scenarios. The scenarios also proved to be a useful tool for furthering the group's discussion of the kinds of support breast cancer patients need from technology and from their social networks.

One participant wrote a particularly thorough reaction to each scenario in her journal. For the Sally scenario she wrote, *"I can really identify with taking notes to ask the doctor so I wouldn't forget to ask some questions I had. Since my husband had died and I didn't have him as another set of eyes and ears –I really appreciated the cassette taping of my appointments to listen to and to share with my daughter for her input."* She also suggested, because Sally's scenario discussed radiation treatments, *"It was very good to bring out the info that radiation does make one tired and the need for skin care to protect from radiation. You might add something re: what the radiation entails e.g. the need to put aside all modesty exposing your breasts. Each breast is radiated for a short time separately and often an x-ray technician is a young man. But they do try to make you feel as comfortable about it all as they can."* This comment led to a discussion with the group about modesty and their own comfort levels with different people. This discussion related to the technology the group designed because some types of help are best done by people the patient feels more comfortable around (e.g. helping at home after surgery or attending an appointment where there is a physical exam).

As well as engaging with the scenarios and reflecting on their own experiences, participants were able to identify many of the themes I intended to embed in them. A participant rattled off a long



WHO HELPS?

SIGNIF. OTHER
CHILDREN
GOD SONS
PARENTS
CHURCH MEMBERS
FRIENDS (ESP. W/ EXPERIENCE)
NEWS MEDIA
SUPPLEMENTS STAFF
ONCOLOGY DEPT.
DOCTORS, ASSISTANTS
PASTOR
SCCA SURVIVOR CLUB
NEIGHBORS
WAITING ROOM PEOPLE
GILDA'S CLUB
'SHARING GROUPS'
BOSS

Figure 4-5: Design group 1's list of people who help and people who might receive cancer-related information list of the themes she connected with in the Sara scenario, *"It brings out several realistic scenarios that need to be considered... the daughter and her husband knowing everything the doctor is saying; being open with her health needs yet being sensitive to her younger grandchildren's abilities to understand; accepting the possibility that her daughter and son-in-law may eventually have to make well-informed health decisions for her; her family being sensitive to her diminished ability to help with her grandson, etc."* Participants' abilities to connect with the scenarios validate both the findings in our previous work and validate that the scenarios do accurately depict many of those themes. Their abilities to pull out and discuss the many themes I intended to embed in the scenarios shows that scenarios are a powerful, yet compact, way to bring previous research findings into the design stage.

The scenarios helped stimulate discussion of sharing and helping within social networks. One participant wrote, *"Some people really need to ask for help and not try to do treatment alone and people (neighbors, friends, and relatives) need to speak out and offer help or information."*Another participant lived in a small community where she and two other women were diagnosed with breast cancer at almost the same time. In her response to the scenarios, she journalled *"It was a privilege to help care for the oldest one of our 'trio' in her home before she died –she had wanted to be able to stay in her home –so several of her friends were able to help her daughter to keep her at home. (She was 90 years old and had never believed in mammograms so the cancer was quite large when it was discovered.)"* The discussion of people being happy to help in one of the scenarios made her bring this up. This view, that others are often happy to be able to help, was shared by other members of the group and bolstered the need to incorporate "helping" features into the technology we designed.

4.4.3 The Value of an Informed Social Network

Given the opportunity, a social network can do many things to help a breast cancer patient. A large list of specific ideas, generated by both groups, is available in Figure 8. The benefit of a helpful social network is difficult to overstate. Members of the design group recognized that, during their cancer treatment, there were things they were incapable of doing for themselves. At doctor's appointments, *"I brought my friends because they brought along their pad and pencil and they actually asked questions while I sat there looking at the doctor. All I could think about was, 'oh my god, this is what I have.' I mean, I was thinking about totally opposite things, you know, 'What am I going to do? How am I going to work?' I mean just things, while they're sitting* *there writing the information, like this could take 4-6 weeks, you know, just information! And that was really helpful.*" Another participant got help with things she was not physically able to do, like visiting the library, "*My Mom would get books for me, because I would go on the Internet and check out what I wanted and she would go pick them up for me.*" The strong link between information and ability to help was consistent throughout both design groups. Specifically, there were four types of information social networks used: (1) health information, (2) status information, (3) knowledge about the person, and (4) information about living through cancer.

Health Information

Participants in both design groups recognized that keeping friends and family up to date about their health status served to foster active helping networks. In the first design group, one of the participants drew a storyboard about her diagnosis process to describe to the group where technology could have helped. When she explained her storyboard to the group she described the picture after she got home from the doctor, "*This is me telling my friends and my relatives and asking them to help look for information. Because, like I said, I didn't have a computer for years. Asking them to go on the Internet, any kinds of books, or anyone they know who might have the same thing, because there are different kinds of cancer, and basically looking for that. And to tell them I'm scared. Could you please keep by me? I'm scared.*" Telling her social network about her diagnosis went hand in hand with asking them for help finding information and asking them for emotional support.

Status Information

Participants in both groups described, with appreciation, supporters who would proactively seek information about how they were doing even when they weren't forthcoming, "*Even better than a phone call is to just go see them, because then you can see what they need.*" A patient might not tell their social network what they need, "*If they're embarrassed or something and they don't want you to know...*" Others agreed that just checking in on the phone could be insufficient, "*Because they could be telling you over the phone you know, 'I'm fine. I'm eating. I'm healthy. I'm clean.' And then you go over and it's like, 'Oh my God!'...'cus they don't want you to know or worry.*" They cautioned, however, that there is a fine line between assertive and helpful social networks and being overly pushy. The timing and the way helping was approached seemed to make a great deal of difference in how help was received.

Knowing the person

Knowing someone well makes it easier to predict what that person would want, what that person needs and how to approach that person about helping. The nuances of tailoring support to the person and the situation are difficult and participants reported that people who knew them better often did a better job. While the groups were able to come up with lots of ideas for ways cancer patients could be helped, they also said that "*it's so individual!*" and can also depend on the timing and the person's emotional state. Another issue was not just what people needed, but also "*what people will accept.*"

There were also more straightforward ways of using knowledge about a person to help them. A participant from the first group explained, "*I think it's important for people to know, you know, well I like gardening. And I still like to garden, even though I can't get out and do gardening. So maybe somebody could come over and do some weeding for me or whatever.*" Another participant declared "*I love movies!*" and thought it would have been nice for people to bring her movies because she loves them so much.

Understanding the Cancer Experience

Knowledge about the cancer experience helped members of the social network know what to do. People who have been through cancer themselves or have had someone close to them go through treatment were a good resource because, "*At least they'll know a little bit more about what to do, what you should do.*" In contrast, people who were out of touch with the realities of cancer treatment, "*just don't know or realize how hard it can be with this sickness and going through it.*" Several participants described how they had used their knowledge to help other cancer patients.

Having an informed social network is a requirement of receiving good help. Sometimes social networks even have to take it upon themselves to actively investigate a patient's situation and find ways to help. Social networks that know a patient well and have some understanding of the cancer experience were most helpful, but anyone with a desire to help and to listen to what is needed and what is unwelcome can provide invaluable service to a cancer patient.

4.4.4 Barriers that Inhibit Social Support

Design group 1 began to touch on some of the difficulties they experienced receiving the support they wanted. We talked extensively during design group 2 about the barriers standing between patient needs and social networks' abilities to provide for those needs. Participants characterized

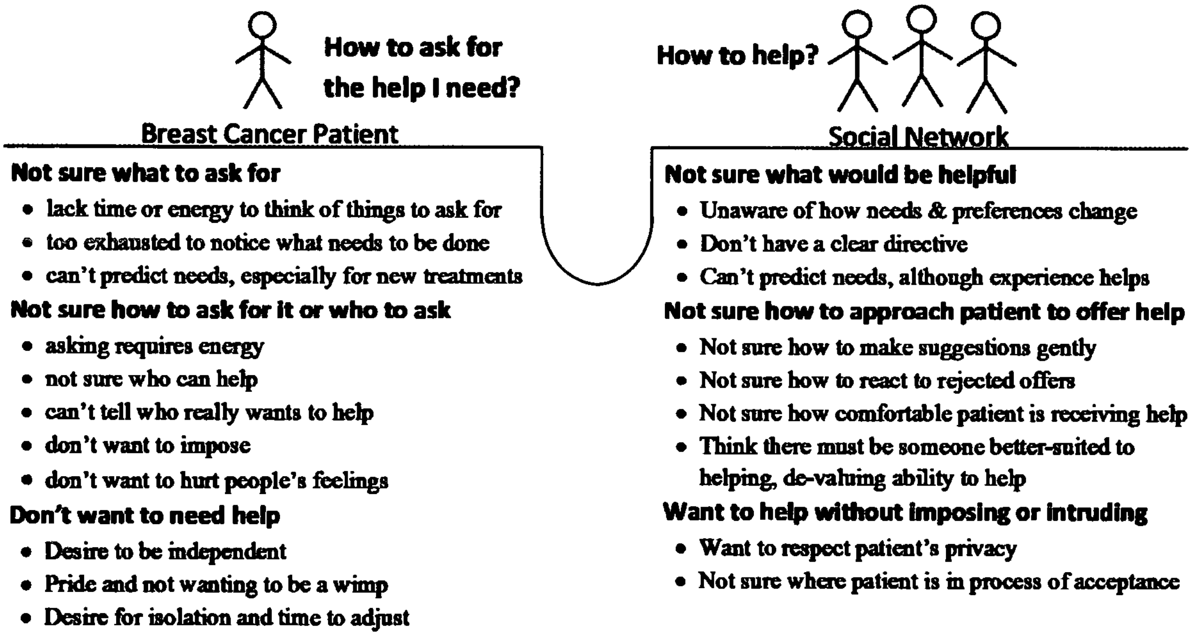
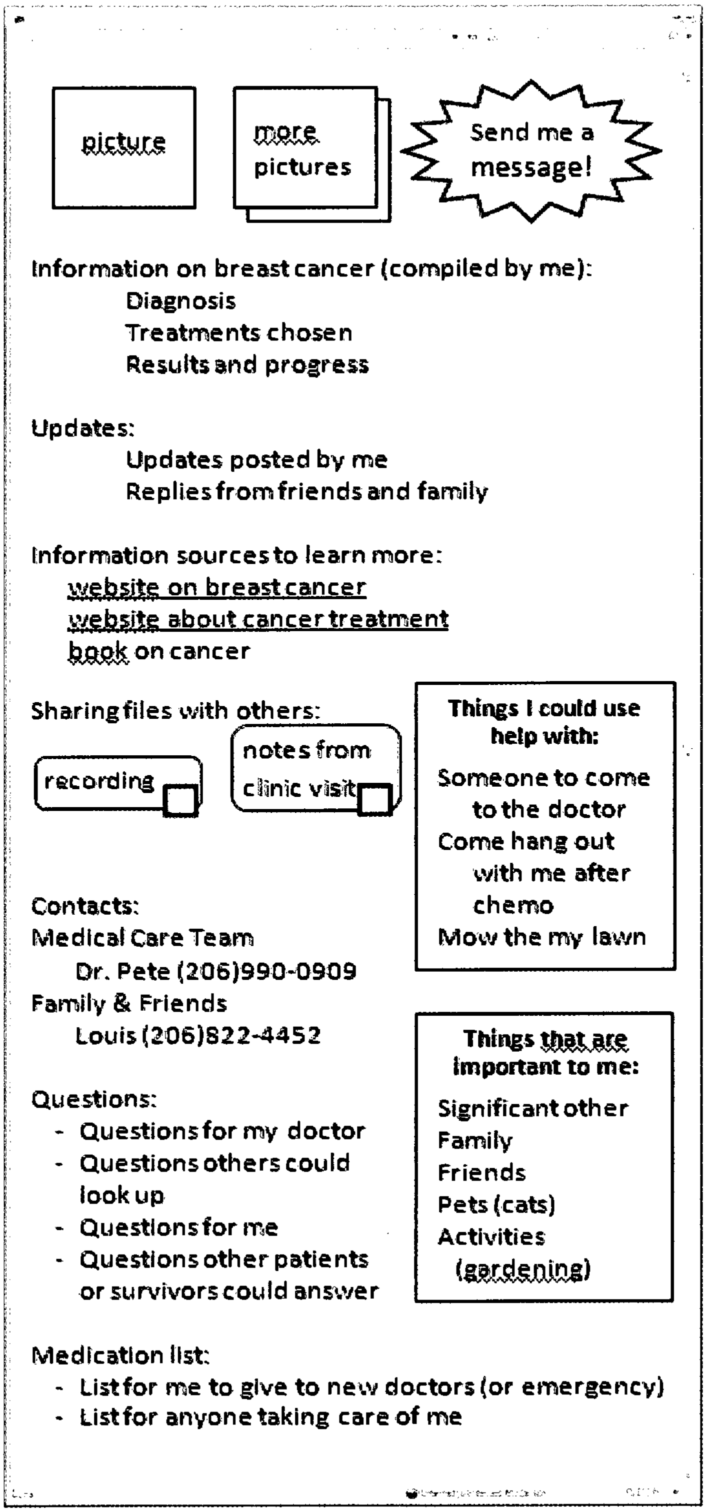


Figure 4-6: Barriers that Inhibit Social Support

the problem as a gap between the patient—who would benefit from help—and members of their social network who want to provide help. To probe further, we had a 45-minute discussion during which the group generated lists of barriers that foster this gap from the perspectives of both the patient and their social network. The results of that discussion are summarized in Figure 4-5.

Participants identified four strategies to ameliorate these barriers in an online system. First, participants recommended explicit representations of help requests. Making help requests explicit could help the social network overcome the barrier of not knowing what would be helpful or whether help is wanted.

Second, participants recommended visual overviews of their social network and helping activity. These overviews would help people within the social network visualize existing helping activity and identify additional opportunities to provide help. This strategy makes explicit what is—and what is not—occurring, and could alleviate the problem where family and friends think that someone else probably knows the patient better or is better-positioned to help. An additional goal of this strategy is to encourage a sense of community and activism in support of the patient.



Information on breast cancer (compiled by me):
- Diagnosis
- Treatments chosen
- Results and progress

Updates:
- Updates posted by me
- Replies from friends and family

Information sources to learn more:
- website on breast cancer
- website about cancer treatment
- book on cancer

Sharing files with others:

Contacts:

Medical Care Team
  Dr. Pete (206)990-0909

Family & Friends
  Louis (206)822-4452

Questions:
- Questions for my doctor
- Questions others could look up
- Questions for me
- Questions other patients or survivors could answer

Things I could use help with:

Someone to come to the doctor

Come hang out with me after chemo

Mow the my lawn

Things that are important to me:

Significant other

Family

Friends

Pets (cats)

Activities (gardening)

Medication list:
- List for me to give to new doctors (or emergency)
- List for anyone taking care of me

Figure 4-7: Design group 1 described the functionality and content they would want on a secure webpage for their social networks.

Third, in response to suggestions that the system provide a way for social networks to suggest help, participants recommended features to say 'no thank you' to help they do not want. This feature also supports the social network's desire to tailor their help to the patient's individual preferences because they can be assured that patients had the opportunity to say 'no'. Polite template messages for saying 'thank you for thinking of me, but no thank you' will make it easier for patients to say no, but will not entirely alleviate the social difficulties of rejecting unwanted help.

Fourth, participants recommended features to assess the willingness of specific individuals in their social network to help. Breast cancer patients did not want to ask for help from people who did not want to give it or who would have to overextend themselves to provide help. Having a system where members of the social network can identify themselves as someone who wants to help could enable patients to overcome the barrier of feeling unsure about whether someone really wants to help. Another aspect of the system that addresses the difficulty of asking for help is that the patient is asking a whole community of friends and family instead of a specific person who might feel obligated to help if asked individually.

4.4.5 Designs to Create an Informed Social Network

As we described previously, an informed social network needs health information, status information, knowledge about the patient, and an understanding of cancer. Ways to provide these types of information can be observed in the functionality participants designed. Figure 4-6 shows the second iteration of a mock-up created by the researchers between sessions to pull all Group 1's design ideas into one document.

Health Information to Share

Participants described several types of functionality for giving their social network health information and status information. They envisioned creating background reading and resources, updating the network with blog posts as time passed, sharing their records online, and providing caregiving information to those around them.

Background reading and resources

Patients envisioned creating content to educate their social networks about the patient's health condition. Participants wanted to post general background information about their diagnosis and treatment plan as well as add educational links where people could learn more if they were interested. This might serve to answer people's questions and prevent the patient from answering the same question repeatedly from different people. This functionality might also give members of the social network information that they wanted, but were not comfortable asking the patient.

Health Updates

Content would also be created specifically for the purpose of keeping the social network informed and up to date. In addition to the background information about their health situation, they envisioned blog functionality for posting updates and getting replies from friends and family. In addition to informing the network about their health status, this would also serve as a way for the network to stay up to date on how they were feeling and the issues they were struggling with. The more informed the network is, the more appropriately they can offer help and support.

Health Records

Participants kept a wide variety of health information and were interested in the ability to share it online with select members of their social network. Information they envisioned supporting included: Appointment info & calendar, Question list, Contact information, Notes from clinic visit, Recording from clinic visit, Hand-outs & brochures, Medical records (e.g. blood work, pathology report, x-rays, etc.), Medication List & Prescriptions, Books, Journal or Diary, Photos, and Websites (see Figure 4-6). The list they generated is consistent with the types of information other researchers have observed patients collecting (CaringBridge, 2010a).

Caregiving Information

In addition to making health information available, participants also designed for times when people in their social network might need more information to take care of a patient. To provide this kind support, a friend, family member, or neighbor would need to be informed about what is happening with the patient's health in general, but would also need more specific information about medications and emergency contact information. A participant described how she dealt with this quote, "*When I was first diagnosed with breast cancer I made up a little half sheet of medical information and gave one to my mom, to my ex-husband, gave one to my best friend, and put one on the refrigerator, and one at work. It has who my important medical people were and my best friend's phone number. And on the back of it I had a list of all my medications. So they all got that and then I carried one in my purse.*" Following up, another participant said, "*You do get really sick during your treatment time and could have a friend visiting, and not have your husband or daughter or mother available,*" (who would know how to take care of you).

Correlating the past solution to a future design, one woman said, "*I thought that was a good idea. What really struck me is that people need to know more about what you might have to have during this time and your doctor's name, and all that could be put on the Internet.*" Close friends and family would have access to a lot of medical information, but a larger set of people would have access to information about medications and who to contact in an emergency in case they ever need to help take care of the patient. This functionality is akin to keeping the information on their person and at work in an easily accessible format that someone else could use to help them.

Each participant in Group 1 wanted to share information differently and envisioned having the ability to control how each object was shared. A participant said, *"There are certain people that need to see certain information and other than that, quite frankly, I don't think it's any of their business."* Even between sessions, some participants seemed to change their thinking about what information they would want to share and with whom. The system would need to support these changes and adapt to each individual's sharing needs.

Collaborative Question List

Question lists were of great interest to participants, who imagined having multiple types of question lists that other people could view and add additional questions. For example, other people might add questions for the doctor or might look up and answer questions on a general list. The question lists represent another way to have dialogue with one's social network and the collaborative question list could also help outsourcing research tasks if the social network used that information to seek information for the patient. Having this functionality available would show a patient's network what the patient is thinking about and what answers they need, enabling the patient's friends and family to act accordingly.

Status indicator

The goal of the status indicator was to quickly record and post status information to help keep the social network up to date. These posts could also help people who are unfamiliar with cancer learn more about the patient experience and encourage them to tailor their behavior appropriately. Participants wanted the status indicator to be both flexible and provide for very fast interactions. They envisioned having a text box, check boxes with symptoms, emoticons, and slider bars to indicate things like energy level. Each user would be able to use the feature that expressed their status and that information would be logged over time and shared with the social network.

Maintaining Awareness of the Big Picture

The list of 'Things that are important to me' (Figure 4-6) serves as a way for cancer patients to convey to their social network what they care about. We established that knowing more about a patient can empower a social network to act intelligently when proactively providing help. This list also served as a reminder to the patient and the social network that their life is about more than just cancer. For example, the participant who explained how much she liked to garden wanted to put that on her list in the hopes that it might prompt someone to come help her take care of her garden.

4.4.6 Designs for Catalyzing Helping Activity

The box titled 'Things I could use help with' in Figure 4-6 was expanded upon greatly by the second design group. The first group generated a long list of things other people could do to help, but did not have time to delve into the details of how requesting help and receiving help could be facilitated by technology. After the first group, we generated more ideas for the structure of a helping system. Group 2 used these ideas as a starting point and designed ways to request and offer help, view help requests and offers, and utilize proxy and coordinator roles to ease the burden on over-taxed patients.

Requesting and Offering Help

Participants emphasized the importance of designs to facilitate requesting or offering help. They cited challenges patients face in knowing what to ask for because they have difficulty predicting their needs over time, have low energy levels, and are coping with side effects. Participants expressed concern about the wearing effects of treatment on their energy and personal standards. As patients became progressively more exhausted, they cared less and less about keeping up with regular tasks like bills and housekeeping. One participant remarked: "*I was so fatigued I didn't see the dust bunnies, I didn't care about [doing household chores]*" The social network also typically lacked experience with the cancer experience and required information to determine how to help. Ironically, when patients' needs were greatest, they struggled to reach out for help: "*I just was too tired to even be able...to be able to formulate a way to ask the help...even the thought of having to go through all the reasons that I needed help and what I needed done.*"

To address these problems, participants recommended design features to prime patients—and their social networks—with ideas on what help to solicit or offer. Using an initial list of useful

Medical-Related Tasks	Everyday Chores	Managing/Coordinating Tasks
Come to appointment Provide transportation Assist with drains/self care Provide list of questions Describe non-obvious things to know Research options to consider Gather / collect information Put me in touch with person or organization Put others in touch with me Help interpret medical documents Ensure I'm comfortable after surgery	Run Errands Do Laundry Clean areas of house Change linens Arrange/provide Meals Arrange 3rd party meal service Arrange 3rd party cleaning service Stock shelves with groceries Do yard work/gardening Going to bank Take me shopping Take care of garbage	Help me get organized Help me with bills Discern how to maximize benefits Manage communication with family/friends Coordinated needed help Organize schedule/calendar Arrange outings Make sure I get to appointments on time
Other Ways to Help		
Come over for a visit Bring flowers Send cards Provide play dates/activities for kids Share funny books & movies Offer babysitting Transportation for kids	Share humor strategies Hold fundraiser Help sort out work issues Come exercise with me Go for a walk Check in with me about exercising Come watch movies with me	Do dog walking & pet care Spiritual care visits if desired Bring over reading material Visit to play games/cards Go to library to get books Take me to library/bookstore

Figure 4-8: Help that would be useful to breast cancer patients

help from design group 1, participants from group 2 added new items to make a more comprehensive list. The list participants generated (see Figure 4-7) reflects both kinds of help they received and kinds of help they would have liked to receive.

Participants' insights into a breast cancer patient's state-of-mind when approaching the system directly influenced the interface for requesting help. Initially, we had suggested to participants that the interface could offer a few help suggestions and also provide a blank form users could fill out to ask for any type of help. The problem with the blank form was that exhausted, overwhelmed, or inexperienced patients might not know what their social network would be willing to do. The new interface design will reduce the cognitive load on the patient soliciting help by including a long list of kinds of help that others have found useful, much like Figure 4-7. Next to each item on the list is a 'Yes' and a 'No' button. Clicking 'Yes' next to an item makes it expand so the patient can fill in more detailed instructions and information and say when they would like the help. A user will always be able to go back and change what they want

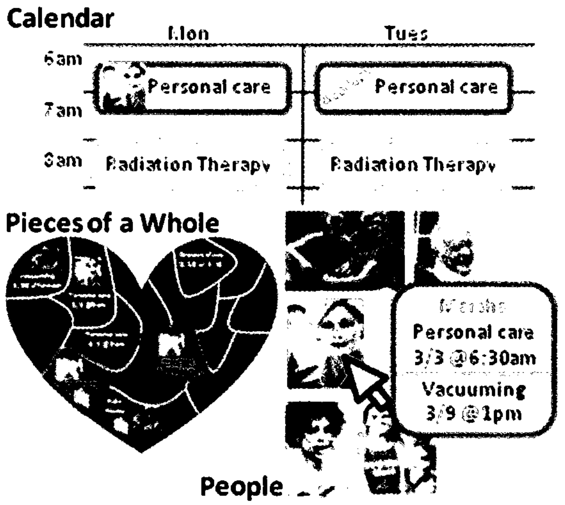


Figure 4-9: Three interfaces for viewing help requests.

and will also have the option to ask for help that is not on our list by filling out a blank form with a title, description, and time(s). A similar interface supports the social network in suggesting ways in which they could help the patient.

Viewing Help Requests and Offers

As a group, we made paper prototypes of the interfaces for seeing all the help a patient has asked for, what people have signed up for, and what help will be needed soon. We generated three main visualizations for seeing help requests (see Figure 4-8). Participants felt it was very important to integrate pictures of members of their network into all these visualizations. In the example of the calendar, a participant explained that with the picture, "*I can start thinking about that person, that they're coming.*" They advocated using pictures, even when there was limited space (e.g. on a weekly calendar).

Calendar

A weekly calendar view could be used to visualize all the upcoming scheduled help events. Members of the social network could use the calendar to see upcoming requests that are unfulfilled and to sign-up for those slots. The calendar could also display other relevant events, such as upcoming treatments or appointments, so the social network is aware of the patient's schedule and can volunteer or suggest appropriate help. This view also helps the patients see upcoming help embedded with the other items on their calendar.

Pieces of a Whole

A personalized shape, such as a wreath, cross, or heart, is shown divided into small sections (see Figure 4-9). Each section represents a help event (someone doing something helpful). When members of the social network sign-up to help, that piece becomes theirs. They can have a copy of the pieces they have signed up for (electronically) and can see how their contribution fits into a bigger effort. The patient also sees a visual representation of their helping community.

People

A visualization of everyone who has helped or signed up to help can be explored to see what help each person has signed up for or completed. This view allows the social network to see the extent of the patient's social network, and it provides another way for patients to see everyone who is part of their helping network. Where the pieces-of-a-whole visualizes each contribution a person makes, this idea explores just who is participating in helping events.

Supporting Proxy and Coordinator Roles

Motivated by vivid memories of the exhaustion they experienced during cancer treatment, design group 2 participants recommended designs to support two new roles that people in their social network could fill. The first of these roles is a "proxy," which patients described as someone they trust to interact with their social network on their behalf. Proxy responsibilities include (a) setting up the help system to *"start the ball rolling,"* (b) inviting people into the patient's helping network, and (c) deflecting unwanted offers (i.e., participants felt a 'no thanks' coming from the proxy was gentler than a rejection from the patient). Besides being too tired and overwhelmed to have time to set up a profile and invite people, participants also expressed reluctance to ask people to be part of their helping network. One participant explained, *"I don't want to bother anybody."* Participants specified that a proxy would have permission to do everything a patient can do –ask for help, edit requests for help, accept offers of help, field questions, and triage incoming messages of support. In sum, a proxy acts on the patient's behalf with full access to system features. However, concern was voiced over tiring out the proxy, with one participant noting *"I think they would get burned out real fast if they were doing everything."*

In addition to the proxy, participants also envisioned a new "coordinator" role. Participants described a coordinator as someone who would manage one piece of the social support puzzle. Functionally, coordinators have a more limited scope of access within the system than proxies. For example, a coordinator could arrange rides or manage meals for the patient. The meals coordinator would have permission to edit the help request, answer questions about meals, and would be the contact point for people who sign-up to provide meals. Coordinators could help ease the burden on the patient, or on a proxy, by taking on more manageable chunks of the work.

Returning to our fictitious patient Sally, her husband Jim could be a proxy who gets the system set up with Sally's information and sends a link out inviting friends and family to become part of the helping network. Sally's friend, Martha, could just sign-up to vacuum the house once – or she might ask to become a coordinator for all the housekeeping tasks. As coordinator, she could answer questions about what is needed such as where the cleaning supplies are kept as well as add new time slots as more help is needed.

4.5 Contributions

My goal for the participatory design phase of this research was to design technology that facilitates collaboration between breast cancer patients and their social networks. Working with breast cancer patients, survivors, and proxy information managers has resulted in new design ideas and promising new directions for technology to support these needs. In addition to generating new designs, this research has also deepened my understanding of the underlying needs and difficulties faced by breast cancer patients and their social networks. Throughout the design process, participants shared their own experiences collaborating with their networks and educated me on the importance of an informed network and the difficulties of creating a helpful network. Their values, needs, and experiences shaped the direction of the technology we designed together.

Chapter 5

Technology to Support Sharing within Patients' Social Networks

In Chapter 4, I described the participatory design process and the many design ideas the groups generated. The result of the PD process was both a much deeper understanding of patients' needs and experiences as well as many partially prototyped design ideas. During the group sessions, we prototyped design ideas to the point that we understood what the important functionality or interface components should be and how people might use the technology. Because of time constraints, we focused on generating ideas and iterating on them only to the point that everyone understood and was happy with the idea instead of creating more finished interface designs. In this chapter, I combined and polished the design ideas the groups developed and I describe a complete system to help cancer patients collaborate with their social networks.

The technology I present in this chapter is designed to enable patients to keep their networks informed and to enable collaboration with their network. Social networks can do a great deal of good by supporting and helping patients through the cancer process. This technology will enable social networks to offer useful help and to detect when support is needed. Members of the social network can use this technology to communicate with the patient and with one another. Patients can push information out to their network, but can also maintain as much privacy as they desire through detailed privacy controls.

To date, some aspects of this technology have been implemented by Christopher Powell, a developer with whom I have collaborated. Aspects of the interface that have been implemented are described with screenshots; aspects of the interface that have not been fully implemented are described using wireframes and mock-ups.

Throughout this chapter I will use the fictional life of Sally and her social network. Sally is the main character in one of the scenarios I developed (see Appendix C). She is retired and lives with her husband, Dan, who goes with her to doctors' appointments and treatments. As an example for this chapter, Sally is going through chemotherapy treatment. She asks for some help and support from her friends and family, receives an offer of help, and posts a blog update. This coming week, Sally has an oncology appointment and what she hopes will be one of her last chemotherapy infusions. Sally's daughter is also coming into town for a visit.

In this chapter I present technology designed to create informed social network and foster sharing and collaboration within those networks. In the following sections, I describe the functionality of the system I designed and provide a combination of wireframes and screenshots to illustrate the functionality and the interfaces.

5.1 Homepage

A logged-in user's homepage (see Figure 5-1) is designed to provide an overview of all upcoming helping activities and communication with the social network. The homepage includes a newsfeed of the network's helping activities, intended to quickly update the user on upcoming events occurring in the near future. The homepage also includes a weekly calendar that shows a small picture of everyone who has signed up for a helping event, just as Design Group 2 prototyped. There is also a blog section where new posts and comments are displayed to keep users apprised of any new content. The pictures on the right side of the interface show the people who are helping the user, the people the user is helping, and all the people who can see the user's content.

In addition to the information on the current implementation of the homepage (Figure 5-1), my design includes additional content. Figure 5-2 is a wireframe of my envisioned homepage. A status indicator will be visible on the homepage. As part of providing information to the social network, the status indicator will be a quick way for patients to give information to their network without having to compose a blog post. The indicator could also be used by patients to reflect on their current state as well as look for trends in their past state. As another way to help keep the network informed, there will be a preview of an "About Me" page, described further in Figure 5-3. Additionally, the high level view of the latest blog posts and comments are also available on the homepage.

The system enables users to collaborate on information work through functionality supporting discussion of notes and lists as well as the ability to uploaded files. The homepage will include a preview of the latest comment activity on notes and lists and also on uploaded files. Other methods of helping, such as asking for help, offering help, and signing up to help, will also be previewed on the homepage in the box titled "Helping." Beyond signing up for specific help events, members of the social network will also be able to provide support by sending messages to the patient. Patients will get a preview on their homepage of all of these messages in their "inbox." The bottom of the page will have an acknowledgement section where patients can quickly thank and acknowledge the contributions of their network.

5.2 Informing the social network

One of the main themes that emerged from my research is that informed networks are helpful networks. Many of the features in this technology focus on informing the network and facilitating communication between the network and the patient. In particular, these features are designed to lower the barrier to keeping the social network informed. In this section, I describe the aspects of the technology focused on informing and updating the network.

5.2.1 About Me

The About Me page is designed to share three types of information: general educational information about breast cancer, specific health information relevant to the patient, and information about the patient beyond their health status (see Figure 5-3). The page begins with a box titled "This is who I am…" where patients can describe themselves using free text. The top left of the page has a box called "Things I care about…" where patients can list the things that are important to them. These two boxes serve to remind the social network and the patient that they are not just a cancer patient and that cancer does not have to consume every aspect of their lives. Participants in my research described wanting a "break" or wanting to spend time not talking

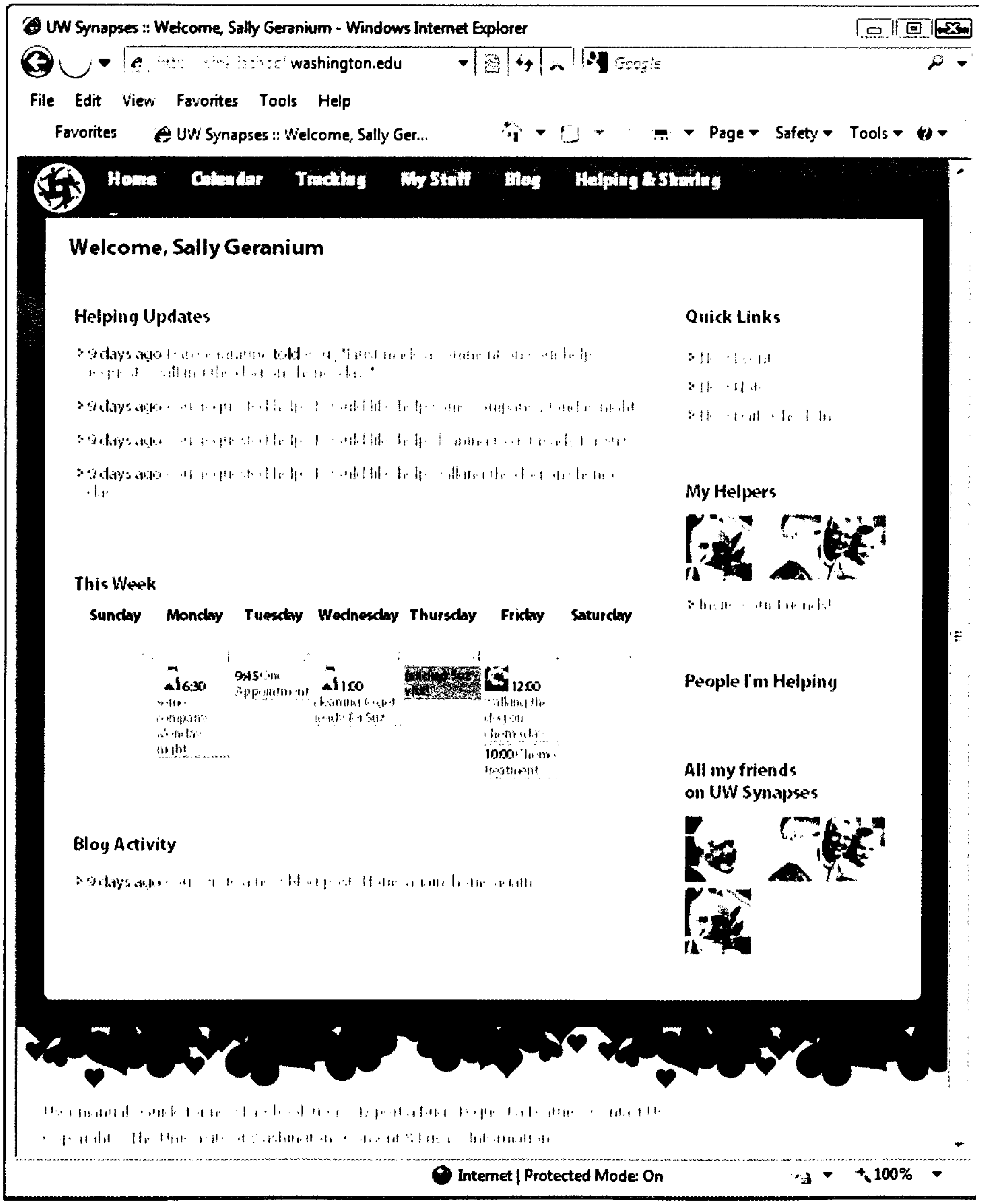
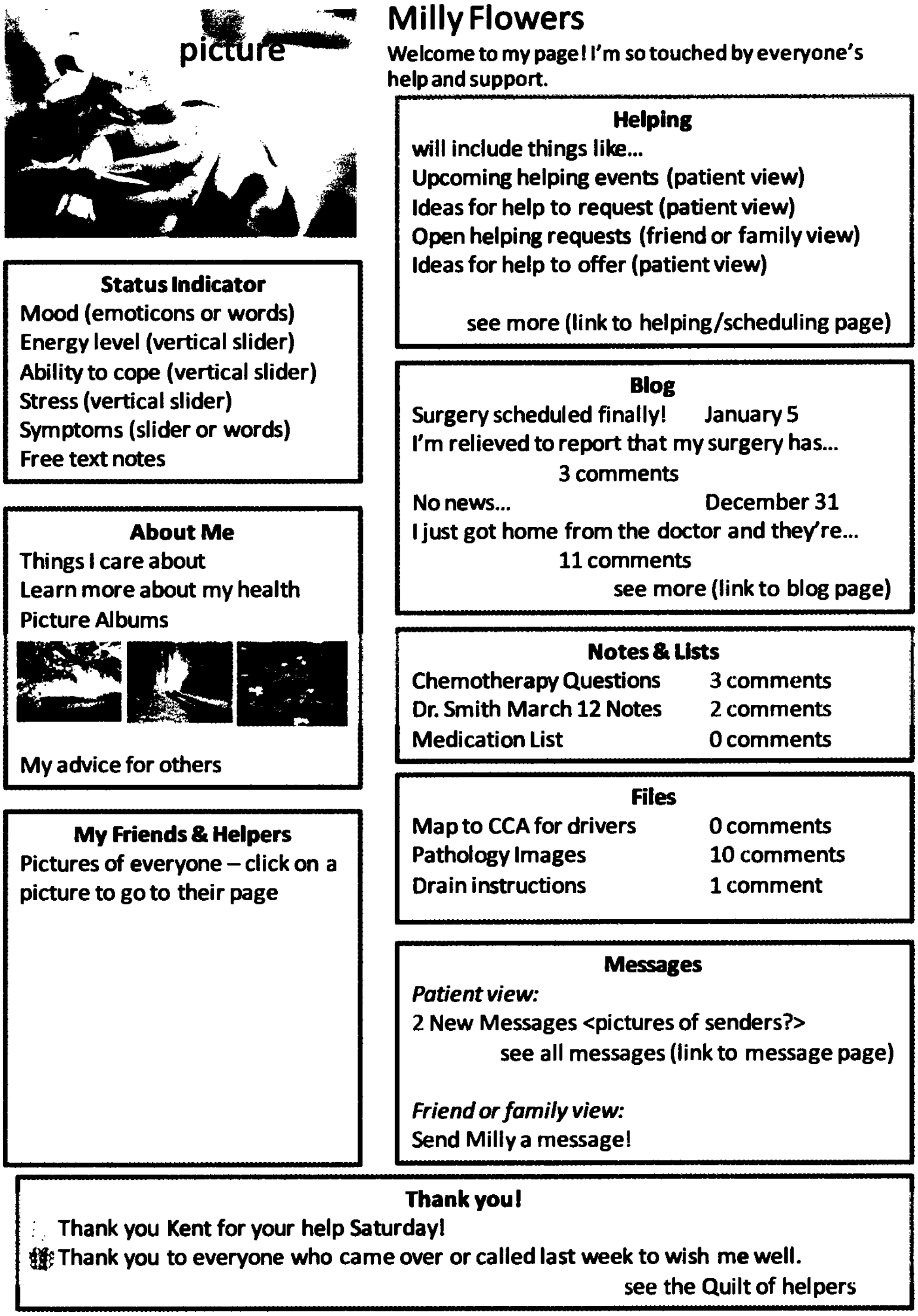


Figure 5-1: Screenshot of the current, implemented homepage.



Milly Flowers

Welcome to my page! I'm so touched by everyone's help and support.

Helping
will include things like...
Upcoming helping events (patient view)
Ideas for help to request (patient view)
Open helping requests (friend or family view)
Ideas for help to offer (patient view)

see more (link to helping/scheduling page)

Status Indicator
Mood (emoticons or words)
Energy level (vertical slider)
Ability to cope (vertical slider)
Stress (vertical slider)
Symptoms (slider or words)
Free text notes

Blog
Surgery scheduled finally! January 5
I'm relieved to report that my surgery has...
3 comments
No news... December 31
I just got home from the doctor and they're...
11 comments
see more (link to blog page)

About Me
Things I care about
Learn more about my health
Picture Albums

My advice for others

Notes & Lists

Chemotherapy Questions	3 comments
Dr. Smith March 12 Notes	2 comments
Medication List	0 comments

Files

Map to CCA for drivers	0 comments
Pathology Images	10 comments
Drain instructions	1 comment

My Friends & Helpers
Pictures of everyone – click on a picture to go to their page

Messages
Patient view:
2 New Messages <pictures of senders?>
see all messages (link to message page)

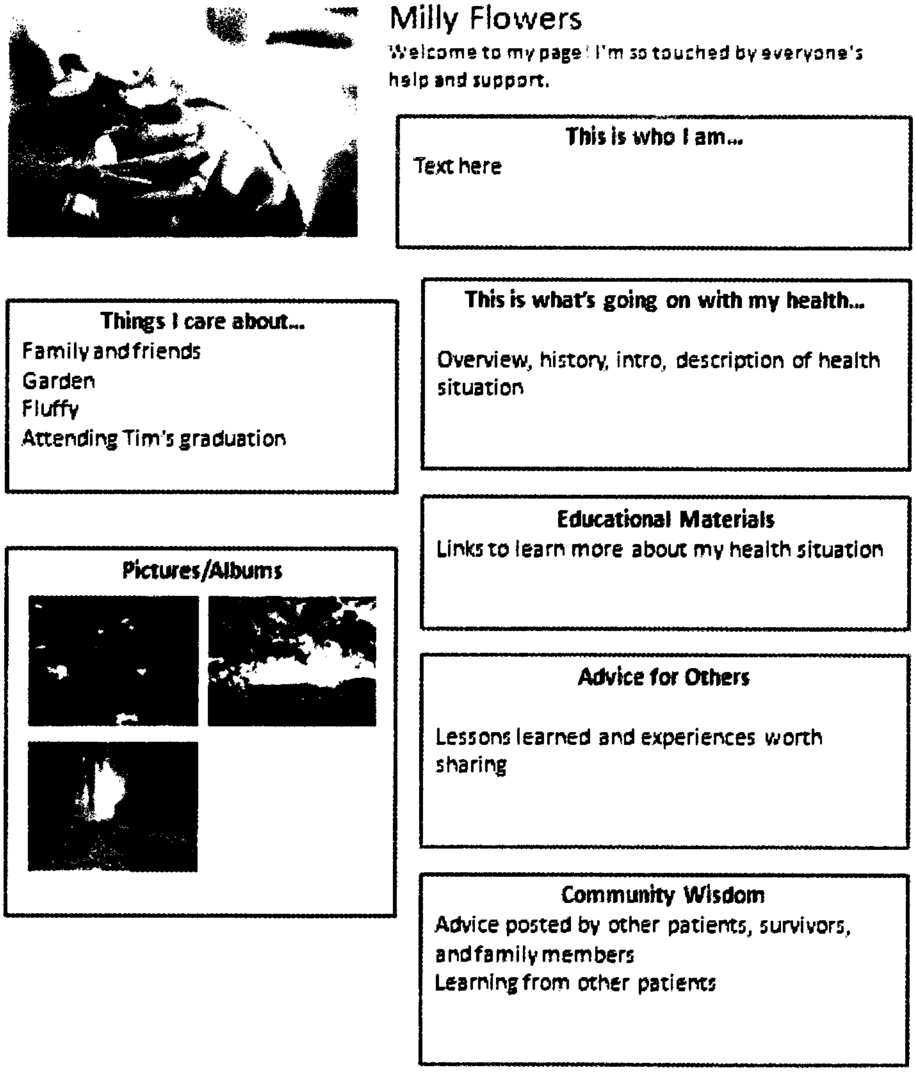
Friend or family view:
Send Milly a message!

Thank you!
Thank you Kent for your help Saturday!
Thank you to everyone who came over or called last week to wish me well.
see the Quilt of helpers

Figure 5-2: Wireframe mockup of envisioned homepage showing additional functionality not yet present in the implemented version.

about cancer or not thinking about cancer. Providing this information will encourage patients and their networks to take that break and to remember that there is still life outside of cancer.

To provide information about their specific health situation, patients can compose a short narrative in the "This is what's going on with my health…" box. The blog will also be a way to



Milly Flowers

Welcome to my page! I'm so touched by everyone's help and support.

This is who I am…

Text here

Things I care about…

Family and friends

Garden

Fluffy

Attending Tim's graduation

This is what's going on with my health…

Overview, history, intro, description of health situation

Educational Materials

Links to learn more about my health situation

Pictures/Albums

Advice for Others

Lessons learned and experiences worth sharing

Community Wisdom

Advice posted by other patients, survivors, and family members

Learning from other patients

Figure 5-3: Wireframe mockup of envisioned "about me" page. This page was designed to share educational information about cancer, information about the patient's health status, and information about the patient outside of their current health condition.

update the social network about health events as the situation changes over time, but this box will provide a reference to members of the social network who need to get up to speed on the patient's condition. By putting this information online we might also be relieving some of the burden on patients, who often have to repeat the same difficult information to many different people. In other cases, members of the social network might be reluctant to ask specific questions, but could find the information on the webpage.

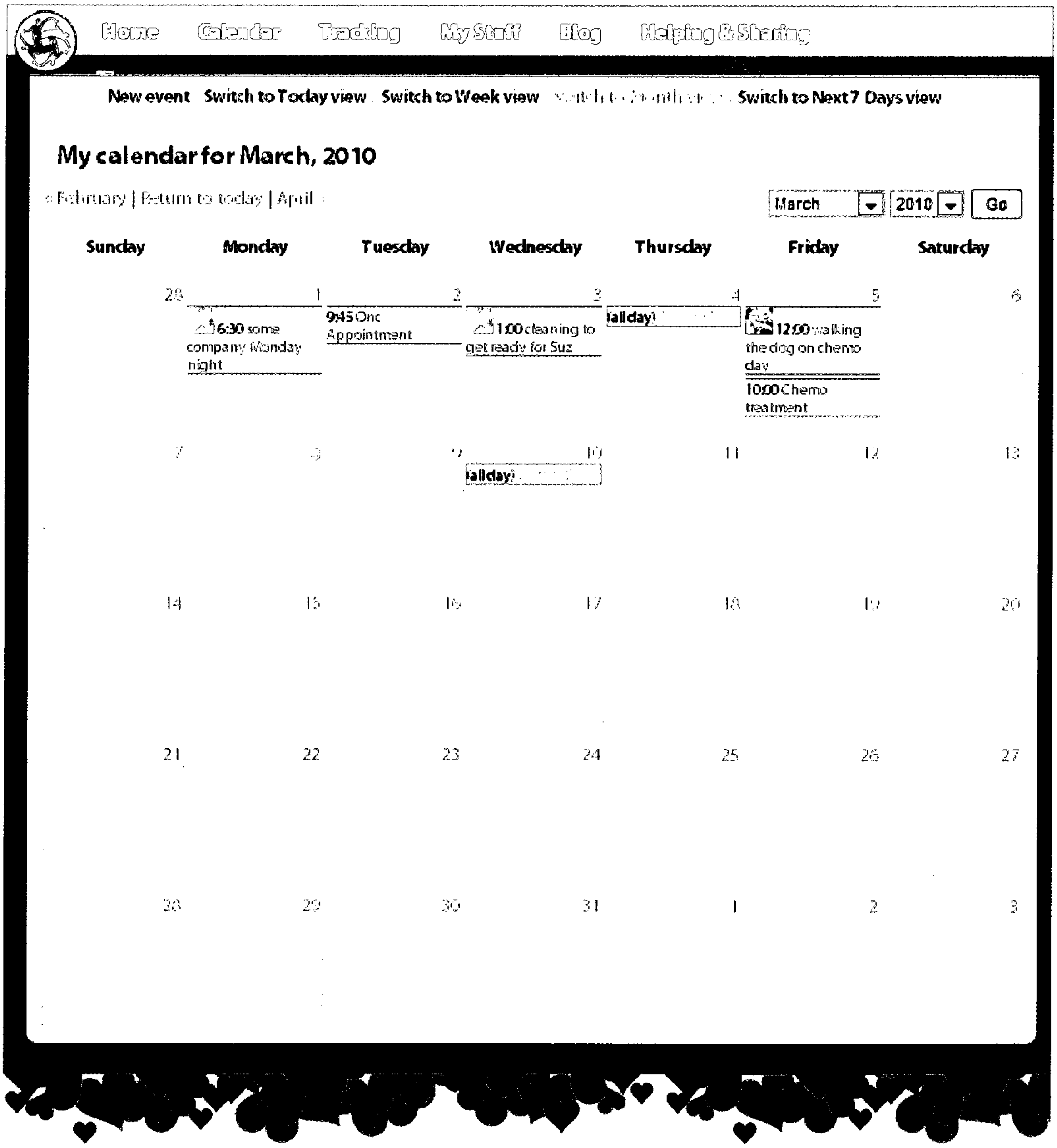
The final type of information that patients wanted to spread was general educational information about breast cancer. The "Educational Materials" box will contain links to articles and webpages where members of the social network can read more about cancer and cancer treatment. Again, this will alleviate the burden from the patient and close family of repeating information for everyone with whom they talk.

Participants showed a great deal of interest in pictures throughout our design discussions. The idea of using pictures of their helpers throughout the interface was very appealing. They also reacted strongly to keeping pictures related to their cancer journey. Some people used pictures to document their experience; others used pictures to remind them of happy times with the people they love. I have been told that some patients take pictures with their doctor or with their infusion nurse to help document the experience and share it with family. Pictures, arranged in albums, will be part of the "About Me" page. Family and friends should also be able to upload pictures for the patient that are related to their cancer experience or that are simply for the patient's enjoyment.

The "Advise for Others" box is not something that I discussed in depth with patients because a colleague's entire dissertation focused on the expertise patients develop over time. (Civan, 2009) However, patients in the early interviews (see Chapter 3) and in the participatory design groups expressed a strong desire to help others by sharing their experiences and telling others what they learned along the way. In the design groups, participants also talked about wanting to be able to find this advice or these experiences from others. This type of information will be found in the "Community Wisdom" box. Participants valued learning from other patients and they hoped that there would be a way to capture that knowledge and show it to people at the right time. For example, if Sally is going through chemotherapy and has been experiencing numbness (and perhaps tracking that with the Status Indicator) she might like to see community wisdom from other breast cancer patients about their own experiences with neuropathy during and after chemotherapy.

5.2.2 Calendar

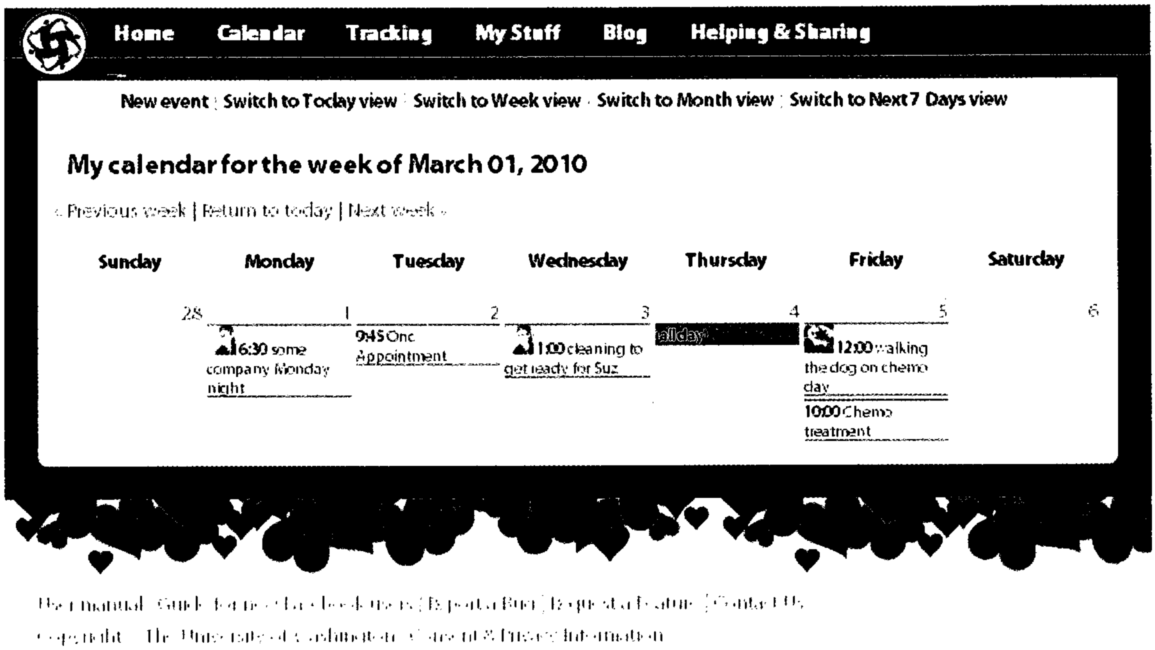
In addition to the weekly calendar previewed on the homepage, there are also daily, weekly, and monthly calendar views. Figure 5-4 shows Sally's monthly calendar, with the option to switch to



My calendar for March, 2010

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
28	1 6:30 some company Monday night	2 9:45 Onc Appointment	3 1:00 cleaning to get ready for Suz	4 (allday)	5 12:00 walking the dog on chemo day 10:00 Chemo treatment	6
7	8	9	10 (allday)	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31	1	2	3

Figure 5-4: Full month view of the calendar. Sally's appointments and helping events are visible.



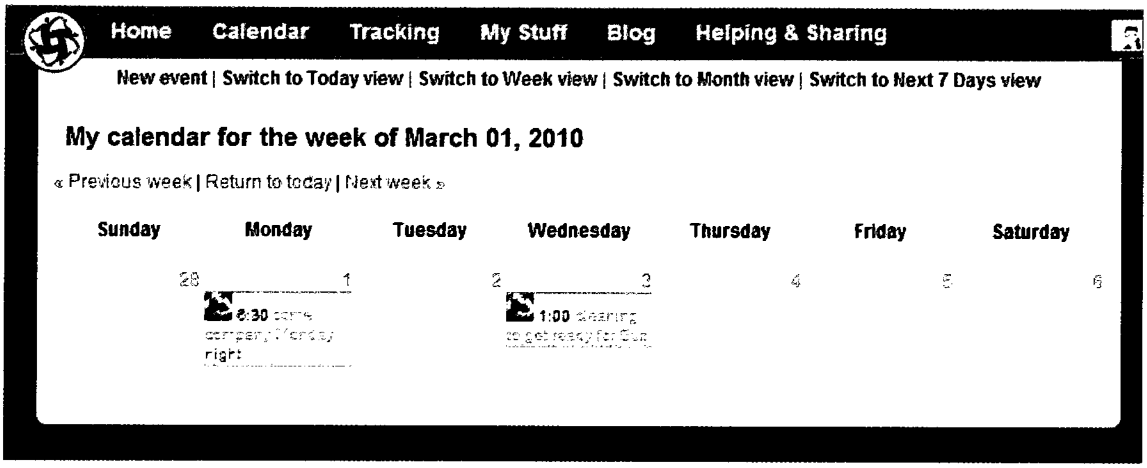
My calendar for the week of March 01, 2010

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
28	1	2	3	4	5	6
	6:30 some company Monday night	9:45 Onc Appointment	1:00 cleaning to get ready for Suz	allday	12:00 walking the dog on chemo day 10:00 Chemo treatment	

Figure 5-5: Weekly view of the calendar. Sally can see all her events during the week. When someone has signed up to help, their picture shows on the event.

a view of one day, one week (see Figure 5-5), or the next seven days. In Sally's case, she can see her health appointments (an oncology appointment and a chemotherapy treatment), scheduled helping events (a Monday night get-together, a Wednesday appointment to get the guest room ready for her daughter's visit, and a Friday appointment for a neighbor to come walk the dog while she is away for her treatment), and big life events (her daughter's weeklong visit). Viewing all of this information in one place will make it easier for Sally to see what her week looks like and plan ahead for managing her day-to-day activities with her cancer treatments.

Sally will also be able to share her calendar with this technology. Friends who sign up to help get a copy of the event they are helping with (see Figure 5-6). For example, Sally's friend, Julie, has signed up to come over Monday night and also to help clean on Wednesday. In Figure 5-6, you can see these events on her calendar with Sally's picture next to them. In addition to seeing events they are signed up for, friend and family might also be given permission to see Sally's health-related appointments. The people closest to Sally, like her husband Dan, might be given access to everything on the calendar so he can see the help coming up as well as the health events all in one place. Patients in the design groups articulated both benefits and concerns about this functionality. A general desire to maintain privacy made motivated some participants to want to



My calendar for the week of March 01, 2010

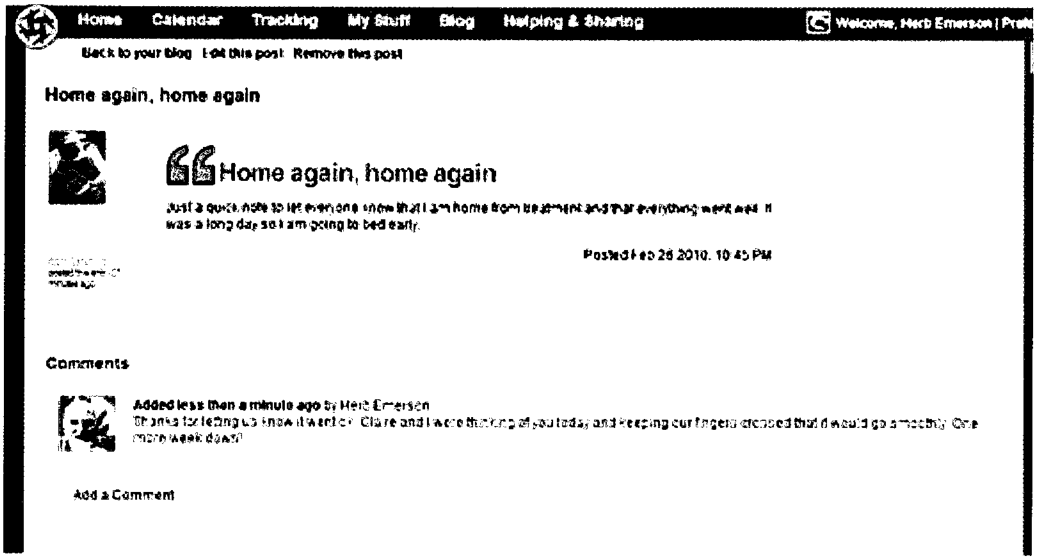
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
28	1 6:30 some company Monday night	2	3 1:00 cleaning to get ready for Sun	4	5	6

Figure 5-6: A helper's week view of the calendar. This is Martha's calendar, she can see her two appointements with Sally.

share minimal calendar information with their social network. However, an informed network is a helpful network, so other patients wanted their networks to have information about their treatment events as well as other important life events. They thought this extra information about their activities would help their network anticipate their needs and act proactively – offering help or getting in touch to show their support when they thought it might be particularly needed. Related research shows the potential impact that sharing calendar information within a family (Plaisant, Clamage, Hutchinson, Bederson, & Druin, 2006) or with family and co-workers (Patil & Lai, 2005) could have for promoting awareness of status and activities and I believe this will hold for cancer patients as well.

5.2.3 Blog

The "About Me" page contains relatively static information about the patient's health and more general references where the social network can go to learn more background information. For more timely updates, the blog feature can be used as a broadcast mechanism (see Figure 5-7). In my early interviews and in the participatory design groups, participants described the ritual of updating their network after doctor's appointments and any time there was a new development. This task is redundant and tiring and often patients were not as proactive as they could be about informing their network because they were tired of repeating the news, tired of reaching out, or didn't want to worry others. The blog is a way for patients to post the information once and broadcast it to everyone in their network who is interested. The blog is also an option for patients who are worried that they are pushing sad or depressing information onto a network that doesn't



Home again, home again

Home again, home again

Just a quick note to let everyone know that I am home from treatment and that everything went well. It was a long day so I am going to bed early.

Posted Feb 26 2010, 10:45 PM

Comments

Added less than a minute ago by Herb Emerson
Thanks for letting us know it went ok. Clare and I were thinking of you today and keeping our fingers crossed that it would go smoothly. One more week down!

Figure 5-7: Blog page. Patients can use their blog to update their networks in a timely fashion and their friends can leave comments. Sally posted a blog post called "Home again, home again" and her brother, Herb, posted a comment.

want it. Members of the social network will need to take the step of looking at the blog to get this information; they are seeking it out instead of having it pushed on them.

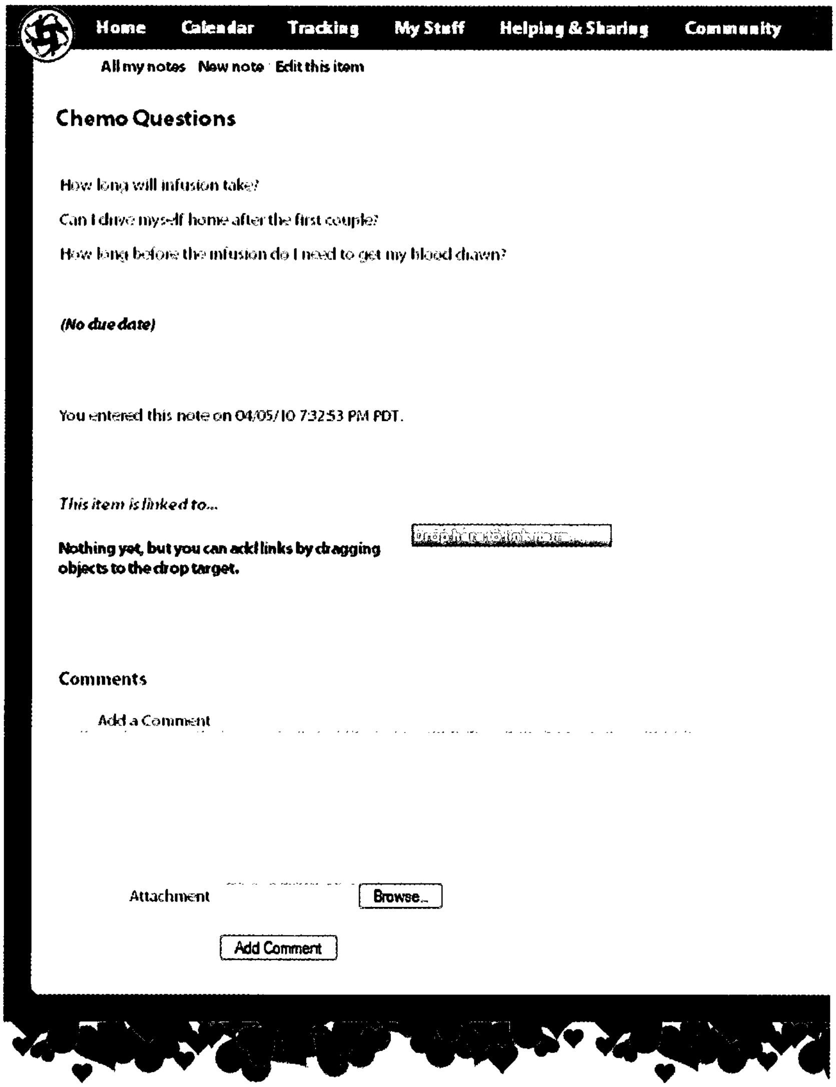
Participants also described getting to the point where they wanted to talk about something besides their health. If every conversation begins with a recap of the latest health news, it can become exhausting. Patients sometimes want a break from this and want to think about and talk about something else besides cancer. I hope the blog will function as a way for people to get updated without going through the patient. This way, when they see the patient they do not have to re-hash the same information and can move on to different topics.

The blog will also serve as an important mechanism for keeping the social network informed so they can act proactively. Knowing more about upcoming events via the calendar, coupled with knowing more about the patient's state of mind and concerns via the blog will help create an informed and helpful network. Anticipating needs and being proactive were valuable attributes for a social network and the blog will provide clues and actionable information about what kind of support or help the patient might need in the near future.

5.3 Collaborating

The first participatory design group focused on the information they would share with their social network. As we discussed sharing information, it became clear that patients actually collaborate on information work with their social network –they do not usually simply push information to others. This description of information sharing is also consistent with the interview data presented in Chapter 3 where people had several reasons to share information beyond simply informing others for the sake of informing them. We have designed and implemented functionality that enables patients to collaborate on information work with their social network through sharing information and discussions. When patients create content such as a new note, list, or uploaded file (image, pdf, etc.), patients can share that content with members of their social network. One example of a reason to share this sort of information is in a caregiving situation. Participants in the first design group discussed the possibility of needing to hand off a medication list or medical contact list to someone. Other reasons for this type of sharing include to get help brainstorming questions or to use others' expertise to answer questions or to get others to look up information. To support collaboration, each note, list, or document has an accompanying discussion feature. Within the page where the object is viewed, the patient and members of the social network can discuss the document, suggest additions to the document, or ask clarifying questions. In addition to discussing the object, the patient or members of the social network can also upload additional content related to the object.

When Sally was preparing to start chemotherapy treatment she could have used these collaborative features to create a good question list. Figure 5-8 shows her question list entered into the system. Interview participants described talking to other people to figure out what they needed to ask doctors about and make a good question list. After Sally shares her question list, others will be able to add questions to it and they might also be able to answer some of the questions. For example, Sally asked how long infusion will take. This is something she could ask



Chemo Questions

How long will infusion take?

Can I drive myself home after the first couple?

How long before the infusion do I need to get my blood drawn?

(No due date)

You entered this note on 04/05/10 7:32:53 PM PDT.

This item is linked to...

Nothing yet, but you can add links by dragging objects to the drop target.

Comments

Add a Comment

Figure 5-8: Note page where Sally is keeping her question list about chemotherapy. Notes are free text entries that allow patients to use flexibility to record and share clinic notes, question lists, or other information. Sally is using this page to keep track of her questions here. Her social network can add information if they are able to look up the answer to a question or can add questions of their own in the comments section..

at her next appointment, but it is also possible that people within her social network would know the answer to this question or be able to look it up for her. If someone found a relevant article they could attach a file to the discussion with their comments. Sally will have limited time at her doctor's appointment so if her social network can help her find answers to some of her questions she will have more time for her other questions.

5.4 Helping

The social network can provide a great deal of help and social support to patients during cancer care. The helping infrastructure has been nearly fully implemented. I will describe a series of screenshots explaining the helping process from two perspectives:

1. A patient asking for help and someone from the social network signing up to help
2. Someone from the social network offering help and a patient accepting their help

The general process of creating new help requests has remained much like the process explained in Chapter 4. A help request has a description of the help activity, one or more timeslots, and an area for discussion. Friends and family can view these help requests and sign-up to help. Figure 5-9 shows the two ways that a help request can begin; either a patient initiates the request or a member of the social network makes a suggestion.

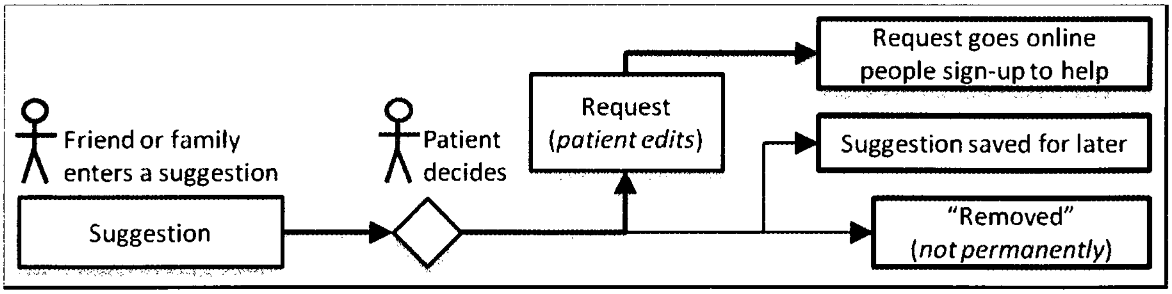
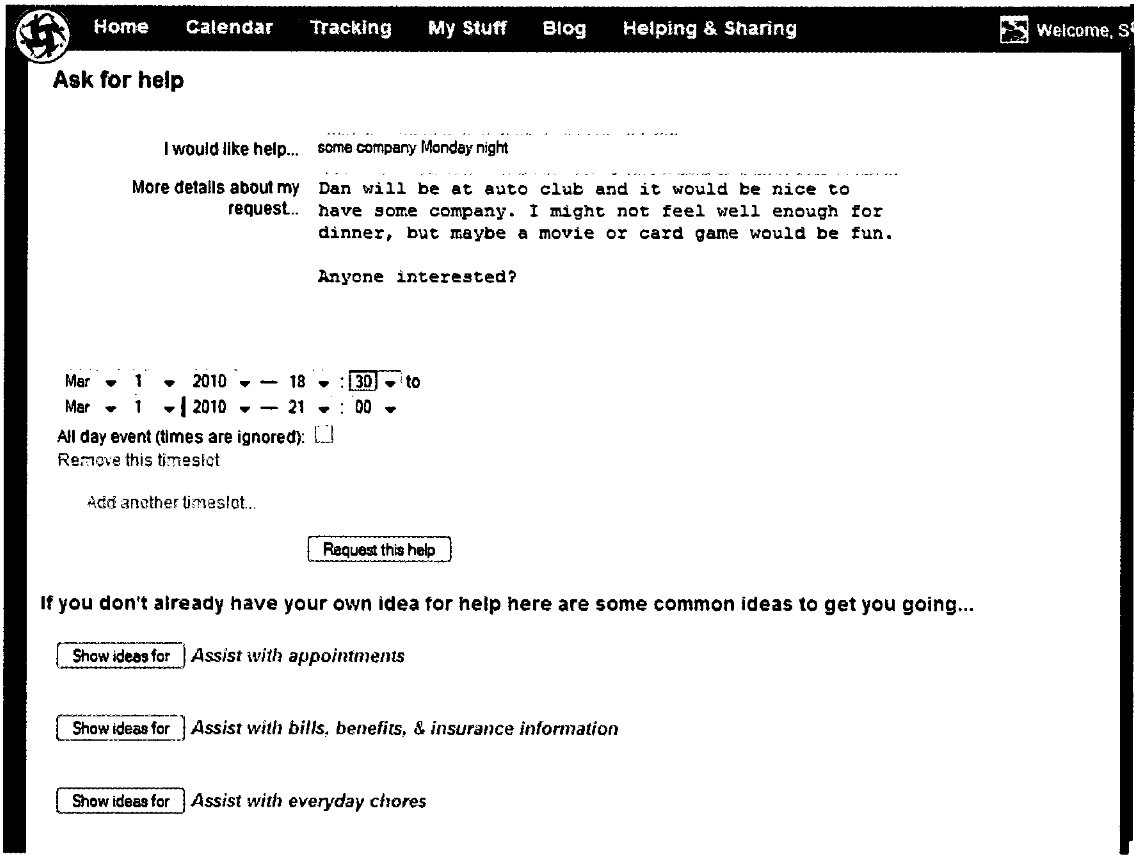


Figure 5-9: A help request can begin either from a patient creating a request or a member of the social network making a suggestion. This is a flow chart describing how help requests are created when they begin with a suggestion from a member of the social network.



Ask for help

I would like help... some company Monday night

More details about my request.. Dan will be at auto club and it would be nice to have some company. I might not feel well enough for dinner, but maybe a movie or card game would be fun.

Anyone interested?

Mar 1 2010 — 18 : 30 to
Mar 1 2010 — 21 : 00
All day event (times are ignored): ☐
Remove this timeslot

Add another timeslot...

If you don't already have your own idea for help here are some common ideas to get you going...

Show ideas for *Assist with appointments*

Show ideas for *Assist with bills, benefits, & insurance information*

Show ideas for *Assist with everyday chores*

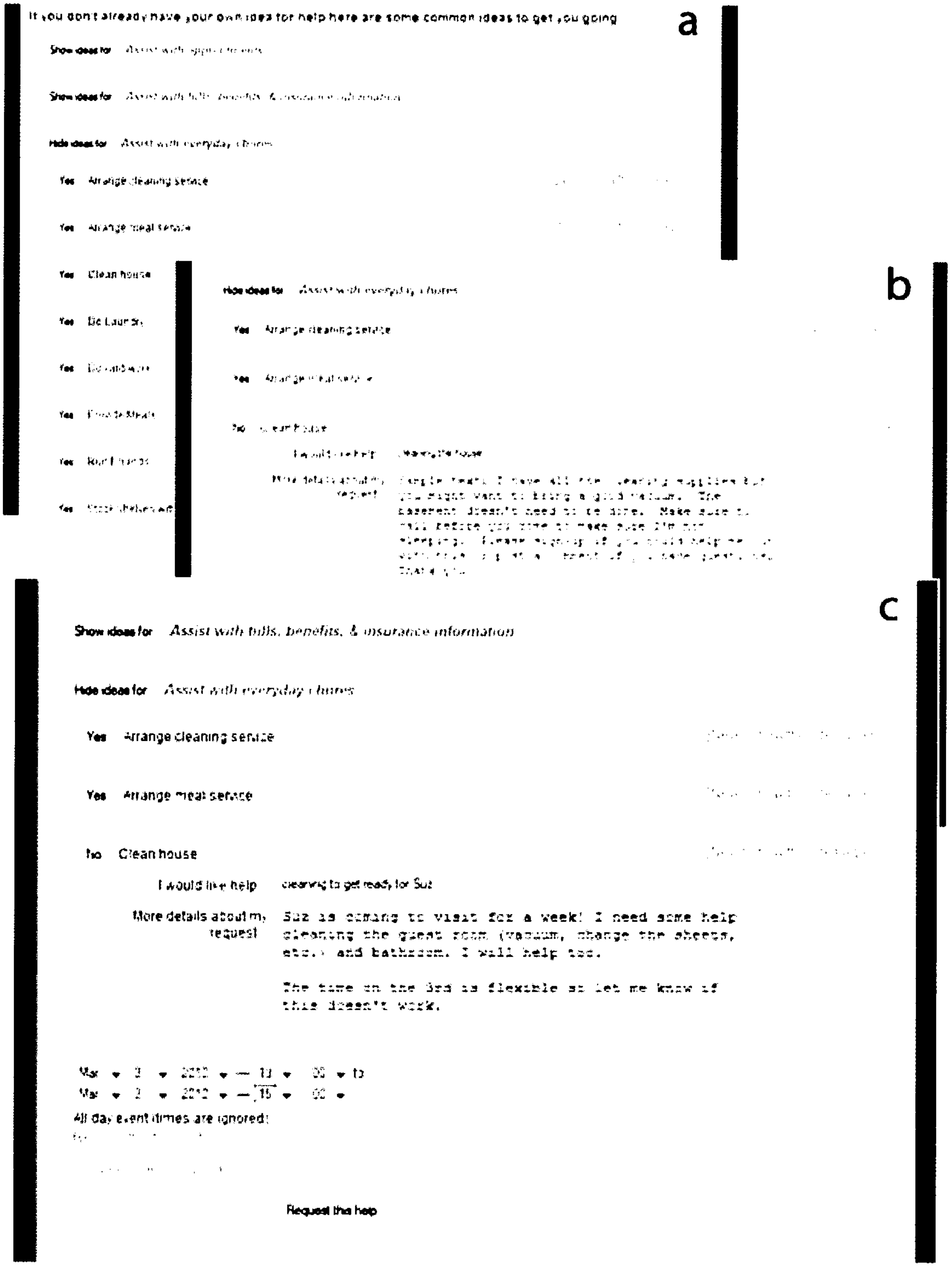
Figure 5-11: Sally has filled in a help request asking for company on Monday night. When she clicks "Request this help" her request will be posted to her network.

5.4.1 Asking for Help & Signing up to Help

We will continue with our fictitious breast cancer patient, Sally. Now Sally is reaching out to her social network for help. She has a busy week coming up. She has an appointment with her oncologist and a chemotherapy infusion. Her daughter, Suz, is also coming to visit and staying for a week. Sally knows that she could use some help and support this week, so she goes to the page where she can ask her friends for help (see Figure 5-10). The page where Sally asks for help is designed to support people who know what they want and also people who aren't sure what to ask for. People who know what they want can fill out the top section with their own description of the help they would like; people who aren't sure what to ask for can browse the ideas listed in the second half of the page.

Sally's husband Dan has a club meeting on Monday night and last Monday Sally was upset about being left alone all evening when she didn't feel that well. She doesn't want to keep Dan away from his friends, so instead of asking him to stay home she decides to see if anyone would like to come spend the evening with her. Figure 5-11 shows the help request Sally fills out to see if any of her friends want to come over Monday night. She specifically mentions that she might not feel well enough for dinner because she wants to make sure people do not bring a lot of strong-smelling food into the house. Her chemo has been making her nauseous.

Once the Monday night help request is posted, Sally browses some of the other helping ideas on the second half of the page (see Figure 5-11). Under the "Assist with everyday chores" category, Sally sees that she could ask for help cleaning the house (see Figure 5-12a). She has been a little stressed about getting the house ready for Suz's visit, but hadn't thought about asking one of her friends to help. Suz of course said that she wanted to visit to help her Mom and didn't mean to impose, but Sally really wants her guest room to be nice and inviting even if the rest of the house is a bit of a mess. In Figure 5-12b, when Sally clicks "Yes" next to "Clean house" she sees some pre-filling-in sample text about how she might word the help request. She deletes most of the text and writes her own explanation of what she wants (see Figure 5-12c). She chooses a time, although in her note she mentions that it is flexible, and posts the request for her friends to see. Sally also puts in a help request asking that someone come over at lunch time and take her dog for a walk.



If you don't already have your own idea for help here are some common ideas to get you going

Show ideas for *Assist with appointments*

Show ideas for *Assist with bills, benefits, & insurance information*

Hide ideas for *Assist with everyday chores*

Yes Arrange cleaning service

Yes Arrange meal service

Yes Clean house

Yes Do Laundry

Yes [illegible]

Yes [illegible]

Yes [illegible]

Yes [illegible]

Hide ideas for *Assist with everyday chores*

Yes Arrange cleaning service

Yes Arrange meal service

No Clean house

I would like help [illegible]

More details about my request [illegible]

Show ideas for *Assist with bills, benefits, & insurance information*

Hide ideas for *Assist with everyday chores*

Yes Arrange cleaning service

Yes Arrange meal service

No Clean house

I would like help cleaning to get ready for Suz

More details about my request Suz is coming to visit for a week! I need some help cleaning the guest room (vacuum, change the sheets, etc.) and bathroom. I will help too.

The time on the 3rd is flexible so let me know if this doesn't work.

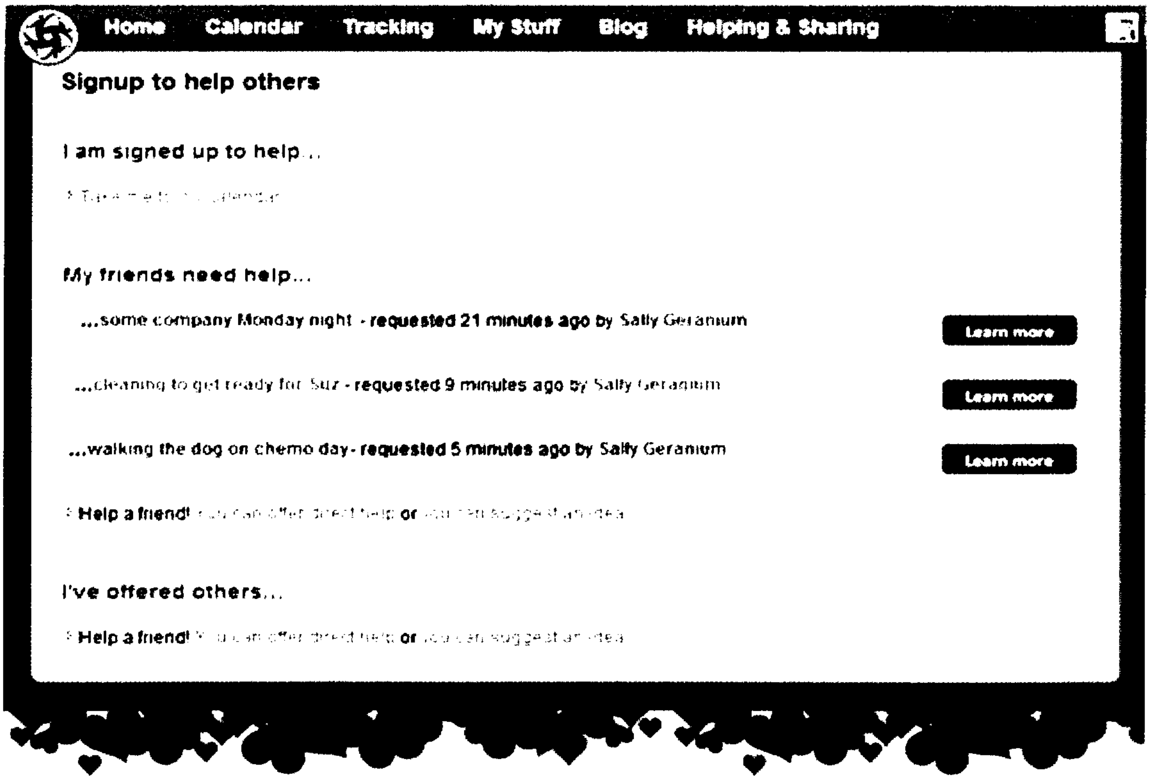
Mar 3 2012 — 11 : 00 to
Mar 3 2012 — 15 : 00

All day event (times are ignored)

Figure 5-12: Sometimes patients are not sure what to ask for. a) Scrolling down the "Ask for help" page (see Figure 5-10) there are several categories of help to browse. b) Within each category of help ideas, patients can open and close each idea to see sample text for how they might word their help request. c) Sally customizes the "Clean house" sample text to ask for help preparing for her daughter's visit.

Sally is not sure what will come of her requests, but she hopes that some of her friends who have offered to help might want to come over Monday or help her get her house ready. She feels a little strange about asking someone to clean her house, but decides to leave the post up and see what happens. She has had several people say they would like to help, but has never really taken them up on their offer before.

When Sally posts her help requests online, her friend Julie gets an email letting her know that Sally has requested some help. Julie logs in and sees that Sally has asked for help with three things (see Figure 5-13). Julie signs up to go over to Sally's house Monday night and also calls their mutual friend Martha to see if she would like to go too. Martha is available and while they're on the phone she also logs into the system and signs up for Monday night. Julie and Martha can both post comments or questions about the event that Sally (and others) can see (see Figure 5-14).



Signup to help others

I am signed up to help...

Take me to my calendar

My friends need help...

...some company Monday night - **requested 21 minutes ago** by Sally Geranium

...cleaning to get ready for Suz - **requested 9 minutes ago** by Sally Geranium

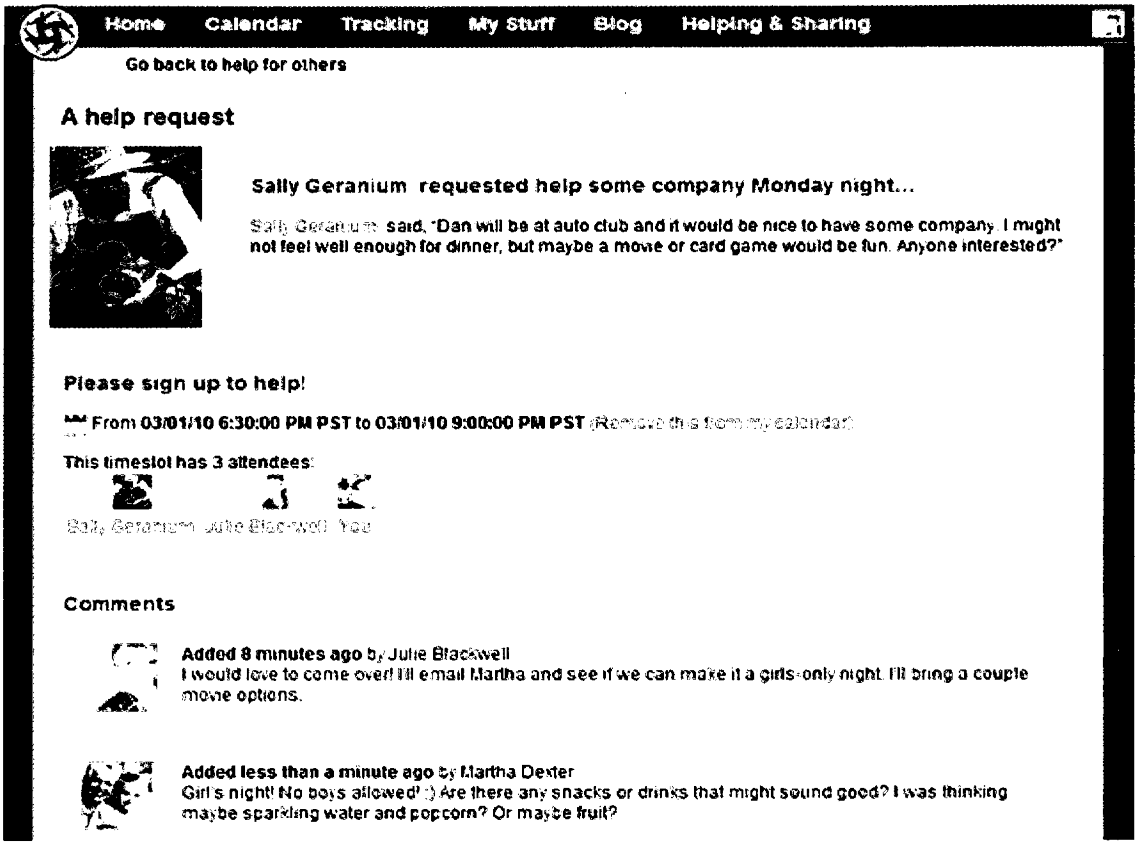
...walking the dog on chemo day - **requested 5 minutes ago** by Sally Geranium

Help a friend! You can offer direct help **or** you can suggest an idea

I've offered others...

Help a friend! You can offer direct help **or** you can suggest an idea

Figure 5-13: Helper's view of the help requests Sally has posted. Julie can click on a request to see the full description. Julie is not currently signed up to help with anything and has not made any offers.



A help request

Sally Geranium requested help some company Monday night...

Sally Geranium said, "Dan will be at auto club and it would be nice to have some company. I might not feel well enough for dinner, but maybe a movie or card game would be fun. Anyone interested?"

Please sign up to help!

From 03/01/10 6:30:00 PM PST to 03/01/10 9:00:00 PM PST (Remove this from my calendar)

This timeslot has 3 attendees:

Sally Geranium Julie Blackwell You

Comments

Added 8 minutes ago by Julie Blackwell
I would love to come over! I'll email Martha and see if we can make it a girls-only night. I'll bring a couple movie options.

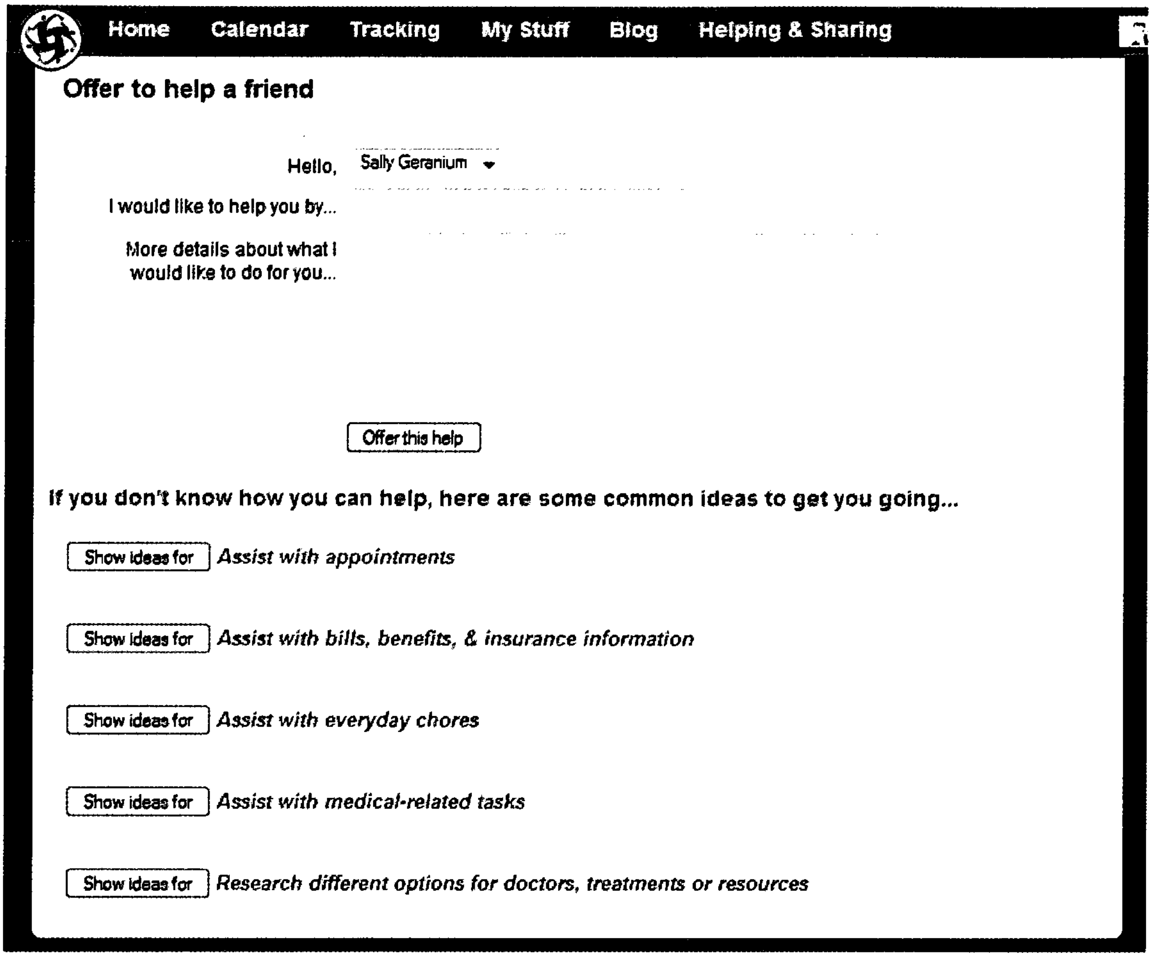
Added less than a minute ago by Martha Dexter
Girl's night! No boys allowed! :) Are there any snacks or drinks that might sound good? I was thinking maybe sparkling water and popcorn? Or maybe fruit?

Figure 5-14: Helper's view of a help request. Julie and Martha have just signed up for a help request and they both posted comments coordinating what they will each bring.

Julie also signs up to come over on Wednesday and help clean in preparation for Suz's visit. Sally's request for help cleaning before Suz's visit makes Julie wonder if Sally could use help cleaning at other times. She has told Sally in the past that she should call if she needs anything, but Sally has never called her to ask for help. Julie decides to make an offer.

5.4.2 Offering Help & Accepting Offers

People I interviewed and people in the PD groups both found difficulty in asking for help. As members of a social network, they also found it difficult to know how to be helpful. Just as patients sometimes do not know what to ask for, friends and family do not know what to offer. We designed the interface for offering help to mirror the interface for asking for help (see Figure 5-15). If the friend or family member already knows what they want to offer they can fill in the blank boxes at the top. If they are unsure of what would be helpful, they can browse the categories at the bottom of the page.



Offer to help a friend

Hello, Sally Geranium ▾

I would like to help you by...

More details about what I would like to do for you...

If you don't know how you can help, here are some common ideas to get you going...

Show ideas for *Assist with appointments*

Show ideas for *Assist with bills, benefits, & insurance information*

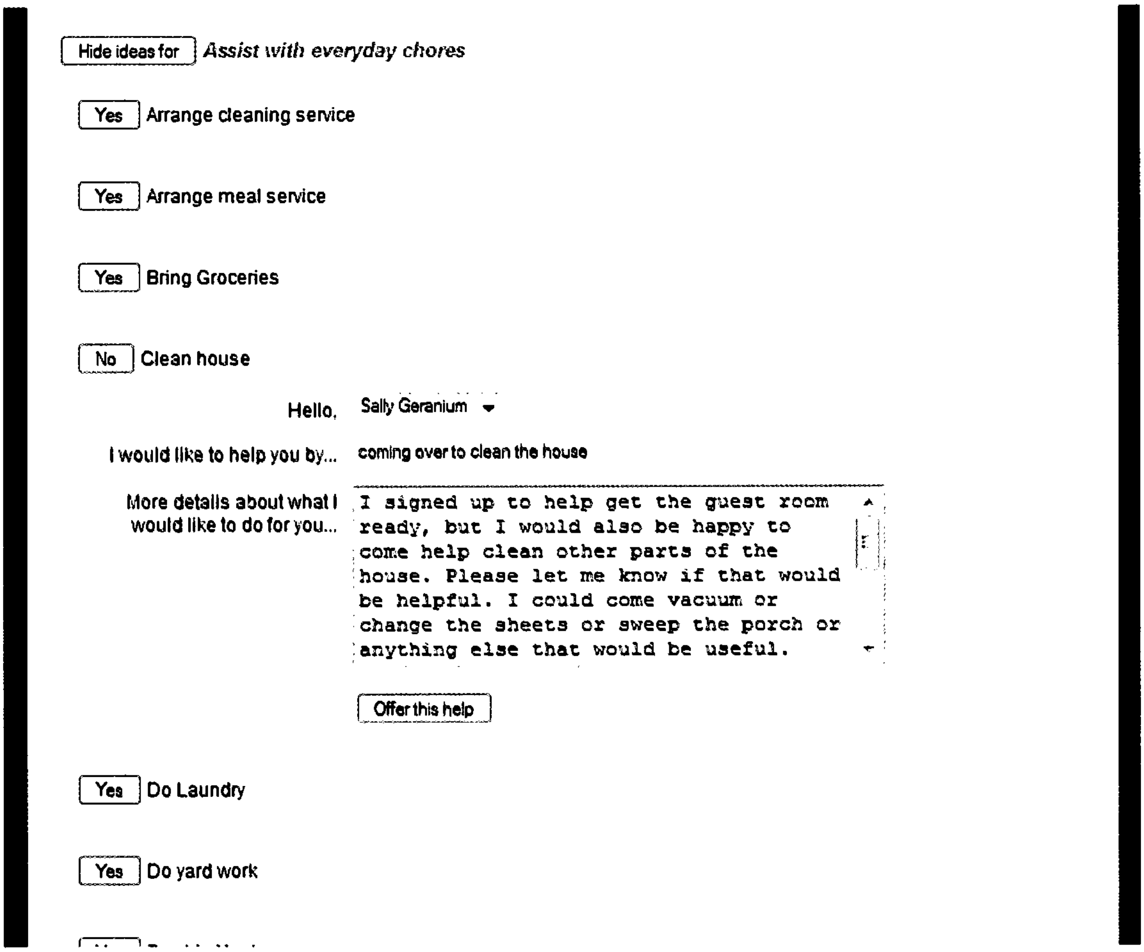
Show ideas for *Assist with everyday chores*

Show ideas for *Assist with medical-related tasks*

Show ideas for *Research different options for doctors, treatments or resources*

Figure 5-15: Helpers use this page to offer help. If Julie knows what she wants to offer she can use the blank text boxes to describe her offer.

Julie wants to offer to do any household chores Sally might appreciate. She browses the categories for inspiration and decides that "Clean house" is the best fit. Just as when a patient makes a help request, the "Cleaning house" template is filled in with sample text. Julie deletes most of the text and writes her own note to Sally explaining that she has volunteered to clean up to prepare for Suz and that she is also interested in doing other household cleaning if it would be useful (see Figure 5-16).



Hello, Sally Geranium

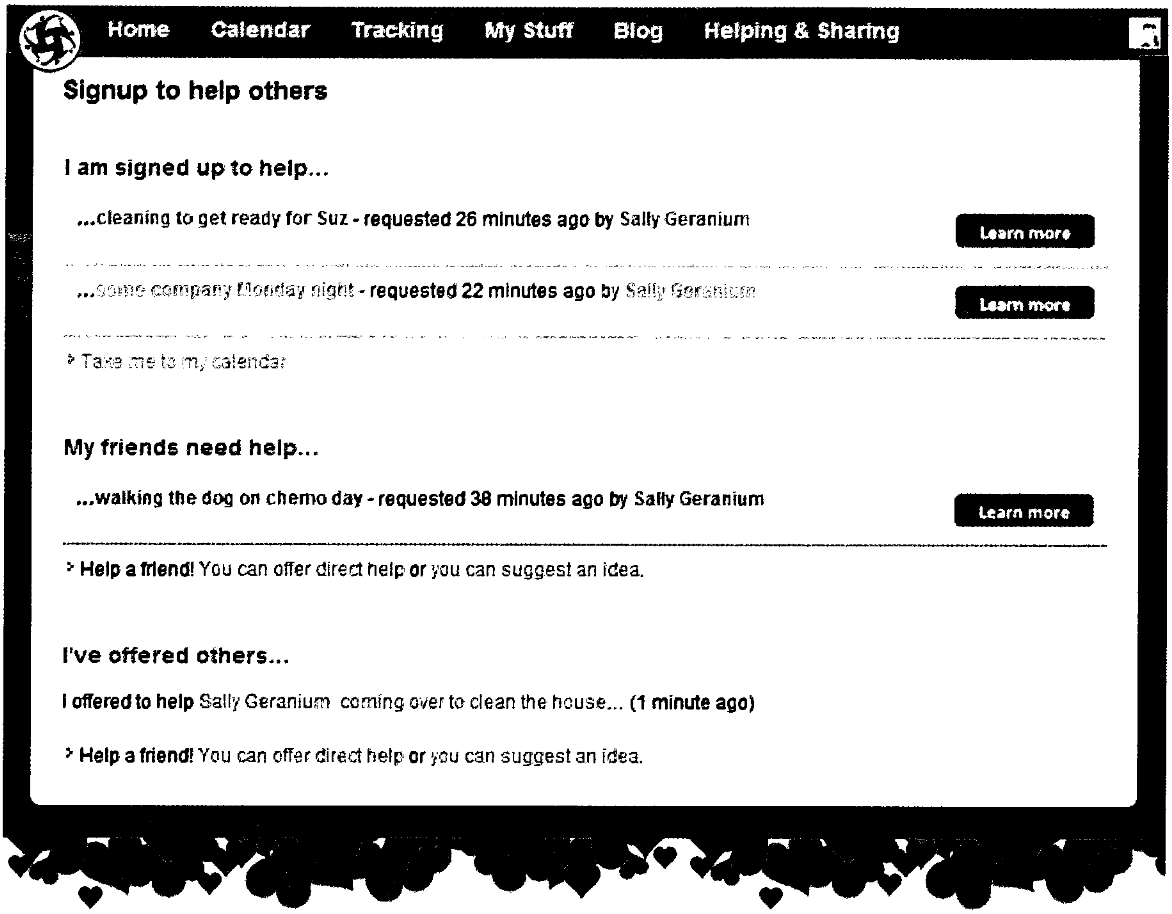
I would like to help you by... coming over to clean the house

More details about what I would like to do for you... I signed up to help get the guest room ready, but I would also be happy to come help clean other parts of the house. Please let me know if that would be helpful. I could come vacuum or change the sheets or sweep the porch or anything else that would be useful.

Figure 5-16: Just as patients can browse help ideas to figure out what to ask for, helpers can browse the same ideas to find help to offer. Julie customizes the "Clean house" idea and sends her offer to Sally.

Julie sends her offer off to Sally and then returns to the page that lists the help her friends need (see Figure 5-17). Here she can see any help requests that haven't been fulfilled and can see what she has signed up for. She can also see her upcoming helping activities on her calendar (see Figure 5-6 above).

Next time Sally logs into the system she will see that Julie has offered help (see Figure 5-18). From my interviews and working with the PD group, I found that both patients and members of their social network were concerned that offers of help be treated carefully. Neither perspective wanted the patient to accept help they were not comfortable with, but there was concern about how to turn down offers without hurting anyone's feelings. When Sally clicks on Julie's offer, she will see the description Julie gave. Sally can then accept the offer, at which point it will turn



Signup to help others

I am signed up to help...

...cleaning to get ready for Suz - **requested 26 minutes ago by** Sally Geranium

...some company Monday night - **requested 22 minutes ago by** Sally Geranium

› Take me to my calendar

My friends need help...

...walking the dog on chemo day - **requested 38 minutes ago by** Sally Geranium

› **Help a friend!** You can offer direct help **or** you can suggest an idea.

I've offered others...

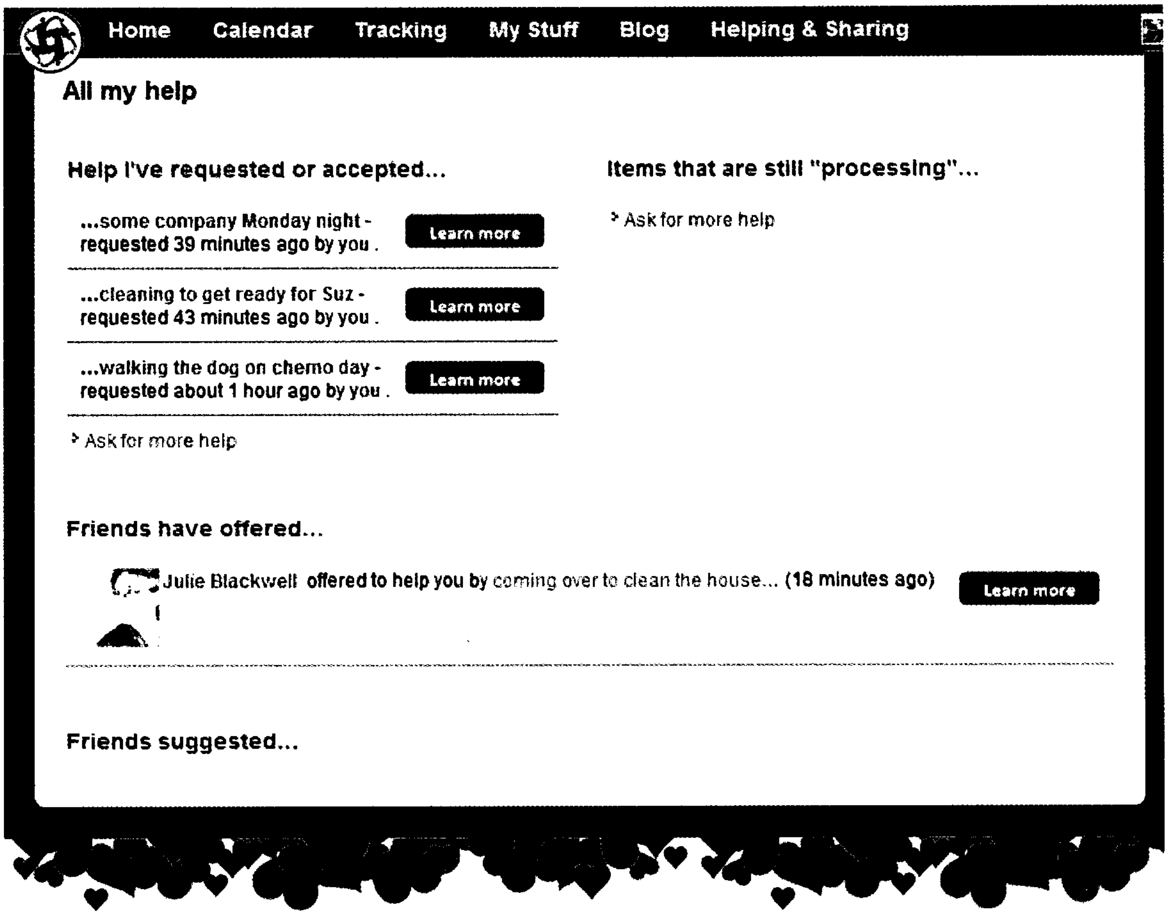
I offered to help Sally Geranium coming over to clean the house... **(1 minute ago)**

› **Help a friend!** You can offer direct help **or** you can suggest an idea.

Figure 5-17: Julie's updated view of Figure 5-13. She can see the two help requests she signed up for, Sally's remaining help request, and the help offer that she sent to Sally.

into a help request that she can edit and post to her friends. Sally can also turn down the offer, or save it for later, and optionally send a note to Julie thanking her for her interest in helping.

I have described Julie's offer to help Sally clean. In this circumstance, Julie made an offer and if Sally accepts it, Julie will be the one signed up to help. Julie will get a notification saying that Sally accepted her offer, showing any changes that Sally made. Instead of offering to do the cleaning herself, Julie also could have made a suggestion that Sally ask her network for help cleaning. In that circumstance, Sally could have accepted the suggestion and posted the help request to her network. Julie would not be automatically signed up and instead other members of the network would have the opportunity to sign up to help.



All my help

Help I've requested or accepted...

...some company Monday night - requested 39 minutes ago by you.

...cleaning to get ready for Suz - requested 43 minutes ago by you.

...walking the dog on chemo day - requested about 1 hour ago by you.

› Ask for more help

Items that are still "processing"...

› Ask for more help

Friends have offered...

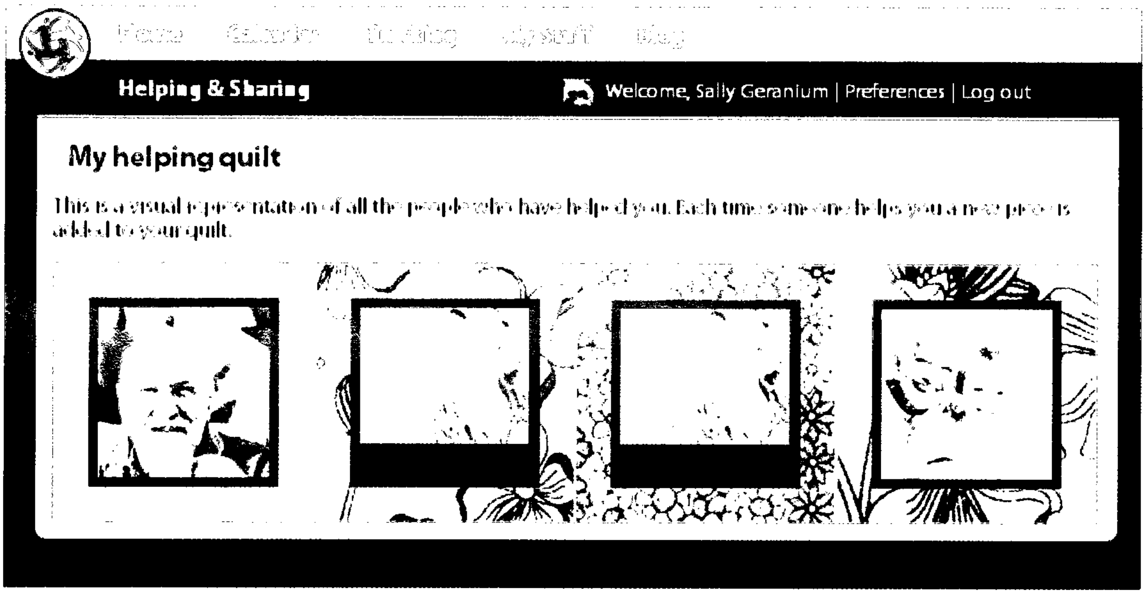
Julie Blackwell offered to help you by coming over to clean the house... (18 minutes ago)

Friends suggested...

Figure 5-18: Patient's overview of their help requests and offers. Sally can see the three help requests she posted and can also see Julie's offer. She can click on Julie's offer to read the details and decide whether to accept, change, or hide her offer.

5.4.3 Acknowledgements

Acknowledging the help people provide will serve two purposes. First, cancer patients want to thank those who help them. This can be a task that easily falls by the wayside when patients have limited energy, but it remains important to them. Second, public acknowledgements raise the entire network's awareness of helping activities. Someone else in the network might notice a public "Thank you" and be reminded that they should check and see if there are any new help activities for which they can sign up.

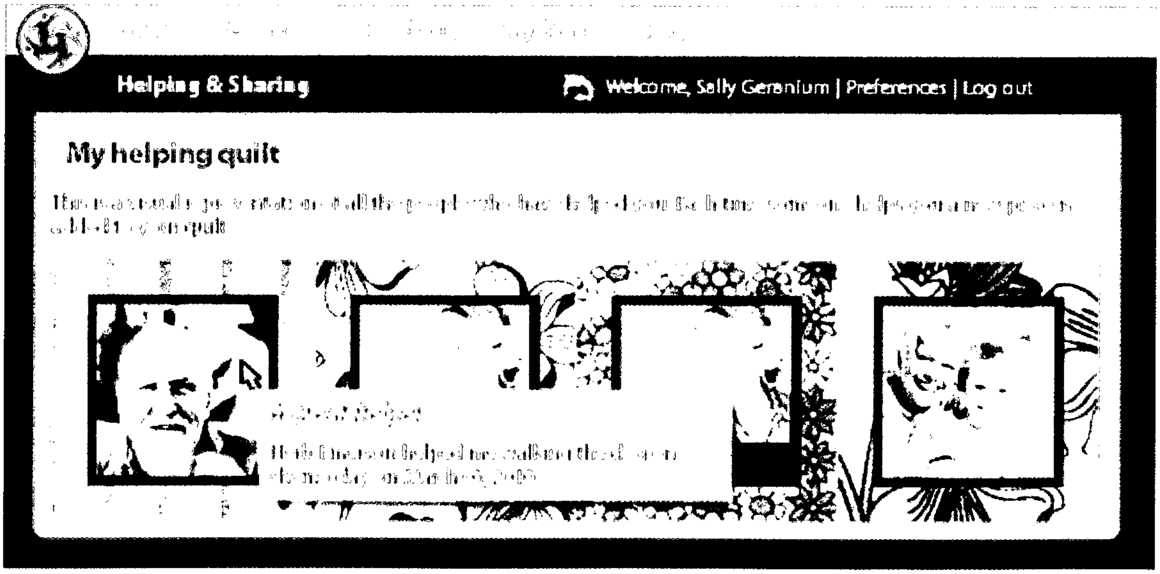


My helping quilt

This is a visual representation of all the people who have helped you. Each time someone helps you a new piece is added to your quilt.

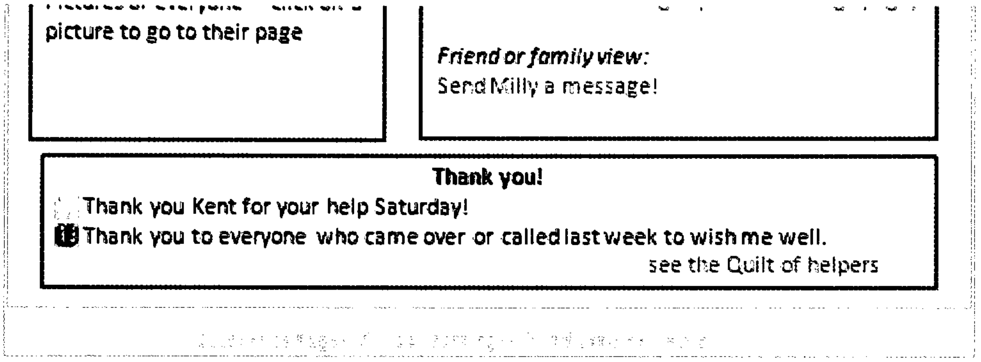
Figure 5-20: Sally's helping quilt after her three help requests are fulfilled. Julie appears twice because a square is generated for each helper associated with each helping activity; Julie helped twice.

To fulfill both these purposes, we have designed acknowledgement of helping activities into this technology. The helping quilt grew out of an idea that someone in the second design group drew in her journal. Her idea was to have some physical object that people could take a piece of; each piece would represent some help activity that they did. This idea was further discussed by the



My helping quilt

Figure 5-19: Mouse-overs on the helping quilt show patients, and helpers who view the quilt, what each square represents.



picture to go to their page

Friend or family view:
Send Milly a message!

Thank you!
Thank you Kent for your help Saturday!
Thank you to everyone who came over or called last week to wish me well.
see the Quilt of helpers

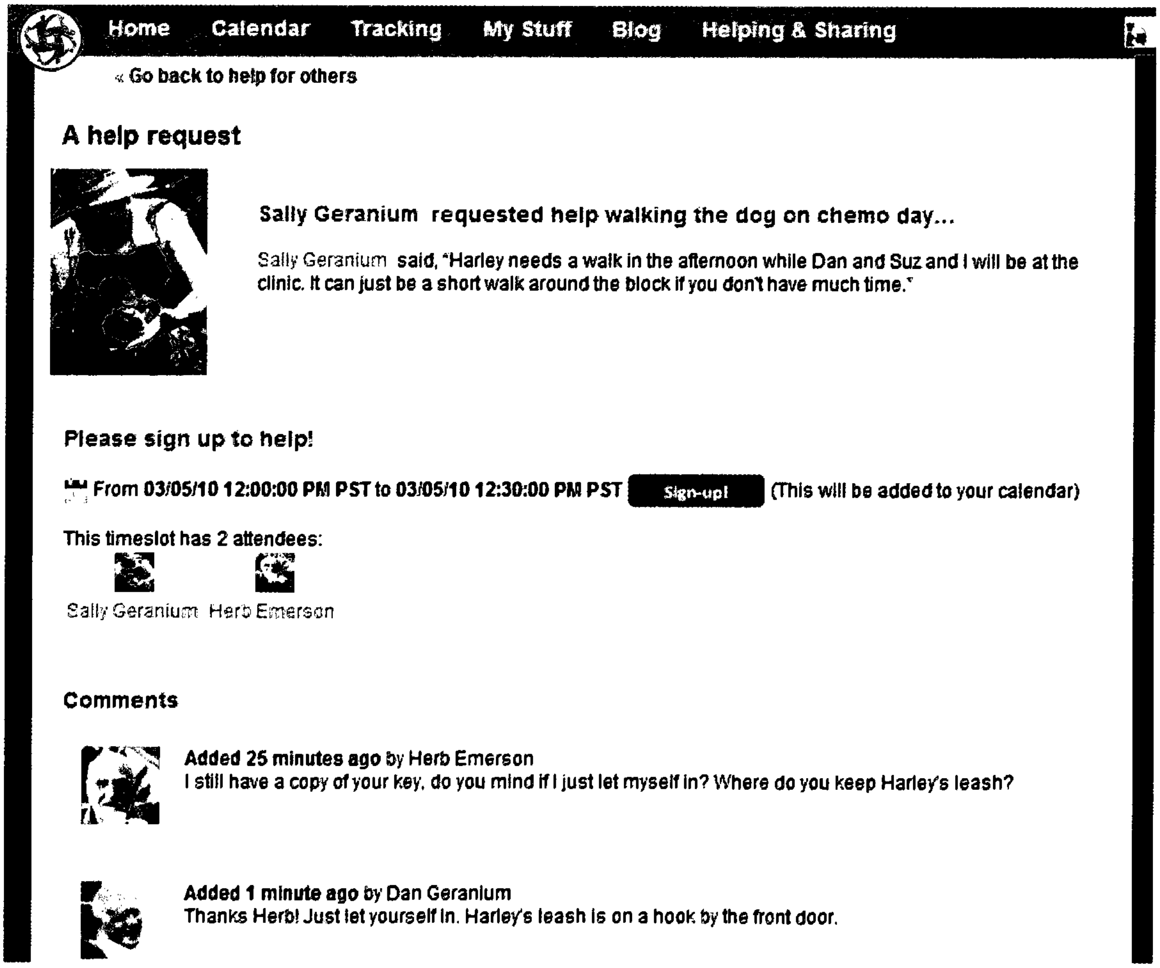
Figure 5-21: New quilt squares being added to a patient's quilt will also be announced in a "Thank you!" portion of the homepage.

group, who appreciated that this sort of visualization would help individuals see that they are part of a larger effort. It would also help cancer patients see everyone who was helping and supporting them. Her original idea has been adapted into a helping quilt. The quilt is scalable because any number of squares can be added over time. Every time someone helps they get a piece on the cancer patient's quilt. Figure 5-20 shows Sally's quilt. Julie got two pieces: one for coming over Monday night and one for helping Sally clean to get ready for Suz's visit. Martha has a piece for coming over Monday night and Herb has a piece for walking Sally's dog. In practice, the quilt piece is added automatically when the designated time for the helping activity passes. Automatic acknowledgement takes the burden off cancer patients to send out individual "thank you" messages.

In the homepage wireframe at the beginning of this chapter, there is a "Thank you" section that will also be used for acknowledgements (see Figure 5-21). Any time a quilt piece is added, there will be a small preview of the piece and a link to see the whole quilt. This will help the entire social network maintain an awareness of the helping activities others are doing and might remind them to sign up to help. The cancer patient will also be able to post thank you messages in this section. In the wireframe, there is a custom thank you to "everyone who came over or called last week to wish me well."

5.5 Coordinating helping activities

Having a single place where patients can let everyone know what they need will help ease the task of coordinating help. We have also included features to further ease the coordination task and minimize the number of interactions the patient needs to have before they can get the help they want. Each help page will have a discussion section. This is an opportunity for the social network to coordinate with one another and to ask clarifying questions. In Figure 5-22, Herb signed up to help walk the dog, but needed more instruction about getting into the house and finding the leash. When he signed up to help, he posted a comment asking his questions. Dan Geranium, Sally's husband, saw Herb's questions before Sally did and replied. This discussion is kept with the help request so that Herb can easily find it (it will be linked from his calendar) and also because it



A help request

Sally Geranium requested help walking the dog on chemo day...

Sally Geranium said, "Harley needs a walk in the afternoon while Dan and Suz and I will be at the clinic. It can just be a short walk around the block if you don't have much time."

Please sign up to help!

From 03/05/10 12:00:00 PM PST to 03/05/10 12:30:00 PM PST (This will be added to your calendar)

This timeslot has 2 attendees:

Sally Geranium Herb Emerson

Comments

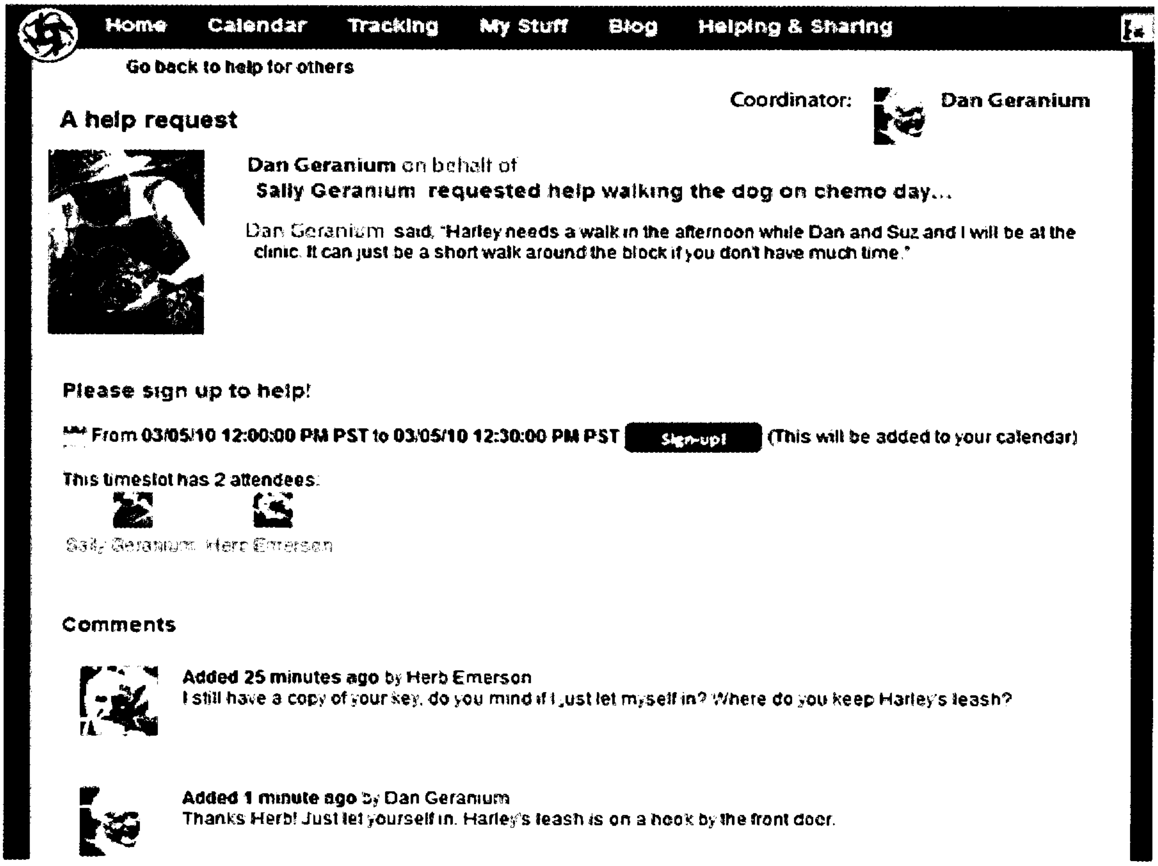
Added 25 minutes ago by Herb Emerson
I still have a copy of your key, do you mind if I just let myself in? Where do you keep Harley's leash?

Added 1 minute ago by Dan Geranium
Thanks Herb! Just let yourself in. Harley's leash is on a hook by the front door.

Figure 5-22: Helpers and patients can discuss helping requests. Dan answers Herb's question about Sally's help request.

could be helpful to others in the social network. If Sally had put in a time slot for each week when she went for her chemo infusion, multiple people might have signed up to walk the dog. They could all benefit from seeing the exchange between Herb and Dan.

To ease the burden on patients even more, we will also include features to allow patients to off-load the work of asking for help and coordinating helpers. The second design group suggested that there be two roles for helping with this work: proxy and coordinator. In our system, a proxy will be someone who can do everything on behalf of a patient – invite friends, ask for help, make decisions about offers and suggestions, and field questions about help. Coordinators will have a more limited role; they will be responsible for one help request. For example, a coordinator could take responsibility for meals. The meals coordinator would be able to add instructions to the help request, add more time slots, and answer questions. The coordinator or the proxy would be the point person for the social network to go to with questions and problems, creating a buffer and



A help request

Coordinator: Dan Geranium

Dan Geranium on behalf of
Sally Geranium requested help walking the dog on chemo day...

Dan Geranium said, "Harley needs a walk in the afternoon while Dan and Suz and I will be at the clinic. It can just be a short walk around the block if you don't have much time."

Please sign up to help!

From 03/05/10 12:00:00 PM PST to 03/05/10 12:30:00 PM PST (This will be added to your calendar)

This timeslot has 2 attendees:
Sally Geranium Herb Emerson

Comments

Added 25 minutes ago by Herb Emerson
I still have a copy of your key, do you mind if I just let myself in? Where do you keep Harley's leash?

Added 1 minute ago by Dan Geranium
Thanks Herb! Just let yourself in. Harley's leash is on a hook by the front door.

Figure 5-23: Mock-up of interface indicating who is coordinating a help request. The help request still appears in Sally's name so the social network knows who they are helping, but as the coordinator Dan can edit this request, add time slots, and be the point person for questions about this request.

shielding the patient from this work. Figure 5-23 shows the interface design indicating that a coordinator or proxy is in charge of a help request. If Dan was Sally's coordinator for getting help walking the dog on Chemo days, for example, the help request still shows up as help for Sally, but the page indicates that Dan is the coordinator who is working on behalf of Sally.

People in the second design group anticipated having one person close to them be a proxy as well as having multiple coordinators. A coordinator could be assigned by the patient or the proxy and they could volunteer for the job when submitting an offer or a suggestion. For example, Martha could offer to clean house for Sally and at the same time volunteer to become a coordinator for that help request. If Sally accepts, Martha would be able to add more time slots for house cleaning, recruit people to sign-up if necessary, and field any questions or address problems that arise.

5.6 Getting the word out

As patients post updates, enter help requests, or accept suggestions, the social network will need easy access to this information. Better still, they should encounter this actionable information about what they can do to help during their everyday activities. People consume information in increasingly customized ways. Homepages with RSS feeds, social newsfeeds such as Facebook and Twitter, and the pervasive use of email have revolutionized the way people stay informed about the world around them as well as the goings-on in the lives of their friends and family.

Of course, within the website, people will be able to quickly see the latest helping activities. New help requests, comments, and people signing up for help are available in a feed on the homepage (Figure 5-24a). The wireframe design (Figure 5-24b) shows additional information that will be added to the feed. Most notably, if a patient hasn't asked for help, the system will select example help ideas from the list generated by the design groups and remind people in the network that they can offer help to the patient. With this page existing only on the homepage for the system, users would have to log in and check for activity. To make sure that members of a patient's social network stay informed about a patient's needs, the system will also push this information out through other information streams.

The website currently uses the Facebook connect API to push help requests to the social network's Facebook Newsfeed. Facebook has been widely used by students to maintain awareness about their friends' activities (Boyd, 2008) and is now being used by professionals to keep up with colleagues activities (DiMicco & Millen, 2007; DiMicco et al., 2008; DiMicco, Geyer, Millen, Dugan, & Brownholtz, n.d.; Geyer et al., 2008; Skeels & Grudin, 2009). I plan to utilize this existing tool to promote awareness within networks about a patient's status and needs –creating an informed and helpful network.

In addition to leveraging the pervasive use of Facebook, these updates could be published using RSS or Twitter. As technology changes and new systems emerge, the key will be making sure that the information from within the system is pushed out to the sources consumed by the social network. Small actionable opportunities to help that friends and family do not have to work hard to find will help catalyze helping.

5.7 Conclusion

The design presented in this chapter pulls together the design ideas generated by the two participatory design groups described in Chapter 4. To bridge gaps in their designs and further refine ideas quickly described during the design groups, I drew on the design rationales presented in the two design groups and on my previous research described in Chapter 3. The resulting design is based on the central insight that a more informed social network is better positioned to provide useful help. This technology can be used to inform the network about the patient's health situation, including background information and periodic updates. It can also be used to inform the network about the patient's current needs so the network has actionable information about how they can help. Making actionable information readily available to members of the social network provides a low barrier way for people to sign up to help. Even if half the network signs up for a small number of helping events, that will generate a substantial amount of helping activity. Networks that provide help perform a service for the patient, but also provide a greater sense of social support. This technology provides a visualization of all the helping activity within a network so the patient can see everyone who has been there to support them. The visualization will also serve members of the helping network because it acknowledges their contribution and shows them that their contribution is an important part of larger effort to support the patient. The visualization of all helping activities also keeps the network informed about what help is occurring and might help identify gaps that someone in the network could fill. The design of this technology also facilitates collaboration between the patient and their network and within the social network. Discussion threads attached to objects will enable people to ask questions and provide information for the patient or for other members of the network. This lightweight mechanism remains attached to objects (e.g. help requests or notes) so that as those objects are re-used the discussion persists and is not lost.

Providing the network with information about the patient's health, their current status, and their needs will enable the social network to provide better help. Without information the network is left to make poorly-informed guesses about what might be useful to the patient. With information about the patient, their health situation, and what other patients have found useful, the network will be able to make well-informed offers of help. Better yet, if patients provide information about what they need via help requests the network has truly actionable information they can use to fulfill patients' needs.

Chapter 6
Intentional Sharing

6.1 Introduction

Up to this point, we have described many ways that sharing information creates a more helpful social network. We have discussed the merits of technology to broadcast help requests throughout a patient's network. This technology has a wonderful potential to create an informed and active network. Design participants imagined they would feel more comfortable asking for help if they were broadcasting their request to a larger group instead of putting pressure on one individual who would have difficulty saying 'no' and might end up feeling burdened.

Here is the caveat: Patients need to control who sees their information and their help requests.

If Sally wants to ask for help bathing after her surgery, she needs a way to broadcast this request to the tiny group of people from whom she would feel comfortable receiving this type of help. When Sally posts updates to her network she might feel comfortable posting most messages for everybody, but might want to limit the people who can see the most personal posts. Similarly, there might be calendar appointments she is not comfortable sharing with everyone, or even with anyone.

From the design groups, we know that people want tight control over sharing. From the design groups and earlier interviews, we also know that the information people feel comfortable sharing will probably change over time. In some cases, people also experience shifts in their social networks during cancer care; they become closer to some people and more distant from others. Interfaces that allow fine control over sharing and make settings abundantly clear to participants remain a substantial human-computer interaction challenge. In this chapter, I compare potential interfaces to identify the one that will give patients the tightest, most understandable, control of their information.

One of the common themes in the Usable Privacy literature, reviewed in Chapter 2, is a focus on access control list (ACL) interfaces. These are the main control panel from which people can set sharing preferences for the entire system. For example, in a file management system users could use this central control panel to control who has access to each folder. I have chosen a somewhat different approach in my attempt to achieve usable privacy controls. I plan to embed information about how each piece of information is shared within the interfaces in which that information is created and displayed. For example, when a patient is creating a blog post they will be able to see with whom it is shared. When a patient is reviewing their list of blog posts, they will be able to quickly review how each is shared. Furthermore, they will be able to use these same interfaces to make changes to their settings. This departure from the traditional access control list model is necessary because I see two potential problems with the traditional approach for the patient community. First, patients sharing preferences change over time and as these changes occur their settings will need to be updated. This fluid adaptation will be better supported by the ability to make smaller decisions using light-weight interactions as content is created instead of relying on patients to return to the large control panel repeatedly. Second, cancer patients in my research have described cognitive challenges associated with the stress of having cancer and especially with chemotherapy treatment. These challenges include short term memory difficulties and the inability to focus on details that would formerly have posed no challenge. They emphasized time and again that interfaces must be exceedingly simple and straightforward in order to be usable to a cancer patient going through treatment.

My goal is to identify interfaces that make sharing settings easy for patients to understand and modify. I have created two different interface options for showing an overview of how an object (e.g. blog post, help request, etc.) is shared in a small icon. I have also created two different

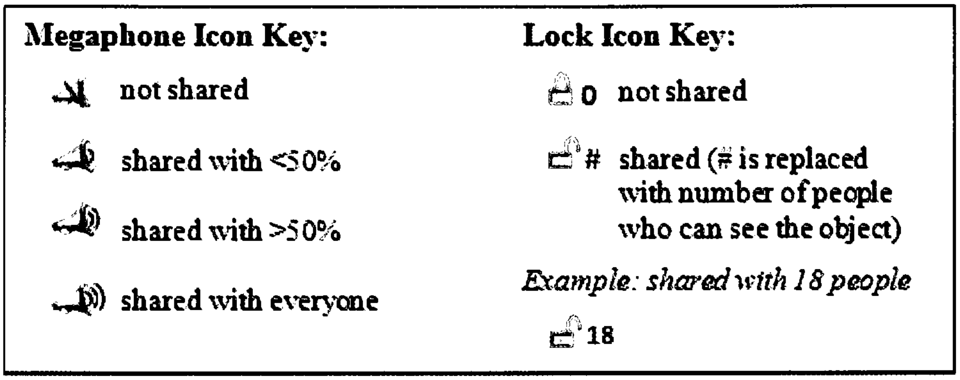


Figure 6-1: Megaphone icons show the proportion of the network that can see an object. Lock icons show a binary representation of whether an object is shared accompanied by the number of people who can see an object.

interfaces for showing more detail about exactly who can see an object. I conducted a study with 20 cancer patients and survivors to identify which of these interfaces is most transparent, easiest to use, and most preferred. A transparent interface is one where users understand the state of the system –they understand how their information is being shared. A system that lacks transparency would make it difficult for a user to understand how information is being shared.

6.1.1 Transparency Visualizations

Two types of transparency visualizations will work as a pair to both show an overview of sharing settings on each item and then allow a user to delve deeper and see exactly how an object is shared. An icon will appear on every object within the interface that can be shared. When a user hovers their mouse over the icon they will see a small pane that shows exactly who can see the object. This sharing list pane is also visible on any page where content is being created. In the study, I tested which of the two icons was most transparent and which of the two sharing list interfaces was most transparent. The winning icon will be paired with the winning sharing list in the final system design.

Icon

For the study, I designed two icons, each approximately 15 pixels tall and 25 pixels wide. One icon combines a binary representation of the "shared" or "not shared" status combined with a number showing exactly how many people can see the object. The second icon uses a megaphone metaphor with volume waves indicating an approximate percentage of people who can see the information. These icons are described in Figure 6-1.

Sharing List

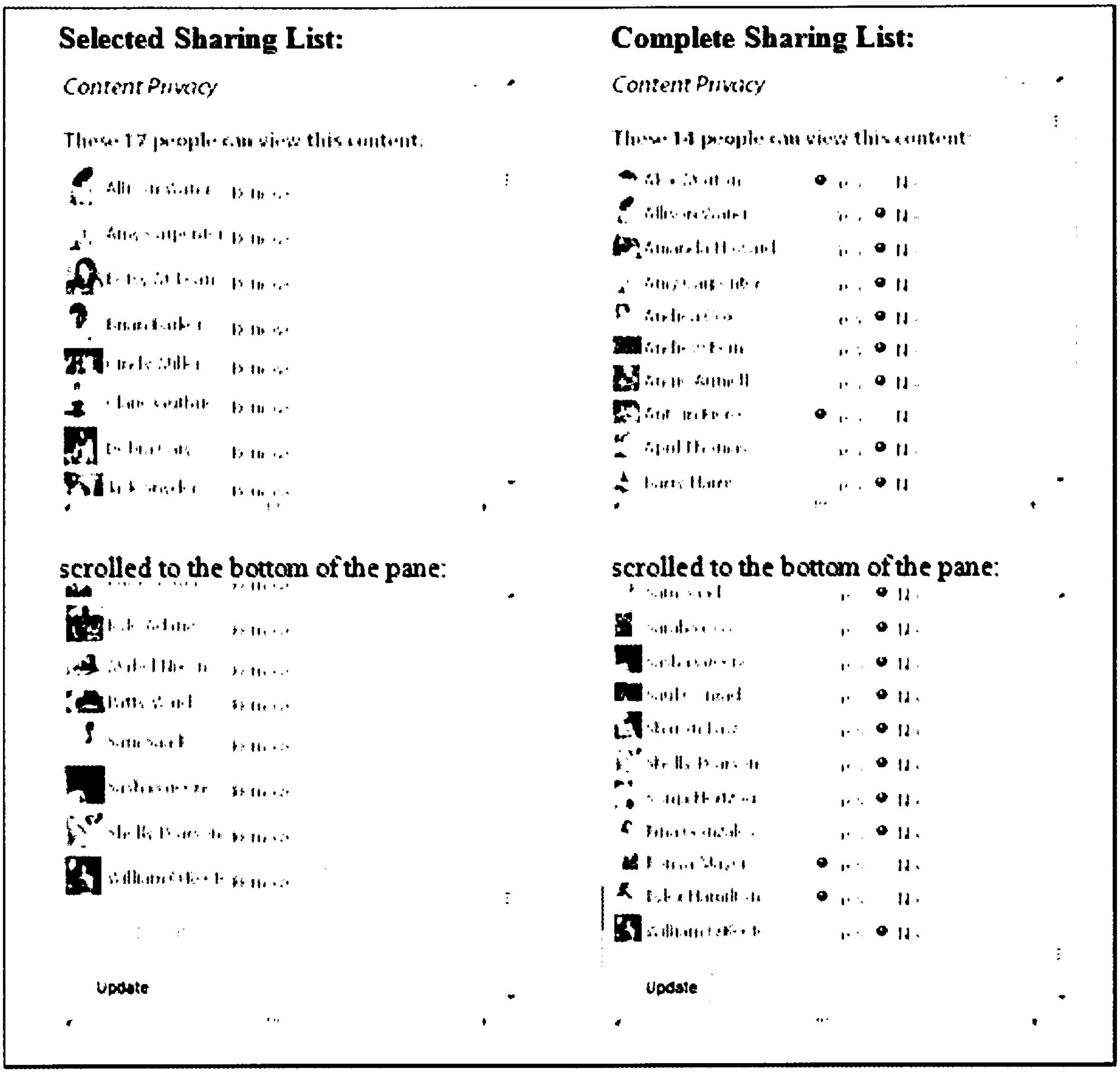
Users will be able to hover over one of the icons in Figure 6-1 to see exactly with whom they are sharing an object. I designed two interfaces for showing which members of the social network can see each object. One interface shows the complete list of people in the social network with an indication of whether each person can see the information. Next to each person there are radio button controls that can be used to change whether that individual can see the object. The second interface shows only the select list of people in the social network who have been given permission to see the object. At the bottom of this interface there are controls for adding or removing people from the list. These two sharing lists are described in Figure 6-2. Both of these interfaces are also embedded in any page where new content is created (see Figure 5-8 and Figure 5-10).

6.2 Methods

The goal of this study is to identify how transparent sharing interface options are. To accomplish a careful comparison I selected mostly quantitative metrics and a tightly scripted study design in which participants used the system to complete tasks and answer questions.

6.2.1 Measuring Transparency

I used three difference concepts to evaluate which icon and which sharing list interface should be used to make sharing functionality clear to users. The highest priority issue is transparency because this indicates whether users understand how their information is being shared. Ease of use is an indicator of how well people are able to make changes to their sharing settings and is also important, although it depends somewhat on the transparency measure. A user who has difficulty understanding what the interface is showing about how their information is shared will almost certainly have trouble interacting with that interface to make changes. I also measured which interface and icon each user preferred.



These 17 people can view this content.

These 14 people can view this content

Figure 6-2: The Select Sharing List shows only the members of the social network who can see the object. The Complete Sharing List shows all of the people in the social network with an indicator next to each one showing whether they can see the information (yes) or not (no).

Transparency

Transparency indicates how easy or difficult an interface is for users to understand. A transparent interface makes it clear to participants what the system is doing with their information; when a system lacks transparency it is difficult for users to tell what the system is doing with their information. I have operationalized transparency into three metrics:

Metric 1: User can tell if the information is shared or not.

Example question – Does anyone besides you have permission to see this information?

Metric 2: User can tell approximately how many people the information is shared with.

Example question – Approximately how many people have permission to see this information?

Metric 3: User can tell exactly who has permission to see the information.

Example question – Does Mary J. have permission to see this information? (users should be able to answer this question both when Mary J. does have permission and when she does not)

If a user can successfully understand all of the concepts described in the three metrics, I consider the interface transparent to that user.

Ease of Use

I measure ease of use by asking participants to complete tasks using the two sharing lists. For each of the two sharing list interfaces, users were asked to make it so that someone could see the information and were also asked to prevent someone from seeing the information. The icons were omitted from this aspect of the evaluation because they are not interactive on their own.

Confidence

With each transparency question and each ease-of-use task, I asked participants how confident they were in their answer or their ability to complete the task. Participants used a four point scale from "Guess" through "A little confident," "Fairly confident," and "Completely Confident." This gave participants a chance to make their best guess, but indicate that the interface did not make them feel confident in their answer.

Interface Interpretation

After each transparency question or ease-of-use task, I also asked participants to answer aloud "What information on the screen did you use to answer the question?" This could be a simple statement like, "that number there" or a longer description of how they are interpreting the interface and what portions they are unsure of. This data was collected with particular interest in participants who were misinterpreting the interface. My hope was that this data could be used to identify ways the interface lead users astray and fix those problems.

Preference

After using the two icons to answer transparency questions, I simply asked users which icon they preferred. Users also sometimes supplied reasons for their judgment, which I recorded in field notes. I also asked users which Sharing List they preferred after they had used both lists to answer transparency questions and complete ease of use tasks.

6.2.2 Study Setup

Each participant completed the study in one session using a fake social network and fake data pre-seeded in the system. The lab study setup included a laptop, mouse, and audio recorder. The prototype was fully implemented and available on the Internet, so the study could be conducted wherever was most convenient for participants. Most participants chose to do the study at home, but some chose the University of Washington campus, or a coffee shop. Participants were compensated $30. Anyone who had been diagnosed with cancer and was 18 or older was eligible for the study. I used email, flyers, and online posting to recruit 20 cancer patients.

Each study session began with participants filling out a demographics form and reading a short introduction to the system. The introduction told participants about the general goal of the system and described some of the specific functionality they would encounter during the study. It was not a tutorial or walkthrough. All sessions were audio recorded. I also used field notes to record observations of participants' use of the system, breakdowns, and comments.

In the introduction, each participant was told that they would be using the system playing the role of "Terry." Terry is a fake cancer patient who has 74 friends and family using the system. To frame the study appropriately, I asked each participant a few questions about their own social network. They recorded the number of people they had shared health information with during their own cancer experience and recorded what kinds of people (e.g. friends, neighbors, co-workers) those people were. They were instructed that they should think of Terry's 74 friends and family as the same kinds of people as they have in their own network.

The system was pre-seeded with "Terry's" fake data, including 2 notes, 2 lists, and 21 calendar appointments. Each of these objects was shared with portions of Terry's social network. The 2 notes and 2 lists were shared with 4 disparate sets of Terry's network so that when participants answered questions about how each object was shared, they would not try to reply on memory to answer the question or be confused by their memory of past questions. Each of these four objects was shared with enough people that the Sharing List interface required scrolling to see the entire list.

One adaptation to the system was that the blog functionality was re-named "list" for the study. The interfaces remained the same, but instead of "new blog" users saw "new list" and instead of "My blog posts" users saw "My lists." I made this change to ensure that users' predisposed ideas about how blogs are shared did not affect the way they answered questions in the study.

After the introduction, participants used the sharing lists to answer transparency questions, complete ease of use tasks, and select their preferred interface. Following this, participants complete transparency questions using the two icon options overlapped on calendar appointments.

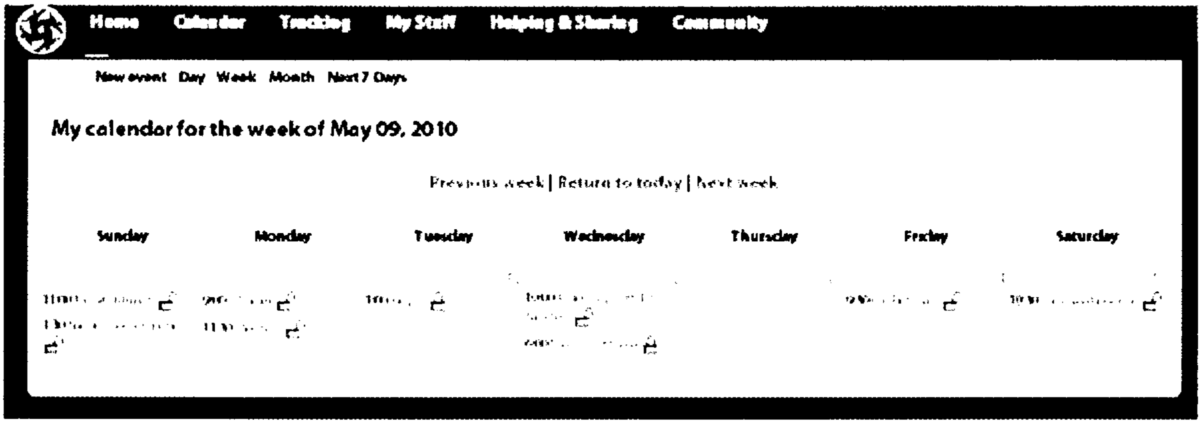
6.2.3 Icon comparison

The lock and megaphone icons (see Figure 6-1) were compared on the weekly view of the calendar. These icons are designed to be placed on every sharable object in the interface and I tested them on the calendar because this is the most space-limited interface. Based on previous studies with patients, I created 20 realistic calendar events and randomly distributed them across two weeks. One week used lock icons and the other week used megaphone icons. I then randomly assigned the number of people who would be able to see each event on one calendar week and replicated these numbers on the next week. Participants used four events on each week (with identical sharing numbers) to answer transparency questions using the icons. See Figure 6-3 for the study design. The events and icons used in the study can be seen in Figure 6-4.

	Icon	
	Lock	**Megaphone**
Weekly Calendar	***Transparency questions (M1, M2) about:*** **Event shared with 0** **Event shared with 74** **Event shared with 12** **Event shared with 71**	***Transparency questions (M1, M2) about:*** **Event shared with 0** **Event shared with 74** **Event shared with 12** **Event shared with 71**

Figure 6-3: Icon comparison study design.

Calendar with lock icons



Calendar with megaphone icons

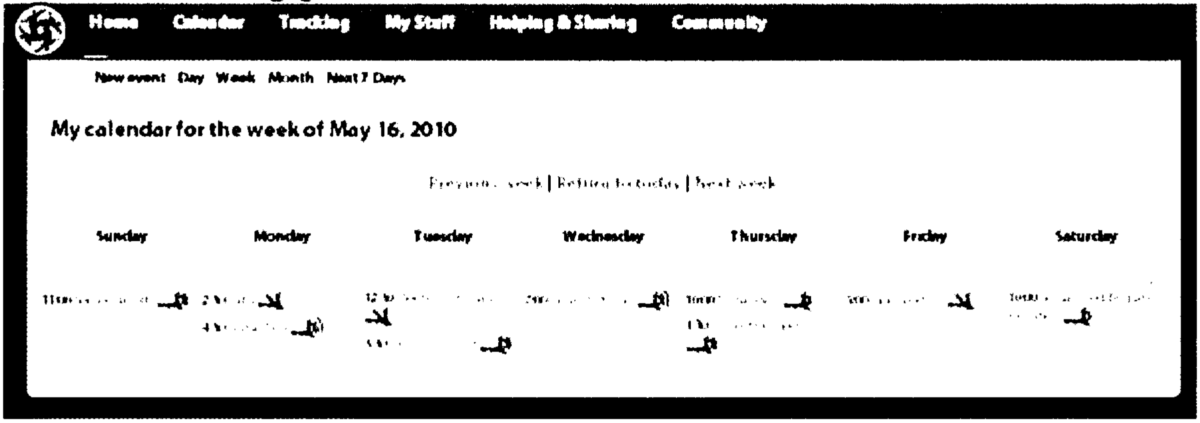
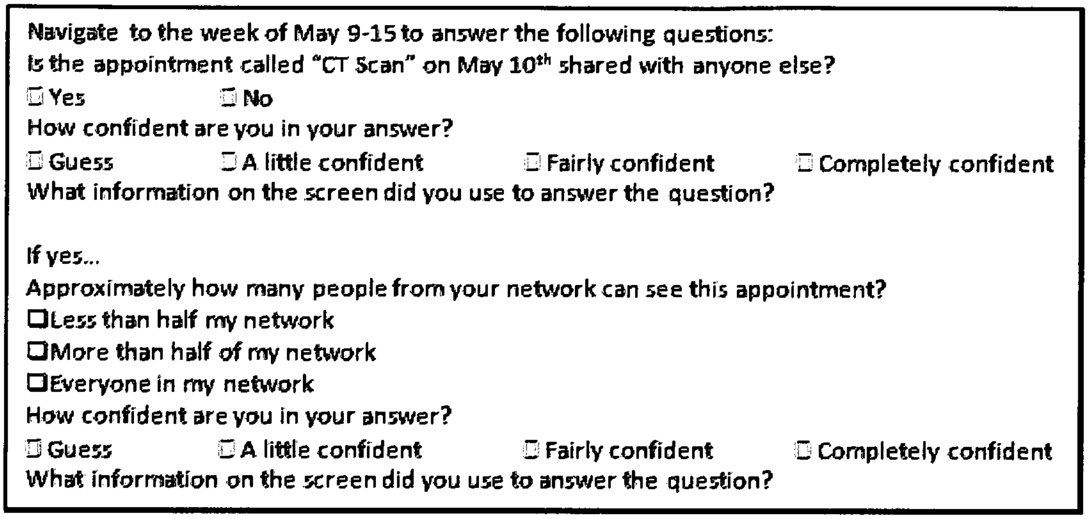


Figure 6-4: Weekly calendar view showing events and icons used in the study.

The eight calendar events (four with the lock icons and four with the megaphone icons) that participants answered questions about were randomly ordered for each participant and no two participants had the same order of events. With each event, participants answered two transparency questions and reported their associated confidence. Figure 6-5 is an excerpt from the study and shows the exact transparency questions for one event. The entire study questionnaire is available in Appendix E. Using the icons, participants identified whether the event was shared, Metric 1 (M1), and answered a multiple choice question about approximately how many people in their network could see the event, Metric 2 (M2). To make these questions reasonable, the four megaphone icons corresponded exactly to the four possible answers to M2. To decrease the likelihood that numeracy issues would impact the study, we asked lock icons events that did not require careful math to determine whether more or less than half of the network could see the event (e.g. 12 out of 74 participants is far less than half).



Navigate to the week of May 9-15 to answer the following questions:
Is the appointment called "CT Scan" on May 10^{th} shared with anyone else?
☐ Yes ☐ No
How confident are you in your answer?
☐ Guess ☐ A little confident ☐ Fairly confident ☐ Completely confident
What information on the screen did you use to answer the question?

If yes...
Approximately how many people from your network can see this appointment?
☐ Less than half my network
☐ More than half of my network
☐ Everyone in my network
How confident are you in your answer?
☐ Guess ☐ A little confident ☐ Fairly confident ☐ Completely confident
What information on the screen did you use to answer the question?

Figure 6-5: One of the 8 tasks participants completed using the icons on the calendar. Four tasks were completed with the lock icons and four were completed with the megaphones.

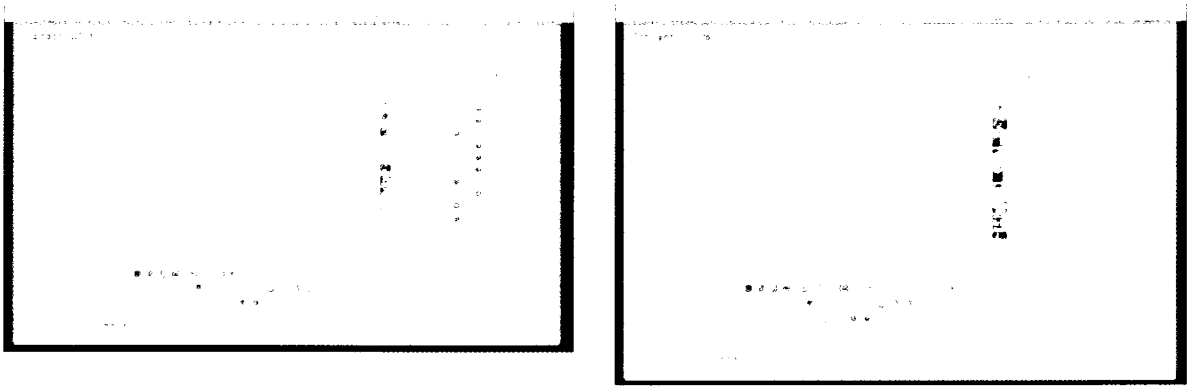
For each event, I collected accuracy data about participants' abilities to answer Metric 1 and Metric 2 transparency questions. I also collected confidence judgments with each metric and qualitative field notes about participants' comments and justifications for their answers.

6.2.4 Sharing List comparison

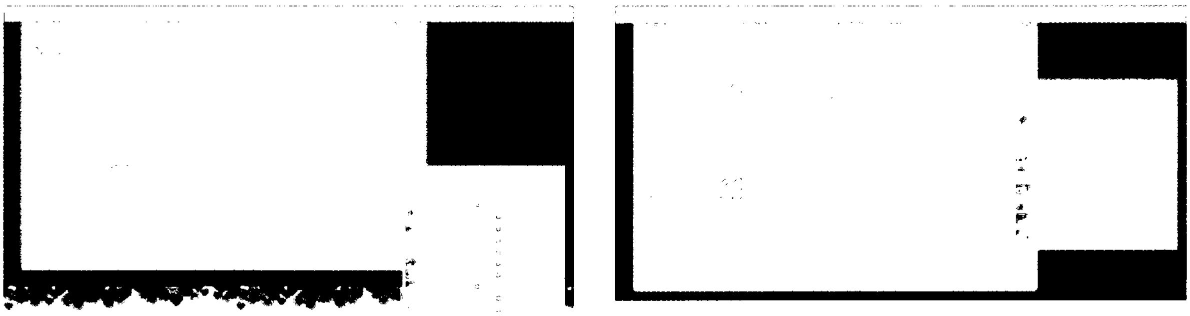
The Complete Sharing List and Selected Sharing List interfaces (see Figure 6-2) were compared in both content creation and hover conditions. Figure 6-6 shows the 2X2 study design I used to compare the two interfaces for transparency. The main comparison of interest is which of the two sharing list interfaces is most transparent. However, the interfaces will be included in both hovers (over the best icon) and embedded in pages where users create content so I included this condition. It seems unlikely that appearing in a hover versus embedded in a page would greatly influence a user's understanding of the interface, but it is impossible to make this judgment

	Sharing List	
	Complete	**Selected**
Content Creation	*Transparency questions (M1, M2, M3a, M3b)*	*Transparency questions (M1, M2, M3a, M3b)*
Hover	*Transparency questions (M1, M2, M3a, M3b)*	*Transparency questions (M1, M2, M3a, M3b)*

Figure 6-6: Sharing list comparison study design.



Complete Sharing List at Content Creation **Selected Sharing List at Content Creation**

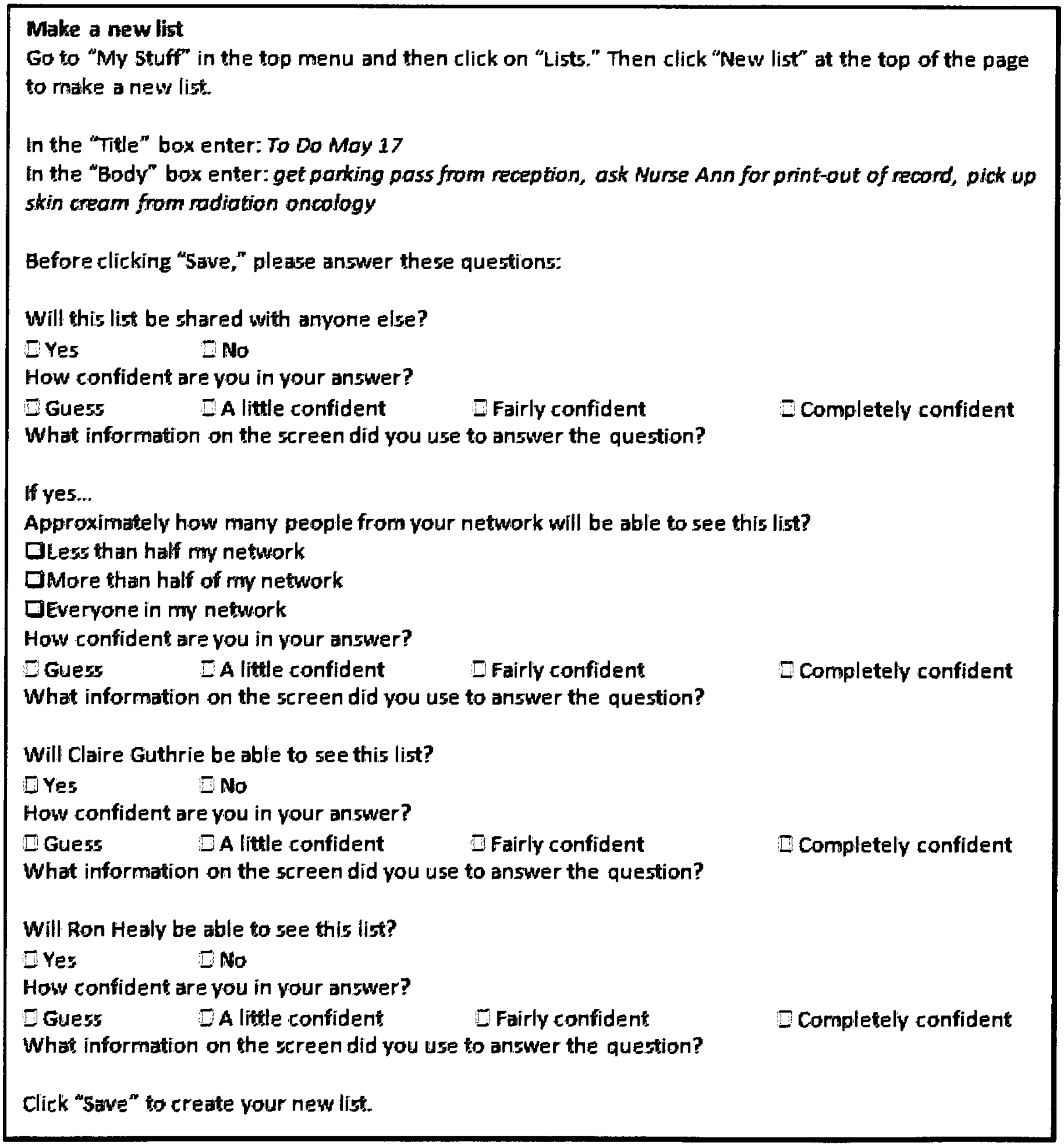


Complete Sharing List in Hover **Selected Sharing List in Hover**

Figure 6-7: Complete Sharing List and Selected Sharing List as they appeared for Content Creation (top row) and Hover (bottom row) conditions.

without data. Figure 6-7 shows screenshots of the two interface options appearing in the two conditions. I counterbalanced the order of the four combinations of interface and condition to prevent ordering effects. For practical reasons, the Complete Sharing List interface was always attached to the "New List" interface and the Selected Sharing List was always attached to the "New Note" interface. However, I do not believe that this affected the results as the interfaces are nearly identical (see Figure 6-7). The hover condition used the pre-seeded notes that "Terry" had placed in the system. These lists each had a placeholder, "Sharing Information" link, for the icon that participants hovered over to see the sharing list interface. With each combination of condition and sharing list, participants answered all three types of transparency metrics. They identified: if the list of note was shared (M1), approximately how many people could see the list or note (M2), and then identified whether specific people had permission to see the list or note (M3). I used two M3 questions to measure whether participants could identify if someone could see the information when that person could (M3a) and when that person could not (M3b). Figure

6-8 is an excerpt from the study and shows the exact transparency questions for creating a new list. The entire study questionnaire is available in Appendix E. With each transparency question I also asked users how confident they were in their answer and asked them to explain their reasoning.



Make a new list
Go to "My Stuff" in the top menu and then click on "Lists." Then click "New list" at the top of the page to make a new list.

In the "Title" box enter: *To Do May 17*
In the "Body" box enter: *get parking pass from reception, ask Nurse Ann for print-out of record, pick up skin cream from radiation oncology*

Before clicking "Save," please answer these questions:

Will this list be shared with anyone else?
☐ Yes ☐ No
How confident are you in your answer?
☐ Guess ☐ A little confident ☐ Fairly confident ☐ Completely confident
What information on the screen did you use to answer the question?

If yes...
Approximately how many people from your network will be able to see this list?
☐ Less than half my network
☐ More than half of my network
☐ Everyone in my network
How confident are you in your answer?
☐ Guess ☐ A little confident ☐ Fairly confident ☐ Completely confident
What information on the screen did you use to answer the question?

Will Claire Guthrie be able to see this list?
☐ Yes ☐ No
How confident are you in your answer?
☐ Guess ☐ A little confident ☐ Fairly confident ☐ Completely confident
What information on the screen did you use to answer the question?

Will Ron Healy be able to see this list?
☐ Yes ☐ No
How confident are you in your answer?
☐ Guess ☐ A little confident ☐ Fairly confident ☐ Completely confident
What information on the screen did you use to answer the question?

Click "Save" to create your new list.

Figure 6-8: Making a new list is a "Content Creation" task using the Complete Sharing List interface. These instructions and questions were used by each participant, counterbalanced with other sharing list

Ease of use was assessed after transparency. Using the hover condition, users were asked to add someone to each pre-seeded list and remove someone from each pre-seeded list. They were also asked how confident they were that they performed these tasks. I collected accuracy data, confidence, and field notes about how participants approached these tasks. After using the interfaces to answer transparency questions and make changes to the sharing settings, participants selected which interface they preferred.

6.3 Results & Discussion

The main analysis of interest is in the comparison between the two icons and the comparison between the two Sharing List interfaces. In this section, I present the data supporting these comparisons and the statistical analysis I used to compare the two options. I then discuss my interpretation of the data and what it means for future interface development.

6.3.1 Participants

The 20 study participants were between 33 and 64 years old with an average age of 51. Most participants were female (17 female, 3 male) and breast cancer was the most common cancer diagnosis among all participants. The participants were also heavy computer users. Everyone in

Icon Comparison: Is this information shared? (M1)

Shared with everyone (X^2=0.5, p=0.48)

	Lock 🔓 74 correct	incorrect
Megaphone 📢 correct	18	0
incorrect	2	0

Shared with no one (X^2=1, p=1.00)

	Lock 🔒 0 correct	incorrect
Megaphone 📢 correct	19	1
incorrect	0	0

Shared with > half (X^2=1.33, p=0.25)

	Lock 🔓 71 correct	incorrect
Megaphone 📢 correct	17	0
incorrect	3	0

Shared with < half (X^2=0.8, p=0.37)

	Lock 🔓 12 correct	incorrect
Megaphone 📢 correct	15	1
incorrect	4	0

Figure 6-9: Comparison of Lock icon and Megaphone icon for transparency Metric 1 (Is this information shared?).

the study reported using a computer at least most days and eleven participants reported using a computer most of the time on most days. All participants used the Internet and all but one person had Internet access at home. Because this study involves sharing information, I asked participants about their use of social networking software, blogs, and websites that enable personal health information sharing within a social network. Half of participants used some form of social networking software (e.g. Facebook or LinkedIn) daily and the other half did not use them at all or had a profile they did not use regularly. Everyone had read a blog, but only three participants had their own blogs. One participant even used her blog as her "health log." Seven participants had used one of the websites for sharing personal health information within a social network. Three of these people had used the system to get information about someone else or coordinate help for someone else. Two people reported setting up a CarePages profile for themselves, but not really using it. One person who had a friend who used one of the systems to set up a caregiving schedule for her while she was getting weekly cancer treatments.

6.3.2 Icon Comparison

The results of the transparency questions indicate that the lock icon was more transparent than the megaphone. There was no significant difference in participants' abilities to judge whether the information was shared (transparency Metric 1), but participants were significantly better at using the lock interface to determine approximately how many people in their network could see the information (transparency Metric 2).

When asked "Is this information shared?" seven more people made mistakes using the megaphone icon, but this was not a statistically significant difference using a McNemar chi square test. Figure 6-9 shows the data comparing transparency Metric 1 for the lock and megaphone icons. Participants were able to answer transparency Metric 2, "Approximately how many people can see this information?" more accurately using the lock icon than the megaphone icon. Figure 6-10 shows the data comparing the transparency Metric 2 for the lock and megaphone icons. Using a Wilcoxon signed-rank test, there was no difference in the how confident people were using one icon over the other.

The icons were compared in four states:

- Everyone in the network can see the information
- More than half of the network can see the information
- Less than half of the network can see the information
- The information is not shared with anyone

When information was not being shared, the icons were equally transparent; the megaphone with a slash through it to the locked lock with a zero next to it showed no statistical difference for transparency (see Figure 6-9). When there was sharing taking place, the lock icon performed significantly better than the megaphone. To show approximately how many people could see the information, the lock showed a number and the megaphone used waves (lines) representing the proportion of the network who could see the information. From this, we can conclude that the number is a more effective means for communicating to users approximately how many people in their network have permission to see an object.

All study participants (20/20) preferred the lock icon over the megaphone icon (p less than 0.001 with McNemar chi square test). When making the preference decision, some participants reported having trouble figuring out the megaphone metaphor. One participant who figured out the megaphone metaphor described exactly what it meant; he explained that more waves meant louder volume and that this was a metaphor for more sharing. However, he still preferred the lock with the number because it required less cognitive process than interpreting the metaphor each time. Although the lock was preferred, some people also did not immediately see that the icon

Icon Comparison: Approximately how many people can see this information? (M2)

Shared with everyone ($X^2=3.125$, $p=0.08$)

Lock **74**

		correct	incorrect
Megaphone	correct	11	1
	incorrect	7	0

Shared with no one

Lock **0**

Megaphone (Does not apply)

Shared with > half ($X^2=8.1$, $p=0.004$)

Lock **71**

		correct	incorrect
Megaphone	correct	6	0
	incorrect	10	3

Shared with < half ($X^2=7.1$, $p=0.008$)

Lock **12**

		correct	incorrect
Megaphone	correct	9	0
	incorrect	9	1

= Significantly better accuracy

Figure 6-10: Comparison of Lock icon and Megaphone icon for transparency Metric 2 (Approximately how many people can see this information?).

was a lock (at least two participants thought it was a purse at first glance) and some reported using the number alone without realizing that the lock opened and closed until they answered questions about the event where nothing was being shared. One participant also noted that the lock icon has other meanings in other interfaces. A system he used at work used the lock icon to indicate whether he would be allowed to edit a document or not.

6.3.3 Sharing List Comparison

There was no statistically significant difference in the transparency of the two different sharing list interfaces. Using a McNemar chi square test to compare transparency Metrics 1, 2, 3a, and 3b

Table 6-1: Comparison of Complete Sharing List interface and Selected Sharing List interface showed no difference in transparency, ease of use, or confidence. *refers to McNemar chi square test **refers to Wilcoxon signed-rank

		Accuracy			Confidence		
		Interface Comparison	X^2*	p-value*	Interface Comparison	WRS**	p-value**
M1	Content Creation	Selected = Complete	0.25	0.62	Selected = Complete	1.5	0.68
	Hover	Selected = Complete	0	1	Selected = Complete	1.5	0.68
M2	Content Creation	Selected = Complete	0	1	Selected = Complete	1	0.5
	Hover	Selected = Complete	0	1	Selected = Complete	3.5	0.77
M3a	Content Creation	Selected = Complete	0	1	Selected = Complete	3	0.17
	Hover	Selected = Complete	1.33	0.25	Selected = Complete	2	0.5
M3b	Content Creation	Selected = Complete	1.67	0.68	Selected = Complete	3	0.17
	Hover	Selected = Complete	0.5	0.48	Selected = Complete	4	0.39
Use	Remove	Selected = Complete	0.5	0.48	Selected = Complete	3	0.17
	Add	Selected = Complete	0	1	Selected = Complete	4	0.39

Key	
M1	Transparency Metric 1. User can tell if the information is shared or not.
M2	Transparency Metric 2. User can tell approximately how many people the information is shared with.
M3a	Transparency Metric 3. User can correctly identify that someone has access to the information.
M3b	Transparency Metric 3. User can correctly identify that someone does not have access to the information.
Use	Ease of Use. Remove = User can remove someone from the list of people who can see the information. Add = User can add someone to the list of people who can see the information.

(see key in Table 6-1) showed no difference between the two interfaces. Additionally, the same test showed no difference in users' abilities to change the sharing settings (ease of use tasks) using the two different interfaces. Based on Willcox signed-rank tests, there was also no difference in how confident users were with each interface. All of these results are summarized in Table 6-1.

After identifying that there was no statistical difference in the main comparison, between the two visualizations, I noticed that the Hover condition has consistently higher accuracies for transparency questions than the Content Creation condition. However, an evaluation of M 1, 2, 3a, and 3b showed no statistical difference between showing an interface embedded in a page and showing it in a hover.

Although the objective measures showed no difference between the transparency and ease of use of the two Sharing List interfaces, there was a significant difference in the subjective measure. Most participants (15/20) preferred the Complete Sharing List interface over the Selected Sharing List. Their preference is statistically significant with a p-value of 0.025 ($X^2=5$, df=1) using a goodness of fit chi square test. Some participants who preferred the Complete Sharing List interface explained that they liked being able to see everyone and see everyone's status. One reason for wanting to see everyone listed was so the participant could be sure that people they wanted to omit were omitted. Another participant wanted everyone listed so that she could check to make sure that she had not forgotten to share with someone. A participant who preferred the Selected Sharing List explained that she understood both interfaces, but liked dealing with the

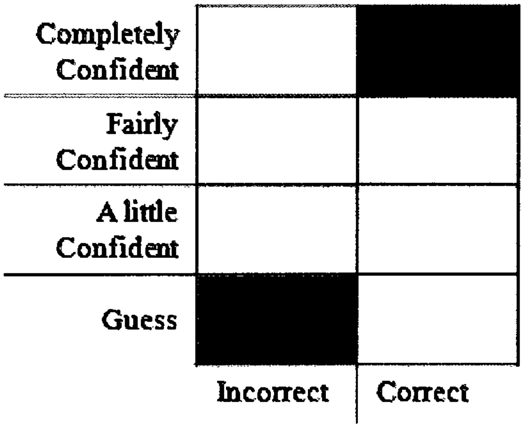


Figure 6-11: Template for comparing confidence with correct and incorrect answers. Color saturation indicates concentration of answers in each cell. This trend would indicate that people were most confident when answering correctly. This trend did not appear in my data.

Content Create with Selected List
(6 additional incorrect lack confidence data)

	Incorrect	Correct
Completely Confident	[illegible]	[illegible]
Fairly Confident	2	14
A little Confident		1
Guess		

Content Create with Complete List
(12 additional incorrect lack confidence data)

	Incorrect	Correct
Completely Confident	[illegible]	[illegible]
Fairly Confident	1	13
A little Confident	1	
Guess		

Hover with Selected List

	Incorrect	Correct
Completely Confident	1	[illegible]
Fairly Confident	1	9
A little Confident		1
Guess	1	

Hover with Complete List
(3 additional incorrect lack confidence data)

	Incorrect	Correct
Completely Confident	[illegible]	[illegible]
Fairly Confident	1	7
A little Confident		
Guess	1	1

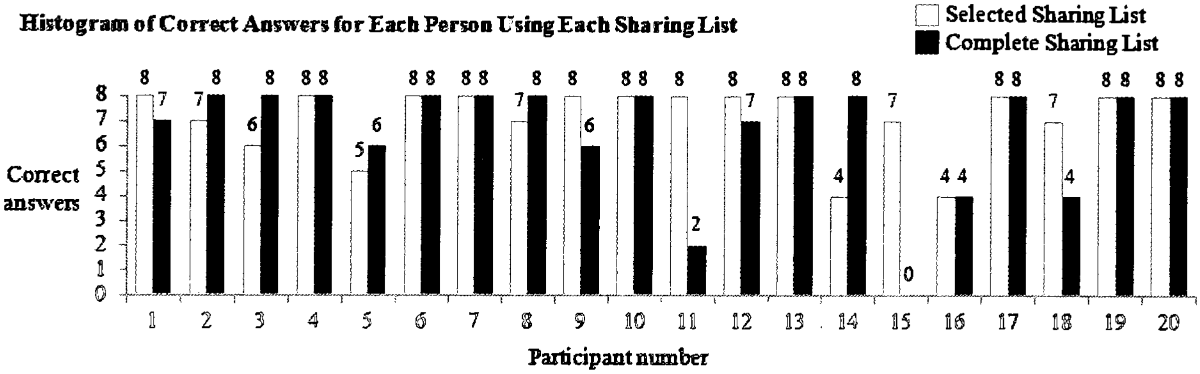
Figure 6-12: Comparing of confidence with correct and incorrect answers. Participants remained confident regardless of whether they were answering correctly or incorrectly.

shorter list of people.

There is one final analysis of the Sharing List interfaces to consider. My original interest was in establishing which of the interfaces was most transparent and which would be better to use in the future. Since there is no difference in transparency, I am inclined to recommend the Complete Sharing List because participants strongly preferred it. However, there is a larger issue to consider: whether either interface is transparent and usable enough to recommend. I find the error levels observed with both interfaces troubling. Furthermore, participants did not seem to recognize their errors.

Participants seemed equally likely to report being confident in their answers regardless of whether their answers were correct. Figure 6-11 shows a visualization I designed for examining user confidence associated with correct and incorrect errors. Each color-coded column represents incorrect or correct answers. Color saturation corresponds to the percentage of answers from a column that fall into each cell. I would hope that the largest concentration of answers would be correct and that users would be confident in their correct answers. Similarly, I would hope that when users are incorrect they would be less confident in their answers. The data does not reflect this pattern (see Figure 6-12). Instead, participants remained confident in correct and incorrect answers. There are only a small number of errors to analyze, but they appear to trend toward the top of the column in the same way that correct answers do.

Not only were participants troublingly confident while making errors, the fact that they made errors is troubling. These errors represent a misunderstanding about how health information is being shared, so even one error could lead to unintentionally sharing health information. Figure 6-13 shows the transparency metric data (M1, M2, M3a, and M3b) for all 20 participants with each Sharing List interface. Participants answered eight questions total with each interface (across the two conditions) and some participants missed multiple questions with each interface. Eight participants did not make any mistakes with either interface, indicating that they fully understood both interfaces. Another six participants made one or two mistakes across their use of the two interfaces (1-2 mistakes while answering 16 total questions). The remaining six participants (P5, P11, P14, P15, P16, and P18) made more than one or two mistakes. The graph in Figure 6-13 shows a histogram of how each participant performed using each interface. These error numbers are inflated somewhat because participants who judged that something was not shared when it was did not just miss one question –they missed that question (M1) and also the remaining three questions about how many people could see the information (M2) and about whether specific people could see the information (M3a and M3b). P11, P14, and P18 made one such error; P15 and P16 made two such errors. If we omit those errors from the dataset, we see an error rate of 7% using the Selected Sharing List interface and 8% using the Complete Sharing List interface (11% and 17% respectively leaving those errors in).



Histogram of Correct Answers for Each Person Using Each Sharing List

Percentage of Correct Answers for Each Person Using Each Sharing List

% correct Selected List ☐	100%	88%	75%	100%	63%	100%	100%	88%	100%	100%	100%	100%	100%	50%	88%	50%	100%	88%	100%	100%
% correct Complete List ■	88%	100%	100%	100%	75%	100%	100%	100%	75%	100%	25%	88%	100%	100%	0%	50%	100%	50%	100%	100%
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

Participant number

Figure 6-13: Transparency data for each person using each Sharing List interface. The four transparency questions in both the hover and content creation conditions were combined for a total possible score of 8 correct answers using each Sharing List interface. This data considers missing data incorrect. P11, P14, and P18 each have three missing data points. P15 and P16 each have six missing data points.

Given the errors participants made, we are left with the question: How many errors are acceptable when sharing personal health information online? Ideally I would want 100% accuracy for all the transparency measures, indicating that everyone understood the interface. However, that might be an unattainable goal; we might need to decide what error rate is acceptable. I leave this question to the reader to ponder. This is a judgment call with no clear correct answer. After watching participants systematically answer questions wrong and mark that they were confident in their answers, I am concerned that these interfaces are not ready for wide use.

6.4 Limitations

There are several important limitations inherent in selecting the lab study methodology. First participants are using the system under superficial conditions, with a researcher sitting next to them watching their every move. Being observed might make participants more prone to making mistakes or might make them more careful. Second, participants had never used the system before. The do not have the benefit of being familiar with the system and I did not include a tutorial. The results of this study are based on first-time use and might not hold over time. Third, the activities participants did and the questions they answered were entirely dictated by me. Based on my interactions during the design groups, I tried to make the activities realistic, but they might not represent the ways participants would use the system on their own. Finally, participants were not using their own data or their own social network. They did not have the benefit of being familiar with the contents I pre-seeded in the system or the social network. This fake setup creates additional cognitive load that complicates using the system. The fake setup could also hinder participants' motivation to complete tasks and questions correctly, although that did not appear to be a problem based on my observations.

A sample size of 20 participants might have limited my ability to find differences that were too small to detect with such a small sample size. I would expect that if there was a really large difference between the two Sharing List interfaces that my study design with 20 participants would detect it, but I cannot say that conclusively. Another limitation of the sample is the unequal gender distribution. If gender has an effect on a person's ability to answer transparency questions and use the system our skewed sample would be concerning. I do not believe that gender will affect the metrics I used, but it is a factor to watch for in future studies.

6.5 Conclusion

Embedding sharing information throughout an interface and including the ability to make sharing decisions in context is an important step forward from the traditional control panels for setting up access control lists. Patients' social networks evolve over time and their comfort sharing information also changes. To keep up with this fluid process, I have designed sharing controls that can be embedded in all shared objects throughout an interface. Embedding sharing information on the shared object will also support patients who are experiencing memory problems due to treatment side effects or stress. I have identified a small icon that can be displayed on objects throughout an interface to remind users how many people those objects are shared with. I have also evaluated the transparency of two different options for showing exactly who can see a particular object. This analysis did not identify a difference in the transparency between the two interfaces. The results also raised troubling questions about whether it is acceptable to make *any* errors that result in unintentionally sharing personal health information online. Even the most secure system can be thwarted by user errors and misunderstandings that cause users to share more than they intended. My findings provide important steps forward towards the eventual goal of entirely transparent sharing controls that allow users to fully understand what they are sharing and that prevent any unintentional sharing.

Chapter 7

Designing with Health Consumers

One of the biggest challenges in creating new technology is designing the technology so it fits users' needs, values, and environments. Technologists struggle with the difficulty of designing for someone else and users struggle with technology designed by people who do not fully appreciate who they are, what they do, and what they need. Two classes of methods for designing technology have focused on the importance of creating technology that fits users: user-centered design and participatory design. User-centered design methods focus on studying users and then designing technology with the user in mind. Studying the user can involve field work, interviews, observations, or any other method of collecting data about users and their environment. In contrast, participatory design methods both study users and engage users in the design process, asking them to help envision and design new technology. Technology for health consumers is relatively immature in comparison to workplace technology, but researchers have begun to utilize both user-centered and participatory methods in the recognition that successful technology must fit the needs of the health consumers they are designed to help.

In this chapter, I describe what I have learned working with five groups of health consumers to design new technology. As part of a larger research effort, the two participatory design groups I described in Chapter 5 were accompanied by three additional participatory design groups focused on other aspects of personal health information management. The methods I used in the five groups were similar and the population was similar. The five groups included breast cancer patients, survivors, and a few people close to a breast cancer patient.

Participatory design was developed with the principle that democracy should exist in the workplace and that workers have the right to influence the technology they will have to use. Inherent in that belief is a second principle, that workers have valuable skills and expertise that should be appreciated and utilized in the design process, and in the resulting technology (Spinuzzi, 2002). As participatory design methods have moved out of the workplace and into other settings these principles have been adapted, but still hold. First, there is still the belief that users should have the right to influence technology that will influence them. Second, people are experts of their own experiences and their own lives and this expertise should be appreciated in the design process. As participatory design has moved beyond its original political birth, others have also come to appreciate it from a purely practical viewpoint; participatory design methods create designs that are firmly rooted in user needs, values, and experiences. This highly practical argument, that participatory design can help create better technology, has been used in the United States as an argument to use participatory methods (Kyng, 1998; Muller et al., 1991). However, this practical argument has caused tensions in the research community in cases where the principles of democracy and valuing skills were not forefront in the rhetoric, and perhaps motivations, of the design work (Spinuzzi, 2002).

I believe that the technology we create should truly reflect the needs of breast cancer patients and that it is our responsibility to involve those users in the design process. I have learned a great deal from the people who participated in the design process during my dissertation research and in the larger personal health information management research project. The impact participants had on the technology we have designed together is clear. They led this work in unanticipated directions and contributed to both the larger vision for the technology and to the interaction-level design of functionality and interfaces.

Involving users with participatory methods has been written about in great detail in many venues. In this chapter, I will share what I learned from working with breast cancer patients and survivors. I begin by describing how I have adapted the methodology to fit the health domain and work with breast cancer patients and survivors. The second large portion of the paper then focuses on presenting practical advice that I did not glean from previous literature before embarking on this design process. I believe this practical advice will be useful within the consumer health domain and in other settings.

7.1 Methodology Challenges: Design with actual users cannot happen in many health contexts

Moving from workers who will use technology in their workplace to breast cancer patients and survivors requires some methodological adaptation. I have encountered three methodological challenges inherent in this new venue. Some of these challenges have parallels to past participatory efforts, and I discuss those similarities and differences. The ways that past efforts have dealt with these challenges inspired the adaptations I made to my own methods. In this section, I outline the health specific challenges and the methodology I have made to overcome these challenges.

1. **Breast cancer patients are not in a persistent state of being patients.**

Patients move through the states of being newly diagnosed, going through treatment, and monitoring for signs of recurrence. A woman can go from thinking of herself as healthy to being diagnosed with breast cancer in a matter of days. Once the initial tests and diagnosis has been made, a treatment plan is created and treatment begins. The four main treatments for cancer are surgery, radiation therapy, chemotherapy, and hormone therapy. Any or all of these are done in combination depending on the diagnosis and the patient's preferences. If all goes well and the treatments successfully rid the body of any evidence of cancer, then the patient enters a phase of monitoring for recurrence. A "survivor" is someone who has successfully gone through treatment and does not have any evidence of cancer.

This situation presents a substantial challenge to including breast cancer patients in the design process. Participatory design originally included the actual end users in the design process (the people who will be using the newly created technology as a part of their occupation). Past efforts to include representatives of likely users have been hotly debated as not being true involvement (and therefore not truly democratic) (Bødker & Iversen, 2002; Muller, 2003; Spinuzzi, 2002). However, in cancer care and much of health care, there is simply no way to involve actual end-user patients in the design process and produce a product in time for those patients to use it, unless they are in treatment for years. To create technology that is useful for breast cancer patients, including newly diagnosed patients, we need to use representatives.

2. Patients are not organized into co-located groups.

I am designing technology for breast cancer patients and this, by definition, encompasses hundreds of thousands of people across the country (Altekruse et al., 2010). Breast cancer patients do not work together with other patients during the course of their treatment in the way that people would in a workplace. I have resorted to recruiting and creating groups of patients and survivors for my design teams. This decision has drawbacks because the participants do not know each other and do not have a working relationship before the first meeting. I have worked to overcome this by starting meetings with introductions and talking about how to work together as a group (see the "Spend time on framing and introductions subsection" below).

3. Time is a precious resource for breast cancer patients.

No one seems to have enough time and being part of a participatory design effort is often extracurricular. In the workplace, employees find it challenging to make time to participate in design activities (Ehn, 1993). The situation is even more challenging for breast cancer patients. Patients often add their treatments and breast-cancer related activities on top of an already busy schedule. Patients continue to try to keep up with their everyday duties at home and some patients also continue to work during treatment. Schedules are tight. More importantly, though, quality of life and concerns about limited life spans can influence patients' ability or desire to participate in designing new technology. People with more advanced diagnoses begin to think about how they want to spend their time in a way that those of us who believe we have decades to live do not. Anyone going through treatment has to think about how they spend their energy and time because they have limited energy and limited time when they are feeling good. These concerns layer on top of the regular concerns of not having enough time in life. Therefore, I have decided to limit what I ask from any one participant. Ideally, I would have a single group of breast cancer patients help design this technology over the full three years of the project, but I decided that this was simply too much to ask. Instead, I have limited the participation time for any one person to three meetings. These meetings have been held weekly with some groups (three meetings over three calendar weeks of participating) and bi-weekly with other groups (three meetings over six calendar weeks of participating). Because I recognized the limitations of this approach, I made it clear to participants that I were eager for continued participation. I have worked out a formal way through the Internal Review Board at the University of Washington for participants to give me permission to contact participants again in the future with updates about my research. My group has used this permission to send out a newsletter to update past participants about our research activities. Participants are also welcome to contact me at any time. Past participants have sent me links to websites or information related to our work, further examples of issues that come up in the group, and resources they have created for other breast cancer patients. They have also used email to continue to discuss the larger issues faced by breast cancer patients.

7.1.1 Summary of methods to overcome challenges in the health domain

Given the three challenges described above, I have made substantial compromises and changes to the traditional participatory design methodology. The largest of these compromises is including each individual participant for a shorter duration in the project, thus easing the burden on participants and lowering the barrier to entry for those who might otherwise be unable to participate. I created five groups of people and each group met three times. I created each of these groups and conducted participatory design sessions with them sequentially over a thirteen-month period. Each group meeting lasted two hours. I asked participants to complete about an hour of homework between sessions. Each group was run similar to a future workshop during the first meeting and then continued to iterate on their design ideas and prototypes during their subsequent two meetings. Some groups built on the ideas of preceding groups and some of the later groups saw more finished technology prototypes based on the work of the earlier groups. My approach of creating groups and meeting with each group for a limited time period allowed me to include patients who 1) move from being patients to survivors, and sometimes back to being patients, 2) are not organized into existing co-located collaborative groups, and 3) have limited time and energy to participate in the design process.

7.2 Recommendations for Designing with Patients

Through the course of creating and running these design groups, I have learned lessons that I would like to pass on to others who want to engage patients in the design process. I overcame many small challenges associated with the practical aspects of actually running design groups. For example, in this section I describe what I learned about how to introduce the participatory design process to participants, how to be flexible in about allowing participants to express design ideas by whatever means works best for them, and how to provide useful guidance during a design discussion without dictating the direction the group takes. Many of these issues are not described in detail in the existing participatory design literature and I hope that what I have learned will be useful for others who are new to using participatory design methods.

I see the people I have worked with as experts in being breast cancer patients and adopting this attitude of respect towards participants is a vital ingredient to successfully collaborating with participants. The women I worked with know what they have been through, what has worked for them, and what types of help they need. Furthermore, they have lived through the experiences I have only read about or listened to them tell me about. Cancer patients know more about what it is like to navigate the healthcare system. They know more about the emotional aspects of receiving a cancer diagnosis and going through treatment. I begin participatory design groups by talking about their expertise and what I hope they will contribute to the research. Unfortunately, their knowledge and expertise is not widely recognized within the medical system. They have functioned in a world that at best views them as a source of information about themselves, but at worst treats them as a vessel working their way through the treatment plan. When patients have been treated this way in the past, it is important to take the time to convince them that I do value their expertise. Before we can collaborate effectively, patients need to know that their expertise is valued and that I view them as a knowledgeable collaborator.

7.2.1 Spend time on framing and introductions

It is important to remember the perspective of a participant who has agreed to help with this design work. They have heard about my study, contacted a researcher, talked to the researcher about the study, and agreed to show up for three meetings. They have a general idea of the topic, but might not be familiar with research and have probably never been part of designing technology. Most have never met the researcher, been to the study location, and do not know others in the group. Before the initial meeting, I did my best to tell participants how many researchers and other participants will be there and what they can expect from the first meeting. The way I begin the first meeting of each group has become an important part of my methodology. After conducting informed consent with the group and having them fill out a brief demographic questionnaire, I begin with personal introductions. Each person is asked to briefly introduce themselves and tell the group what their experience is with cancer as well as share an activity they enjoy. I started with a member of my research team and then continued around the table. For example, I told participants that I am a PhD student and that my experience with cancer, beyond my research experience, is that two of my grandparents had colon cancer and one of my grandmothers had cervical cancer. I told them that I remember my grandparents going through treatments. I also told them that I enjoy the outdoors and hiking and camping and that I have a young puppy. Participants choose the level of detail they wanted to provide to the group. The time people spent on introductions varied from two minutes to more than ten minutes. I occasionally had to find ways to politely end lengthy introductions for verbose participants, but these introductions are an essential part of my methodology. They served as an anchor for participants and researchers to begin to build relationships and to understand where each person is coming from based on the experiences they share with the group. Details of these introductions were often referenced during the rest of the meetings and the 'something you like to do' detail served as a starting point for people to make conversation during breaks as well as before and after meetings.

Personal introductions were followed by a presentation by one of the researchers. After refinement, I included the following in a brief 15-minute presentation (see Appendix D for Group 5 slides). The following is an outline of the introduction, and below I describe the process through which I refined the introduction over the five groups.

1. Background on the project
    a. Funding source
    b. Past research activities
    c. Timeline for the project
2. Topic for this design group
    a. Relationship to past research
3. Introduction to participatory design
    a. What I hope participants will contribute and what I hope to contribute
    b. Introduce prototyping, scenarios, and the iterative design process

With the first group, I did not want to spend an extended amount of time introducing the topic and process. However, I found that providing very little introduction caused participants to spend substantial time figuring out what my motivation was, how much I understood about the breast cancer experience, and what the goals for the meetings would be. With the second and third group, I provided progressively more introduction. With the fourth and fifth group, I settled on the above outline and spent very little time after the initial introduction answering the type of questions that unfolded with the first group over their three meetings. Spending a brief but well thought out period acquainting everyone with each other and the process early on helped move us into the design work and prevented unnecessary anxiety or uncertainty on the part of participants who were still trying to figure out the meeting goals.

Providing background on the project serves a few important purposes. First, information about funding and the timeline for the project helped explain to participants what kind of research my research group is doing. For example, participants have wanted to know if their work is going towards product development. Second, the brief discussion of past research activities explains to participants that I have interacted with breast cancer patients in past work. Participants spend time feeling me out to see how much I understand about the breast cancer experience and to gage the level of detail I want, or will be shocked by, until they come to understand that I am well acquainted with the details of cancer treatment. Upon discovering that I have experience being around the grittier details of cancer and do not need to be treated gently, participants felt freer to convey their experiences and opinions. Instead of waiting for this discovery to occur on its own, I began helping it along by including the information in the introduction. Third, discussing the timeline for the project helps anchor participants in the "design" task at hand and describes how one design group fits with other groups. Participants raise the issue that they do not speak for all breast cancer patients and appreciate that I worked with more than just one group.

Introducing the topic for the group has proved more difficult than I anticipated. One of the reasons to use participatory methods is so participants are part of guiding priorities and making decisions about what is most important to implement. However, my research group chose the topic of personal health information management based on extensive field study data showing that this is both an important and difficult activity for which breast cancer patients lack technical support. I further broke this topic into smaller areas for each of the five groups to tackle. There is a delicate balance between prescriptively telling a group what they will work on designing and choosing a small enough topic area that it provides both freedom to influence the design and enough scope that progress can be made on a design in three meetings. The tension between guiding the group versus letting the group lead with their priorities is discussed below in the "guide without dictating" subsection. In the design groups, I introduced the topic I had selected by explaining the topic in relation to the field study data. This framing has worked best when I have been able to accompany it with pictures of documents and people's organizational schemes from the field study. The groups have been very interested in seeing anonymized pictures of the artifacts kept and created by past participants and have been able to recognize and discuss similarities in their own experience – thus anchoring the topic we've selected in their own experiences.

The final aspect of the introductory presentation is an introduction to the design process. I explained that our goal is to design new technology and that I want them to help us. Many participants are concerned that they are not heavy technology users and that they have not designed technology before. I addressed this concern explicitly during the introduction to alleviate this anxiety by describing the concept of mutual learning. I explained that in participatory design, everyone has their own expertise to contribute. I am hoping that they will contribute their expertise as breast cancer patients and that I will bring my own expertise as a technologist and designer. I explained that we can all use our individual skills to work together as a group and to learn from one another. I used pictures from past groups and other design efforts to explain that there are many ways to express design ideas. I introduced brainstorming, prototyping, and scenarios as ways we, as a group or individually, can express our design ideas and emphasized that I are open to any form of expression they want to use.

With both the individual introductions and the presentation, a substantial portion of the first meeting (30-60 minutes) is spent getting everyone on the same page. Initially, I was hesitant to devote this much meeting time to introductions, but I found that if these issues are raised early and questions are addressed early that the comfort level of the group rose quickly and enabled efficient design sessions following the introductions.

I also introduced an agenda for each meeting. With the first group I did not present an agenda to the group because I wanted the freedom to evolve the agenda based on the group's interests and momentum. However, this decision made time management difficult. We did not progress beyond the first activity until the group was aware that I intended to engage in multiple activities during each meeting. After introducing meeting agendas for groups two through five, I did not see evidence that these agendas hampered the groups' ability to pursue their specific interests or steer based on different idea's momentum and energy. We rarely followed the agenda strictly, but we did cover more ground with an agenda as a starting point. Figure 7-1 shows the agenda for the first meeting for Design Group 4.

Meeting #1 Agenda:

Paperwork
Consent and Demographics
Discuss confidentiality

Introductions
Go around the table and give ≈2 min. introduction
- What do you like to do?
- What is your experience with Breast Cancer?

Background & Technology Presentation
Introduction to our past research that we're building on today
Introduction to Participatory Design

Design Activities
Brainstorm list as a group
What kinds of information might go with you to an appointment?
What come home after an appointment?

---------Break---------

Individual reflection & discussion
Draw or write your process for preparing for an appointment
What is a good process for preparing for an appointment?

Storyboard
Draw storyboard describing process of preparing for and attending appointment. Highlight places in the process where technology could be useful.
- How would building technology fit into preparing for an appointment, using information at an appointment, and keeping information after an appointment?
- Who else is involved?
- Would you use this again later?
- How and when would you use this?
- What would you take to the appointment?

Homework ☺
Think of a past appointment you've had or an appointment you're planning for…
List what you need to have with you at the appointment.
If you had this information with you electronically, draw what you would like your bundle to look like (either on the screen or printed out).

Figure 7-1: Agenda from the first design meeting.

7.2.2 Encourage people to express their design ideas in their own way

Individuals vary in what method of expression works best for them to communicate their ideas. At the beginning of my participatory design effort, I envisioned the groups engaging in paper prototyping and discussion at both the level of what the technology should do and what it should look like. After working on the project for a year, I have come to appreciate the many alternative ways participants can express how they think the technology should work. I would encourage other researchers not to expect participants to create functional requirements and paper prototypes in readily recognizable forms. Instead, embrace the ways participants do express design ideas and go the extra mile to translate their ideas into a more familiar specification. I see designs being described at multiple "levels" (see Table 7-1). These levels do not imply a quality ranking; the levels represent the progression from high level concept to interface details.

Table 7-1: Four levels at which technology was envisioned by participants.

	Question form	Statement form
Form	What should it be?	It should be a…
Function	What should it do?	It should be able to…
Interaction	How should it act?	When I… It should…
Interface	How should it look?	It should have…

Group 4 designed a purse-size computer that could be used to store, sort, and retrieve personal health information. One aspect of their design was a "contact list". I use this contact list example in Table 7-2 to describe the many ways functionality can be described.

Table 7-2. Example of a "contact list" described at all four levels.

	Contact List Description
Form	A purse-sized computer with a stylus/scanner.
Function	It should be able to scan business cards and keep information about people. I should be able to re-find people and find information I associated with them.
Interaction	I should be able to sort by name, title, and date. I should be able to type in notes about a person. I should be able to associate information with a person. I should be able to see a person's business card and picture. I should be able to search for a person.
Interface	There should be a drop down list for sorting. There should be a text box for searching. People should be listed vertically with notes and associated information listed next to the business card and picture.

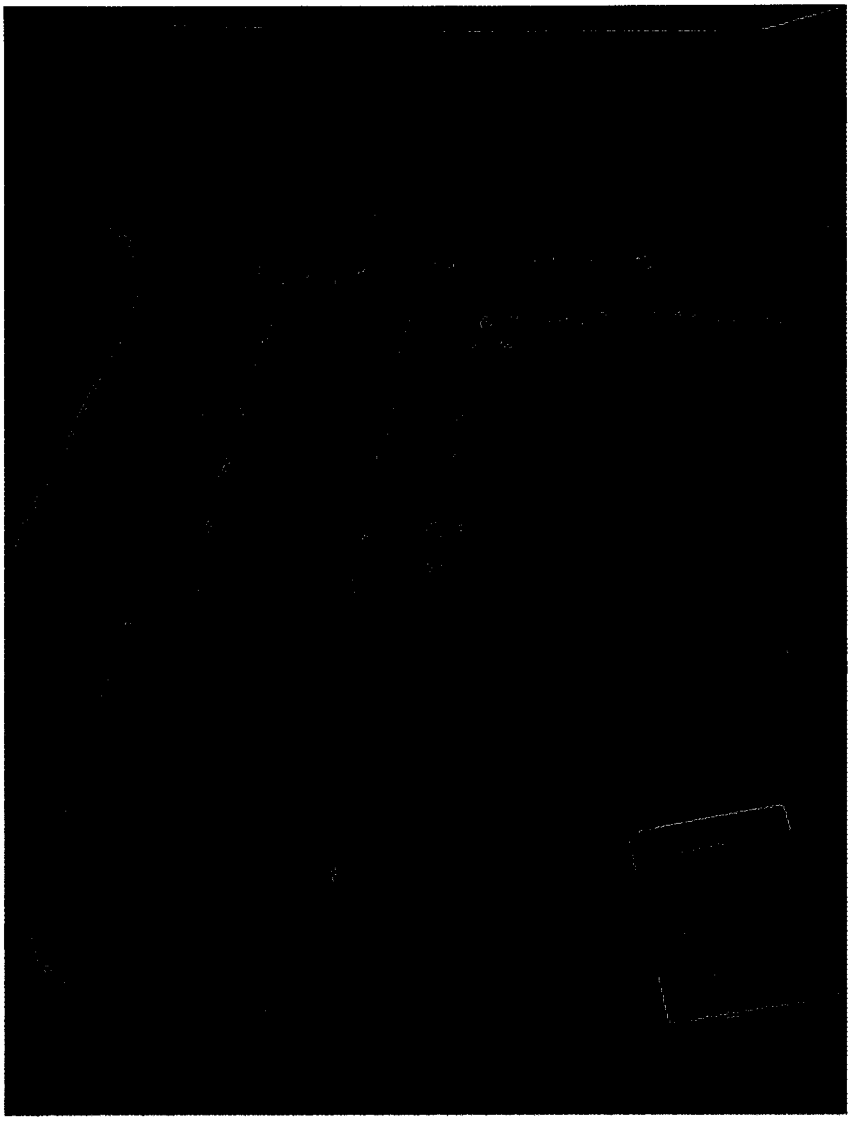


Figure 7-2: Paper prototype of contact list created by Group 4.

Participants might begin the design process at any of these levels and there is no "right" place to start. Some people will first visualize the interface they want and from there work on describing how someone would interact with the interface, including what it would be able to do (probably adding to and changing the interface as they go). Others will begin by talking about what the technology should be able to do and then begin to break down how someone would interact with the system and then finally begin to draw an interface. For the contact list, the group began by talking about keeping contacts and then sketching a list of contacts. As they talked about the contacts, they discussed wanting to find contacts again and add information besides what was on

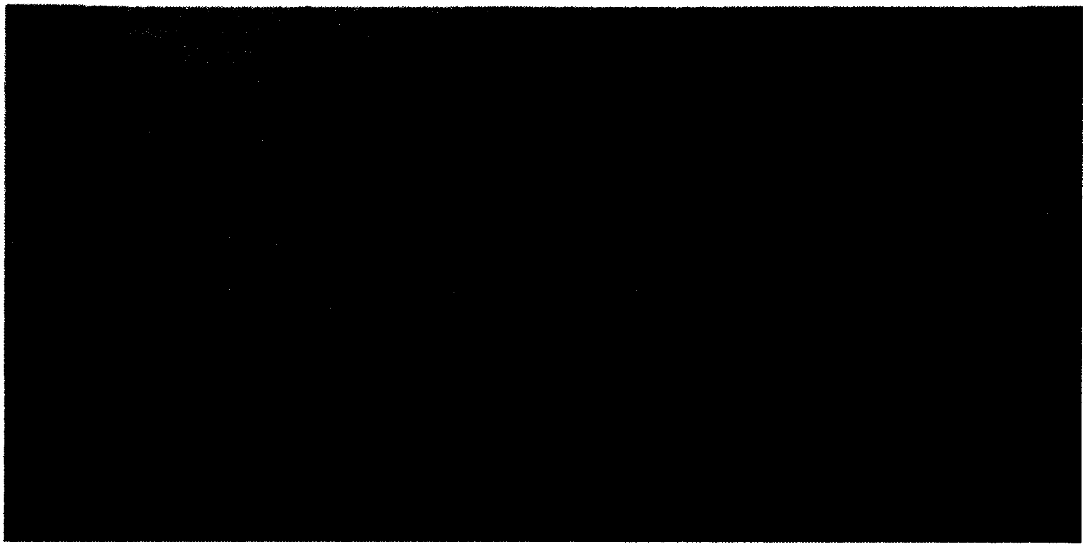


Figure 7-3: Scenario created by Group 4, including description of how contact list would be used.

the business card. As the group talked, they began to sketch their ideas into a visual interface (see Figure 7-2). An example of an aspect of the design that participants illustrated with two different methods of expression is the "search box". Figure 7-2 shows the search box drawn in the upper right corner. Figure 7-3 is a scenario the group created to describe how people could use the personal health information management tool. In this scenario, they describe how Joyce "Searches for everything from Dr. Bob" and the system returns the "appts, notes, plans for treatment, changes" that she had associated with Dr. Bob. The group conveyed this aspect of the tool in a story and in a drawing.

When participants use multiple methods of expressing their design ideas, it allows them to engage in the way that works best for them. It also provides a redundancy that helps the group make sure that they are being consistent in the way they think about the technology. Because the whole team talked through stories or drew stories about when and how technology would be used, people less experienced with technology became comfortable jumping right into drawing interfaces. People who were familiar with technology were inclined to draw interfaces and utilize standard interface features such as check boxes, drop downs, and text boxes.

All of my participants were able to engage successfully in list making activities. Open discussion and brainstorming sessions occasionally turned into long discussions of past experiences that, while valuable, were not easily directed to new design directions. However, more focused discussions provided valuable context for existing practices and problems while also focusing the group around creating an artifact that could then be leveraged to begin design work. Examples of lists that groups have created include: a list of people who receive health information, a list of ways the social network can help, and a list of the kinds of health information our system should keep.

7.2.3 Mix individual, group, and between meeting activities

Just as some people are better at sketching ideas on paper and others are better at writing a scenario, some people are better working individually and others are better in a group. Thus, my groups have benefited from providing a combination of group activities, individual activities during the group meetings, and individual activities outside the group meetings. Some individuals work best in a highly collaborative atmosphere where ideas are bounced off one another and people can quickly build on others' suggestions. Other people work best with a little more space for reflection and quiet contemplation. During our meetings, I strived to encourage introverted styles of working by allowing for personal reflection before discussions, providing breaks, and telling participants about topics before meetings (enabling them to think before they arrive). I strived to incorporate more extroverted styles of working through group prototyping, brainstorming, and collaborative scenario creation. I also utilized the time between meetings for assigning "homework" to participants and researchers. Homework activities required participants to spend some time between sessions thinking about some aspect of their own experience or the group's current design and bringing the results back to the group. With these assignments, I found that the more specific I was the more likely participants were to feel comfortable bringing their results back to the group. When I left assignments too open ended, participants often returned without anything to share. However, when I provided more structure and a deliverable (e.g. bring a drawing, a list, or a description), participants were able to fully engage in their assignment. I asked participants to spend about an hour between sessions, but they often spent considerably more time on their homework and were excited to share their results with the group during the next session. For example, I asked one group of participants to list some examples of things they would like to put on a timeline. The idea was that at the next session we would talk about how a timeline could be used to re-find and organize information. More than one participant spent hours looking through their documents and brought in a complete timeline of cancer-related events. One participant also included all the emails she exchanged with providers, her lab work, and her diagnostic documents because she would want all of these to be included on her timeline. This sort of extraordinary effort has been invaluable and is also indicative of the investment people have in their role in the participatory design process.

7.2.4 Guide without dictating

The most difficult aspect of organizing the design meetings is striking the balance between guiding the group to a topic of interest while still giving a group the freedom to design technology that is a product of their ideas and experiences. As described above, I began each meeting with a plan for the meeting and a topic area that I believed technology could improve. That said, the strength of participatory design is that the technology embodies the priorities of users. Group 2, for example, quickly evolved the topic of discussion from *Sharing personal health information with the social network* to *Collaborating with the social network.* Creating ways to update the social network and sharing information about them is not about the simple transmission of data for the sake of transmitting data. Breast cancer patients share information with their network to get help from their network and to provide the network with the information they need to be a useful network. The group made this change during one of the first list making activities we did. The change did not happen explicitly; no one said, 'It's about collaboration, not just sharing.' Instead they discussed helping and collaboration when I said "sharing." I listened to their discussion and paid enough attention to their proposed design to catch on that they were not most interested in "sharing" alone, but were interested in collaboration.

Another example of the tension between guiding and dictating is deciding whether or not to start participants with an interface or a blank piece of paper. I used blank paper to start some groups and with later groups, I showed them the designs of past groups to build on. The risk with starting a group with an existing design is that they will not have the freedom to design the technology that would be most helpful because they will constrain themselves to what I present them. A proud counter-example of this tension is a time when Group 3 entirely rejected an interface I had created. In this case, I knew that I wanted cancer patients to be able to ask for help, so I presented them with a short form they could fill out to request help. I asked participants to take this home and try to fill it out using a real example for homework. I said that if it wasn't working that they were welcome to start over and design their own. None of the people in Group 3 used the form; every single person created their own. This was a group that I did not need to worry about going along with my ideas! Creating an environment such that participants are *empowered* *collaborators*, free to reject ideas and propose their own, is the goal in any participatory design process. Thus, researchers should be on the lookout for signs that they have succeeded or have not yet succeeded at fostering this dynamic.

Another aspect of guiding groups that has proven challenging is managing time and directing the group towards technology design. Many of my participants had heart wrenching stories about their journey through diagnosis and treatment, and there was certainly interest among the groups in hearing one another's stories and supporting one another. I too am interested in their stories. The tension is that I also wanted to make efficient use of our limited time to design ways to fix (or at least alleviate) the problems they faced. Moving the group on from talking about important and emotional problems to get everyone thinking about solving those problems was difficult. It was difficult on a very personal level because it feels rude and inappropriate to cut off a cancer patient talking about something important to them. When faced with this tension I erred on the side of spending more time talking about the problem instead of transitioning as soon as possible. When it does become important to move onto another topic, it is a good idea to first validate the importance of the topic being covered and the experience being shared. The group understands that there is work to be done, so couching the transition in terms of how the next topic or activity relates to the group's discussion can be a helpful way to move towards problem solving.

Finally, one important transition from dictator to guide is to encourage participants to interact with one another and not just with the researcher. It is easy to fall into a focus group style of interaction in which a researcher asks a question which is then followed by each participant responding in turn to the researcher. Instead, I encourage participants to interact with one another, ask each other questions, and build on each other's ideas. When this happened, I learned more about everyone's viewpoints. Whenever participants established that they saw something differently and worked out the differences among their viewpoints, I got a much deeper understanding of the issue. One tool I used to get this kind of interaction started is having everyone work on something individually and then share it with the group during the first meeting. This activity naturally encouraged them to ask each other questions and compare their idea with the other ideas that had been presented.

7.2.5 Create an open collaborative atmosphere

Working to create a collaborative atmosphere has been a combination of common sense and trial and error. I emphasized from the beginning that I view participants as collaborators and that I see including them in the project as a vital part of creating useful technology. This sets the tone of respect for their knowledge and experiences. The way that I proceed from there dictates how open participants will be if they disagree with me and how far out they are willing to go in imagining new technology. I want participants to feel totally comfortable saying that they do not agree with me or have a different experience than I have assumed. My best advice for bringing this sort of critique out is to explicitly say to participants that if they disagree they should not be shy about speaking up. When the first brave person does speak up, tell them you are happy they said something and listen carefully to what they are saying. This attitude has helped create an atmosphere in my groups where participants have critiqued my proposals and corrected my misunderstandings.

Breast cancer is a serious illness, but it is not necessary for design sessions to be somber affairs. I find that playfulness, levity, and laughter bring out creativity and create an atmosphere where participants are more likely to bring up new ideas or get excited and grab a pen to explain their idea to the group. My most successful PD meetings have been a mix of both deadly serious moments and moments of all out laughter from the group. At the beginning of the project, I was unsure what tone to strike because breast cancer is a somber topic, and it is difficult to know what topics will trigger unpleasant memories or issues. As I have worked with five groups over 15 sessions, I have learned to take my cues from participants and not be afraid to laugh alongside them and inject some silliness into design discussions.

Listening carefully and respecting participants for their expertise is a vital part of the participatory design process that cannot be undervalued. One way that I showed participants that I was paying attention to their efforts was bringing them notes from previous sessions. Sometimes these notes contained finalized versions of a quick mock-up created in the session, sometimes these notes were typed up versions of brainstorming sessions, and sometimes these notes were printed pictures of artifacts created by the group. When I showed how their efforts were useful, it demonstrated to the groups that I was paying attention and valuing their time and effort.

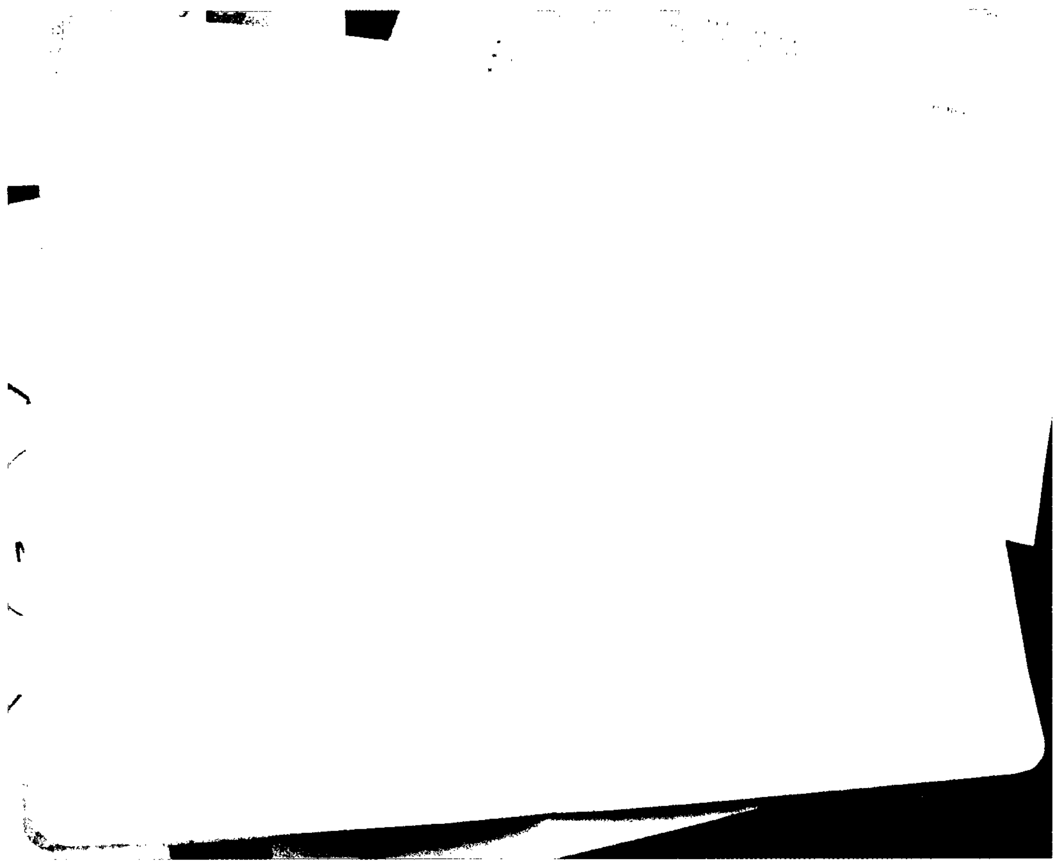


Figure 7-4: Group 3 participant's journal where she sketched her idea for the Pieces of a Whole interface.

7.2.6 Gap between PD session and implementation

Early participatory design efforts (Ehn, 1993) observed that even with a very engaged group of users, momentum is lost in the transition between a final design and a complete implementation. They worked with the users who would eventually adopt the system so participants' buy-in was important in a way that is not as applicable to my methods. However, the other issues of designing behind the scenes are consistent in my project. Even with five groups meeting for six hours each, the meeting time is not sufficient for creating a polished design in the detail needed for implementation. The goal of my participatory design effort is to engage potential users in the design process, but I have ended up doing some design work without participants. I have a substantial advantage over doing this with any other methodology because I have had the benefit of listening to and participating in the discussions the group had about the rational for design decisions and the usefulness of particular aspects of the design. I have been able to use what I

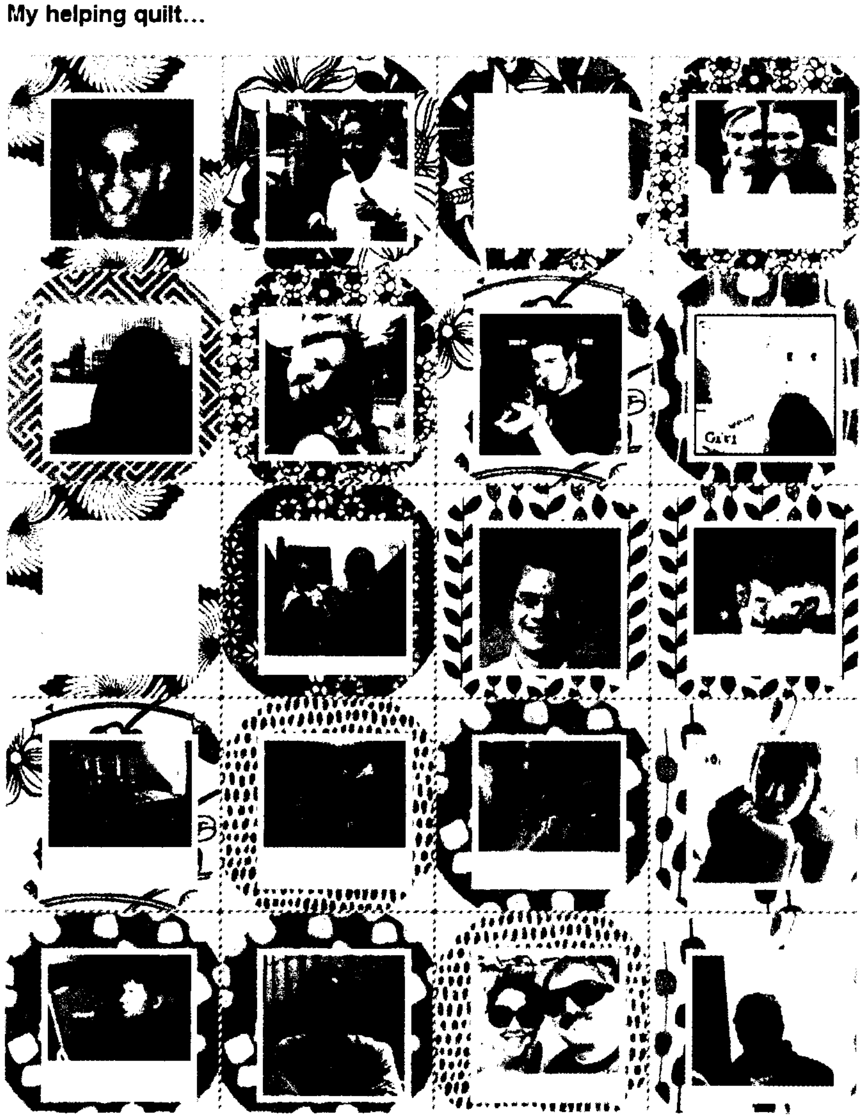


Figure 7-5: The Helping Quilt that evolved from the idea sketched in **Figure 7-4**.

learned from these discussions when new design decisions come up to ensure that I preserve the intent of the participants in the final implementation.

One example of an aspect of the interface that has changed since the initial design work with Group 3 is the "Helping Quilt". This idea originally emerged from a participant's notebook (see Figure 7-4). The idea was roughly based on giving trees and a similar activity that her church group does. When she presented her idea to the group and they discussed it, a few important aspects of the idea emerged:

- Helpers would have a tangible "piece" of some bigger whole that they are a part of
- The person being helped would feel supported by seeing all the help provided by the community
- The community would be able to see all of the help being provided by others
- All the pieces would fit together to make a larger whole
- Helping tasks and names would go on each piece

The group discussed using a wreath, cross, and a heart. During this discussion it was clear that not everyone would need the same shape, but that the larger idea of having a shape with pieces was desirable. Group three discussed in detail the intent behind this idea. For helpers, this shape would give them a tangible "thing" that they were doing, and they could have more than one piece if they were doing more than one thing. This shape would also be a way for the helpers to feel collected to the larger helping community, some of whom they might not even know. For the person getting help, this shape was not as much a way to see what was planned or would be done soon; it was more a way for them to see that many people are contributing. The intent was for the person receiving help to be able to look at a pleasing interface that would make them feel supported and cared for.

As my research group worked on implementing Group 3's ideas, we ran into technical issues of implementing the design presented for the 'pieces of a whole' visualization. The interfaces created in the group required a pre-determined number of pieces to be selected (in order to decide how big the pieces should be) and did not scale to any number of helping events. To remedy this problem, we developed a quilt metaphor for the pieces of a whole visualization. Instead of a static shape, such as a heart or cross, we use a quilt with each quilt square representing a "piece" (see Figure 7-5). I feel comfortable in this evolution because the final interface is consistent with the functionality and the values described by participants during the original design discussions.

I have used the example of the quilt because it is one of the most drastic departures I have made from the designs created in the group. In most cases, the design work I have done without participants has had more to do with usability and screen real estate. During paper prototyping with the groups, I do not place importance on working out relative font size, menu placement, or consistent messaging. These detailed issues are more appropriate for heuristic and usability evaluations farther along in the design process. Instead we spent the group time talking about larger issues of functionality and interaction. The important discussions to have with the group revolved around what the system needs to be able to do, what kinds of interactions it needs to support, and in more general terms what interface elements are important. These discussions provided me with the understanding of patients' values and priorities that I need to work on their behalf as I refine interfaces and implement their designs.

7.3 Conclusion

I have had to make substantial adaptations to the participatory design methods that originated in the workplace. Using my adapted methodology, I have successfully collaborated with breast cancer patients and survivors to create new personal health information management technology. I have created design groups requiring a small time commitment so that people in this community are able to contribute their expertise to this design process. This small time commitment is balanced against the benefit I would get from having these participants involved throughout the project. Thus, I have worked to maintain contact with participants and invite them to continue to contribute as the design progresses.

Through my experiences over course of the project, I have identified several practical lessons I hope other health-related technology design projects can benefit from. I emphasize that designers should view each person as an expert in their own way and be as flexible as possible in providing tools for each individual to express herself. I have found that both technically experienced and novice users can contribute to the design process when given the opportunity and the tools to describe their ideas. By creating a respectful, collaborative atmosphere I have learned a great deal about the realities and problems of being a breast cancer patient. Participatory design has provided both insightful designs and a greater understanding of this community of users.

Chapter 8
Conclusion

An informed social network can be a powerful force on the side of someone facing a serious illness. Friends and family help with going to doctor's appointments, making treatment decisions, figuring out how to cope with symptoms and side effects, and doing tasks patients are unable to do (such as housework, driving, or caring for a pet). All of these efforts can also contribute to the extent to which a patient feels supported. Serious illnesses are typically difficult both physically and emotionally. A diagnosis such as cancer often forces patients to make changes in their life over which they have little control. Cancer treatments necessitate changes to people's daily routines and can drastically alter their physical capabilities. Cancer also sometimes forces patients to rethink their life goals and relationships. During this intense experience, social support can come from many small gestures. A friend who brings over groceries and another who offers to mow the lawn are providing useful services; they are also showing the patient that they care.

Patients can create helpful networks by sharing information about what is happening with their health and what kind of help they need. One of the most important findings from this dissertation is that an informed network is a helpful network. In my studies of how and why people share personal health information, "getting help" was not emphasized as much as other motivations for sharing. Instead, people described sharing information because they wanted to help others in similar situations as well as sharing information because it is simply part of having a close relationship. However, sharing information leads to receiving help. Networks that lack information about a patient's health status or progress through treatment have trouble knowing how they should help or even if the patient would be comfortable accepting help. Using traditional forms of communication (e.g. telephone calls) is a very inefficient and thus very time consuming method of updating an entire social network. When patients feel sickest and need the most help, they are least able to field phone calls and reach out to ask for assistance – they simply do not have the time or energy to engage in such tasks. Even when patients have a spouse or someone else close to them, that individual is often so overwhelmed seeing to all of the patient's needs that they have trouble keeping up communicating with their network. It is a challenging cycle because the more intense the situation gets, the less they are able to communicate with the network; when the network does not have information, they do not know that help is needed.

The technology I have described in this dissertation will help distribute information to the social network. The breast cancer patients and survivors who collaborated on the design emphasized the importance of making interactions fast and simple so that exhausted patients or overwhelmed helpers have a low barrier to getting information out to the social network. These patients and survivors also contributed their knowledge, based on their experiences, about the many ways members of a social network can provide help. Future networks will be able to use their collective knowledge to figure out what a cancer patient might need, because without previous experience with cancer treatment, it is difficult to know what a cancer patient might need. This technology will arm social networks with both the information they need about what the cancer patient is experiencing and the actionable ways that they can help.

8.1 Implications for Technology Designed for Patients

I treated the participatory design process as if we were designing from scratch, with no existing technology to consider. We began by thinking about why it is useful to share information and what is difficult about getting useful help. From there, we considered what role technology should play in disseminating information and catalyzing helping. Because we started from scratch, we can be sure that the designs that we generated are rooted firmly in the experiences of breast cancer patients, survivors, and social network members. However, there is related technology to consider. The existing websites for sharing health information within a social network, in particular, are relevant to the design presented in Chapter 4 and Chapter 5.

8.1.1 Implications for the next generation of websites facilitating collaboration within social networks

In Chapter 2, I described existing technology to support personal health information sharing within social networks. Table 8-1 is a revision of Table 2-1, presented in Chapter 2, to include the technology I designed. The "Sharing by Design" column describes an overview of the functionality. I added four additional rows for functionality not found in existing systems. Three of the existing systems (theStatus, CarePages, and Caring Bridge) share some duplicate functionality with the technology I designed. Lotsa Helping Hands also shares substantial similarities. This overlap is not entirely surprising because I worked with cancer patients to create our technology and these other systems were also developed by friends and family based on their own personal needs. The similarities between these systems indicate that the shared functionality is important and lend support to the case that this technology is needed.

While there are striking similarities between Lotsa Helping Hands and the technology I designed, there are features that Lotsa Helping Hands does not currently offer. Similar to my design, the Lotsa Helping Hands system is designed both to keep the social network informed and to coordinate help within the social network. Both systems enable the patient, or someone working on behalf of the patient, to ask for help by creating help requests with dates, times, and descriptions of the help needed. However, the interface for asking for help in my design is based on an important insight from the participatory design sessions: patients might not know what to ask for and might not ask for anything if faced with an empty text box. Based on this insight, we created an interface with a long list of ways the social network can help and even provided sample text for each help request that a patient could tailor to their circumstance. Lotsa Helping Hands has a few categories of help (Giving rides, Preparing Meals, Shopping, Childcare, Visit, Coverage, Miscellaneous), but their list is not as extensive as the one generated by my design groups.

In my design, the same interface that is used to ask for help can also be used by members of the social network to offer help. Other systems do not include a mechanism for offering help, but this important functionality serves two purposes:

1. Members of the social network might not be familiar with the cancer experience and this interface provides many examples of ways to help, based on the experiences of real cancer patients and survivors.
2. We know that cancer patients can be reluctant to ask for help, even when they need it. Allowing members of the social network to offer help allows them to do more than simply say, "let me know if you need anything." Instead they are offering specific actions. Even if the cancer patient ends up wanting them to do something slightly different, this specific offer will signal to the cancer patient that her network would like to help. Hopefully, these offers will encourage the patient to give her network useful ways they can help.

Also related to helping features, the other systems lack an equivalent of the Helping Quilt. The purpose of the quilt is to show all the helping activity within a patient's network. Every time an individual helping event occurs, a square is added to the quilt with a picture of the person who helped. This feature gives the patient a tangible representation of all the support they are receiving. It also gives people in the patient's network the opportunity both to see what others are doing to help and to see that they are playing a role in a larger effort to help. Another function of the quilt is to provide automated acknowledgements. Patients often want to thank people who provide help, but this adds yet another task. The automated acknowledgment of being added to the helping quilt, and having an announcement posted on the patient's homepage, will give patients the peace of mind that the help they appreciate did not go unacknowledged.

A final piece of functionality that is not present in the other systems is the list of "things I care about." This will serve as a reminder to both the patient and members of the social network that life does not have to be entirely focused on cancer. Patients can list goals or people who are important to them or they can list activities that they enjoy. Lotsa Helping Hands has a related feature where a patient can list their favorite things (e.g. favorite food, favorite flowers, and favorite activities). This personalization effort seems like a good idea because it allows the social network to tailor the help they provide to the patient. For example, if they want to bring over meals they can use the list of favorite foods to choose a menu. If they want to suggest taking the patient out for an activity, they might draw inspiration from the list of favorite activities. I propose that some combination of these two ideas is a useful path to take. Patients should be able to list high level "things I care about" and should also be able to list things they like in the specific categories provided by Lotsa Helping Hands. People in the social network can use this additional information to appropriately tailor offers of help.

One piece of collaborative functionality that appears in both my design and Lotsa Helping Hands is the discussion list. However, the implementation of these features is different. Lotsa Helping Hands has a forum-style discussion functionality where anyone can start a discussion and others can participant. In my design, discussions are attached to objects, such as help requests or offers. They provide a chance for asking questions, providing clarifications, and recording important information for other helpers. Helpers can use this features to collaborate among themselves in

Table 8-1: Functionality of existing information sharing technology for health consumers.

	HealthVault	Google Health	theStatus	CarePages	Caring Bridge	Lotsa Helping Hands	Sharing by Design
Keep and manage health Information	Yes	Yes					
Share information (all or none)	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Share information selectively	Yes						Yes
Give selective write access of health information	Yes						Yes
Collaborate through discussions						Yes	Yes
Share health related & helping calendar						Yes	Yes
Share caregiving information	Some					Yes	Yes
Post updates to your network			Yes	Yes	Yes	Yes	Yes
Share status updates							Yes
Ask for help						Yes	Yes
Get offers of help							Yes
Visualization of all the help provided							Yes
Automatic acknowledgements to helpers							Yes
Sharing photo albums			Yes	Yes	Yes	Yes	Yes
Share background information & resources			Yes	Text	Text	Links	Yes
Well wishes from social network			Yes	Yes	Yes	Yes	Yes
Favorite things (e.g. food, flowers, activities)						Yes	
Reminder of things I care about							Yes

organize helping activities. It is possible that both types of discussions would be useful; discussions outside of the context of a specific object could enable different types of conversations and collaborations.

8.1.2 Implications for the next generation of PHRs

I have described the similarities and differences between existing websites for sharing health information within a social network and the design I describe in Chapter 4 and Chapter 5. Table 8-1 also compares these systems to the two existing PHRs that provide sharing features. Most PHRs have been designed with the model that one personal health record will be used by one person. However, this model is inconsistent with my findings from two studies of how people share personal health information (described in Chapter 3). Even information that is usually found in a medical record was shared within social networks. This finding suggests that more than one person might use an individual's PHR. For example, a spouse who attends every doctor's appointment and keeps careful notes might also want access to lab results stored in a PHR. Patients should have the ability to grant access to their records to others and to make decisions about what information is available to others. Two PHRs do allow some sharing. Google Health's sharing features either provide access to a whole record or no access at all. Health Vault provides the ability to share an entire record or just select portions of a record. Like Health Vault, the my design also has fine grained access controls. These access controls will work on health information posted by patients, but will also work on other content (e.g. asking for help, posting pictures). Lotsa Helping Hands does not have this feature, but it was important to the design groups. Just as some information is best shared with only a few people, some requests for help are best shared with only a few people. For example, after surgery it can be useful to have help bathing without getting the surgery site wet. Very personal tasks such as this might not be the type of help a patient is comfortable receiving from just anyone, so she might want to post that particular help request to just a few close friends.

Today, a functionality disconnect exists between PHRs and the websites designed to support sharing and collaboration within social networks. This disconnect appears to be a factor of who created each type of system and not a reflection of patient needs. Neither type of technology contains the full suite of functionality patients need. Going forward, I advocate that PHRs should include sharing features and move away from the incorrect model that one person will use their record alone. I also advocate that PHRs expand to support patients who want to maintain an informed social network. Taking a patient-centered look at this technology, I see no firm line between the personal information management that people do on their own and the collaboration that takes place with their social network. These two activities intertwine as members of the social network often receive and act on information traditionally kept in a personal health record. I am not advocating that everyone in a social network be given access to health records; I am advocating that patients have the ability to choose who has access to their information. Some patients will choose to keep their health record entirely private while others will share it with their entire family; the choice is theirs.

Advocating that patients be allowed to make the choice to share personal health information within their social networks comes with the responsibility of considering the risks that accompany electronic information sharing. For patients to be the ones making the decisions about what information is shared and what is hidden, we must have secure and private systems that put the controls in patient's hands. To achieve patient control of their privacy, we need interfaces that make it clear to users what information will be shared and with whom it will be shared. My advocacy that these sharing features be enabled immediately is tempered somewhat with the exceedingly practical problem of creating usable sharing and privacy controls. I present a way to embed icons into interfaces so that users can see how each piece of information in the interface is being shared. This approach allows for the fluid changes in preferences and social networks that patients often experience. These icons will also make sharing more continually visible than the traditional approach of using a control panel to set preferences once and then forget them. However, the icons embedded in the interface only present an overview of how each piece of information is shared. Coupled with these icons, there must be a way to get more information about who exactly can see each piece of information. I tested two such interfaces and the results raised difficult questions about what level of accuracy is required for a sharing interface to be considered safe to use. Is it acceptable for participants to make any errors that could result in unintentional sharing of personal health information online?

Security and privacy features must be well designed and thoroughly tested to prevent unintentional sharing of health information. One of the contributions of my work is a systematic way to design and study how transparency sharing and privacy features are. I have pulled apart the concept of usable privacy to include transparency, a user's ability to understand what the system is doing with their information, and ease of use, a user's ability to make changes to what the system is doing with their information. This approach allows us to measure both how well users understanding the sharing settings and measure their ability to use the system. Creating a transparent mechanism for showing sharing controls to patients will be a substantial challenge. I have identified a transparent icon that can be embedded on all shared objects, but more work remains to be done. Providing functionality to support sharing personal health information has the important benefits of creating informed social networks and enabling those networks to be more helpful. These benefits make it worthwhile to take on the challenge and pursue the goal of entirely transparent and usable sharing features.

8.2 Implications for Designing with Patients

The patients and survivors involved in participatory design aspects of this research have contributed substantially to both my understanding of the underlying needs of patients and to the design of the technology I described in Chapters 4 and Chapter 5. They were thoughtful, creative, and eager to share their experiences in the hopes of helping future patients. The community of patients and survivors is an untapped resource that designers of health information technology should use to their advantage. We have long known that designing technology without a firm understanding of users is a mistake, but through my dissertation work, I have shown that we can go farther than just understanding users –we can include their voices directly in the design process. Giving users a voice in the design process has many benefits. For example, they can help make sure the technology is appropriate for the setting where it can be most useful, they can help ensure that the design priorities match the needs of patients, and they can think creatively about how new technology will fit with, or change, existing practices.

I have identified ways to adapt participatory design methods, originally used in workplaces, to work within the constraints of the health domain. I found ways to limit the level of involvement required of each patient in order to enable busy, and sometimes overwhelmed, patients to participate meaningfully in the design process. During the design work I identified the importance of remaining flexible and of working with patients to help them find ways to express their ideas. In Chapter 7, I describe several practical lessons about how to work with patients to do design. I hope these lessons will enable other technology projects in the health domain to incorporate user involvement during the early stages of design work. Finding ways to involve users with busy schedules and challenging health circumstances is not easy, but the payoffs more than make up for the effort required.

8.3 Limitations & Future Work

My dissertation reflects years of work studying sharing and collaboration within the social networks of patients, yet there are still many unanswered questions. Some of my research was conducted with people with a wide variety of health concerns, while the design work was carried out with a narrower population of breast cancer patients and survivors. I saw similar themes, challenges, and needs that did not correspond closely to diagnosis. However, I do believe that there are differences in need based on the severity of someone's illness and the length of their treatment. During the final lab study, I spoke with one man whose entire prostate cancer experience lasted one month in which he was diagnosed and had surgery. His needs for help and support were much different than one of the women in the second participatory design group who had been nearly continuously in cancer treatment for seven years. An important area of future research is exploring the differences in need based on different patient populations and identify how technology might need to be adapted to support different needs.

One important distinction that emerged in my research, but is not fully explored, is between localized and metastatic cancer. People with localized, or even regional, diagnosis usually experience shorter treatment and have a much higher survival rate. Recurrences and metastatic diagnoses usually involve much longer treatment periods and carry the threat of a lower survival rate. What happens when someone needs help from their social network for 7 years instead of 7 months? What happens when the news keeps getting worse? While much previous work has studied caregivers' burden and fatigue, this fatigue might also apply to larger social networks. In the past, close family or friends have been the most burdened by a serious and lasting illness, but if we are able to spread that burden to the entire network, it changes that dynamic. I hope we will be lessening the burden and fatigue experienced by any one person, but another possibility is that more distant friends and family will not be willing or able to maintain the burden (physical and emotional) of being involved for longer periods of time. Our largest design concern was catalyzing social support, but an important remaining issue we have not addressed is sustaining social support. Patients described trying to balance the burden they placed on people by not asking the same person for help repeatedly. Sustaining social support is an issue we and other groups should consider within systems to support longer term helping.

Another potentially difficult issue is that this research is based on the premise that contact with the social network and help from the social network are good and will boost patients' feelings of social support. However, we know from previous research that breast cancer patients, especially younger patients (<50), experience changes and evolution in their social network (Ashida, Palmquist, Basen-Engquist, Singletary, & Koehly, 2009). Younger breast cancer patients showed a correlation between decreasing their network size, over a six month period, and experiencing fewer mood disturbances. The researchers conclude that, "Reducing the number of network members after cancer diagnosis may not necessarily lead to psychological distress, providing support for self-regulation of social network resources among cancer patients." They found that patients might benefit most from "identifying important network members and facilitating positive social interactions between these network members and patients." In my own research, people described becoming much closer to some members of their network and moving away from others. These changes in network size and composition have implications for the technology I designed. Using technology to share information requires codifying exactly who can see each piece of information. Making decisions about who can see what information might bring to the forefront issues of who is "in" and who is "out" in a way that might be less apparent in the offline world. Members of the social network will not necessarily be aware that their permissions are being cut off, but this approach will force the patients to be quite aware of the sharing decisions they are making. This technology will enable patients to maintain awareness of their situation within a larger network. I suggest that these controls will facilitate helping and improve feelings of social support, but we will not be sure of this effect without studying it.

Studying the use and usefulness of the system I designed will be the next important step. Specifically, I advocate a longitudinal field study that will show how people use the system within their existing social networks. This sort of evaluation was outside the scope of my dissertation, but is the logical follow-on to this research. Here, I highlight several important issues a study like this could address. One unknown is how many people a patient will invite to have access to the system. In the design sessions, people envisioned inviting a few dozen people, but we know that with other social networking software, people have much larger networks. The size of the network has practical implications for interface design and might also influence how the system is used. A study could also reveal more about the types of help for which cancer patients ask, a social networks offers, and how over time helping offers and requests change. A final important metric for such a study will be to determine what effect, if any, using the system has on feelings of social support. A longitudinal study could also shed light on important differences between communicating via traditional means and sharing via computing technology. For example, health information can elicit strong emotional responses and there might be both drawbacks and benefits of spreading such information through technology instead of in person. One of the reasons people were reluctant to share bad news is that they did not want to upset others –does technology have any impact on this? Discovering the amount of helping that happens within a social network using a system like ours might also have implications for future designs. My intuition is that for most cancer patients there will be a fairly small number of "helping events" that would take place every week (1-3), but that this small number would make a large difference in their perception of how much help and support they receive.

A final limitation of this work that should be explored further is potential gender differences in how people want to share information and collaborate within their social networks. The design work with breast cancer patients and survivors included only women, which is a realistic representation of that population. The interviews, questionnaires, and lab study also included more women than men, although we recruited both men and women. An important future research goal should be to examine whether there are important gender differences that affect how people share information within their social network. My interview data showed more individual differences among preferences for interacting with social networks than gender-based differences, but that is a small sample and more research is needed. A longitudinal study of this work should consider both the gender of the patient and the gender of helpers.

8.4 Contributions

My research contributes a deep understanding of how people share health information within social networks and how social networks collaborate to help someone facing a health problem. These insights were gained through a mixed methods approach including qualitative and quantitative studies, as well as collaborative design work. For all the investment in electronic health records and the push towards personal health records, relatively little was known about how people will use those records, including who will use those records. My findings show that some people share a great deal of personal health information within their social networks and my findings challenge the model that a personal health record will be used by a patient alone. Further, my research has shown the valuable role an informed social network can play in a patient's experience. An informed network is better positioned to provide help and support. I observed a great deal of interest in helping, but substantial barriers on both the side of the patient and the social network stand in the way of helping activities. Patients who need help often do not know who to ask or for what to ask. Social networks who want to help are unsure what they can do and how to approach the patient about helping.

In addition to providing insight into existing practices and problems, I also designed technology to address these needs. By working with cancer patients and survivors, I have ensured that my designs are rooted in a firm understanding of the environments in which patients operate, the challenges patients face, and the constraints of illness on an individual's ability to use the system. My technology is designed to help create an informed social network, catalyze social support, coordinate helping activities, and foster collaboration within the social network. It provides new functionality, not found in existing systems, as well as affirming the need for functionality already present in other systems. My design also includes new interfaces for existing functionality that are based on design rationales developed by patients and survivors.

I have also identified ways to integrate sharing and privacy features throughout an interface instead of relegating them to one large control panel. Integrating this information will help remind patients of how information is being shared and enable them to change those settings in context as their preferences evolve over time. Evaluating both the transparency and usability of these interfaces revealed understandable icons that can be integrated throughout an interface. The evaluation also raised challenging questions about how well an interface must perform before it should be released for public use. The risk of unintentionally sharing personal health information is high and designing interfaces that entirely prevent unintentional sharing remains an important challenge. My method for evaluating both how well people understanding sharing settings and how usable those settings are can be applied to evaluate future designs.

My research also contributes to the methodologies available to people designing health information technology. It is challenging to find ways to incorporate users in this domain, but I have identified ways to adapt participatory design to enable patients to lend their voices and experiences to the design process. I advocate creating a balance between limiting the required time commitment to participate, thus allowing more people to participate, and still engaging in a deep enough way that patients can dig into the problem and collaborate on solutions. I have also described the importance of allowing patients the opportunity to express their design ideas in a variety of ways. Also, by listening carefully to patients' design ideas we can learn more about the problems they would like to solve and the context in which they experience these problems. The rationales patients provide for their design ideas are a wonderful source for getting insight into their experiences. Our field will benefit greatly from using the expertise of patients in the design of technology to support future patients; patients have thoughtful and creative insights to contribute.

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VITA

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Appendix A
Semi-Structured Interview Guides

A.1 Interview Guide: Patient

I'm interested in understanding how people share health information about themselves with the people around them. So I want to know what kinds of things people share and who they share it with. I'm interested in this because electronic tools are being designed for people to try to facilitate this, but we don't know much about what people do or what people want to do.

Can you briefly describe your health situation? How long ago it started, etc.

What health information do you share? Do you wish it was more? Or less?

Who do you share it with?

Are there people you talk to or email with, about your cancer/heart disease? Family, friends?

I'm interested in the kinds of information you share with different people. So can you tell me about who you talk to the most and what you tell them about? And then who else do you talk to about health stuff?

How well does what you just described work?

Are there people you talk to who don't know much at all, or anything, about your health stuff?

Would you prefer to have more communication or less with these people?

How do you decide what and how to share with different people?

Do you share different kinds or amounts of information with different people?

What do you think influences how much you talk to someone about health stuff?

Why do you share it?

I'm also interested in why people share health information with specific other people, so what motivates you to talk to different people. Why have you chosen to talk to [the person they talk to a lot that they told me about] about your health stuff? So is that the same reason you talk to or tell other people or are there different reasons?

How do you share it?

So we've gone through who you talk to about your health, now I'm also interested in how you share that information. By that I mean, does all this happen in person? Or on the phone, or by email? Do you show them papers? That kind of thing.

What works well and what is difficult about the current process?

What are the most difficult parts about sharing your information?

What's the most frustrating part of what you just described? What part of what you've been talking about works the best for you?

What do you think of a web-based tool? What would you want?

Do you ever use the Internet?

Some people have suggested website-based tools to help people keep family and friends informed and distribute information [or maybe even coordinate rides]. What do you think about that idea?

What comes to mind as the disadvantage of that kind of approach?

What seems like the best part of that idea?

What would you need it to do in order for it to be useful? How would it need to work?

That's all I've got, Is there anything else you can think of that I should know?

A.2 Interview Guide: Family or Friend

I'm interested in understanding how people share health information about themselves with the people around them and how the people around them use that information. So I want to know what kinds of things people share and who they share it with. I'm interested in this because electronic tools are being designed for people to try to facilitate this, but we don't know much about what people do or what people want to do.

Can you briefly describe your [husband's/friend's/etc.] health situation? How long ago it started, etc. And how long have you known her/him?

What health information do you get? Do you wish it was more? Or less?

So how often do you talk to them about things related to their health? What kinds of things do you discuss?

How well does this process work?

Do you feel like you get all the information you want?

So do you ever wish she/he would tell you more about what's going on?

Do you ever feel overwhelmed by being this involved?

Do you ever wish you heard less about her/his health? Is that all the time, or once in a while?

Why do they give you information?

I'm also interested in why people share health information with other people. So what do you think motivates her/him to talk to you about her health?

Do they also give information?

Do you ever give her/him new information? What kind of information do you give them?

[Do you/]Why do you want information?

And then, what motivates you… Why is it important to you to keep up with what's going on?

How (by what means) do you share information?

So we've gone through how much health related information you hear, now I'm also interested in how you share information. By that I mean, does all this happen in person? Or on the phone, or by email? Do you show them papers? That kind of thing.

Is it the same for when they give you information and when you give them information?

What works well and what is difficult about the current process?

What's the most frustrating part of what you just described?

What part of this exchange you've been talking about works the best for you?

What do you think of a web-based tool? What would you want?

Do you use the Internet?

Some people have suggested website-based tools to help people keep family and friends informed and distribute information [or maybe even coordinate rides]. What do you think about that idea?

What would you need it to do in order for it to be useful? How would it need to work?

What comes to mind as the disadvantage of that kind of approach?

What seems like the best part of that idea?

That's all I've got; is there anything else you can think of that I should know?

Appendix B
Online Survey Questionnaire

This anonymous online survey was created using Catalyst WebQ.

Health Information Sharing

We are inviting you to complete a short questionnaire about sharing personal health information as part of a research study at the University of Washington. This page is to help you weigh the risks and benefits and decide whether you would like to participate.

PURPOSE AND BENEFITS
This study is intended to help us understand how you share personal health information with others. We want to understand what kinds of health information you share, who you share it with, and why you share it. Your responses will inform our research on how health consumers use and share health information. We hope this work will contribute to creating better tools for managing health information.

STUDY PROCEDURES
You must be 18 or over to complete this survey. You will be asked to complete a self-administered electronic questionnaire. We estimate the questionnaire will take approximately 15 minutes. It is helpful for us if you complete the entire questionnaire, but you are free to leave any questions blank.

CONFIDENTIALITY
All study information is anonymous. We will not be collecting your name or any other personal identifiers. The survey software that we are using will automatically assign a numeric code that we will use internally to identify your responses. We will ask you to identify your age, gender and occupation so we can describe our participants and determine the generalizability of our results.

RISKS TO PARTICIPATION
Since the study is anonymous we do not anticipate any risks to privacy. There may be some risk of stress or anxiety since we will ask you to think about past health events. We will ask you to summarize your health history and will ask questions about what kinds of health information you share, who you share health information with, and how you make decisions about sharing.

OTHER INFORMATION
We will make a $5 donation to the Red Cross for each participant up to $250. The donation will be made at the end of the study and we will not be able to send participants any confirmation of the donation because we are not collecting any names or contact information.

Participation in the study is completely voluntary. Your consent to the above procedures will be implied at the time that you submit your responses. If you have any further questions, please contact the research coordinator, Meredith Skeels, at (206)616-4626 or mskeels@u.washington.edu. We cannot ensure the confidentiality of information sent via e-mail. Thank you very much for your participation.

Please only complete this survey once

Question 1.

Age

○ 18-29

○ 30-39

○ 40-49

○ 50-59

○ 60-69

○ 70-79

○ 80-89

○ 90+

Question 2.

Gender

○ Female

○ Male

○ Transgender

Question 3.

List your occupation(s):

Question 4.

To provide us with some background information, please briefly describe health conditions or injuries you have experienced.

Examples might be arthritis, cancer, broken bones, pregnancy complications, or tonsillitis.

Question 5.

Have you had a life threatening health condition or injury?

○ Yes

○ No

On this page we will ask what health information you have shared with different people. Please think of the most serious health condition or injury you have had. This could be something as serious as cancer or diabetes, or could be something like a sprained ankle or the flu.

Question 6.

What is the most serious health condition or injury you have experienced?

When you fill out the grid below please think about the situation above and what kinds of information you shared in that situation.

The grid lists different people across the top and different types of information you may have shared or received down the side. Please start by going across the first row and think of someone you know who fits in each category. If there is no one who fits in a category please check "N/A" and leave that column blank in the future.

For each type of information please go across and check the box for each person you shared that information with. If you did not have a particular type of information please check N/A (for not applicable) next to that type of information and leave the rest of that row blank.

Question 7.

Did you ever tell anyone about the following?

	N/A (did not have that information)	Spouse or Partner	Close family	Distant family	Close friend	Friend	Manager	Co-worker	Acquaintance	Someone you only know online
N/A (no one fits this category)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Diagnosis (what you have or what is wrong)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Treatments (such as prescriptions, procedures, therapies, etc.)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Symptoms you experienced	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Side effects from treatments	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

	N/A (did not have that information)	Spouse or Partner	Close family	Distant family	Close friend	Friend	Manager	Co-worker	Acquaintance	Someone you only know online
Likely long term impact(s) of the condition or injury	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Your experiences with doctors or other care providers	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Information you got from the clinic	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Notes you took during a clinical visit	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Records you kept about your health	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

	N/A (did not have that information)	Spouse or Partner	Close family	Distant family	Close friend	Friend	Manager	Co-worker	Acquaintance	Someone you only know online
Information you found (such as webpages, books, articles, etc.)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Payment, billing, or insurance information	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Advice for someone else	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Appointment and scheduling information	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Kinds of help you would appreciate receiving	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

	N/A (did not have that information)	Spouse or Partner	Close family	Distant family	Close friend	Friend	Manager	Co-worker	Acquaintance	Someone you only know online
Records from a clinic (such as medical records, x-rays, etc.)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Question 8.

Did you ever receive the following?

	N/A (did not have that information)	Spouse or Partner	Close family	Distant family	Close friend	Friend	Manager	Co-worker	Acquaintance	Someone you only know online
N/A (no one fits this category)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Advice	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
References to information resources	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Reference to doctors or clinics	☐	☐	☐	☐	☐	☑	☐	☐	☐	☐
Reference to someone who has been through a similar experience	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Encouragement, support, or sympathy	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

	N/A (did not have that information)	Spouse or Partner	Close family	Distant family	Close friend	Friend	Manager	Co-worker	Acquaintance	Someone you only know online
Stories about others' experiences that related to your own	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Offers to help (such as rides, prescription refills, housekeeping, etc.)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

On this page please think about sharing health information in general (not just about the condition you thought of on the last page).

We are interested in what factors influence decisions about sharing health information. Please select whether the following factors encourage, discourage, or have no influence on your decisions about sharing health information with other people.

Please select N/A (for non-applicable) if a factor hasn't ever applied to you. For example, if you have never been worried or concerned about a health situation then select N/A for "Being stressed out, worried, or concerned about a health situation."

Question 9.

	Encourages sharing	Discourages sharing	Does not influence sharing	N/A (does not apply)
Being stressed out, worried, or concerned about a health situation	○	○	○	○
Interacting in a public location	○	○	○	○
Trusting and being close to someone	○	○	○	○
Interacting frequently with someone	○	○	○	○
Someone having experience with similar health situations	○	○	○	○
Someone being a health professional (but not one treating you)	○	○	○	○
Someone seeming interested in your health	○	○	○	○

	Encourages sharing	Discourages sharing	Does not influence sharing	N/A (does not apply)
A desire to maintain your privacy	○	○	○	○
The condition being noticeable by others	○	○	○	○
The condition requiring you to adapt you lifestyle (for example change your schedule, behavior, etc.)	○	○	○	○
The condition affecting a personal area of your body	○	○	○	○
Being concerned you may be blamed for the condition	○	○	○	○
Knowing information about your health may be passed on to others	○	○	○	○

Question 10.

Are there other factors that influence whether you share health information with someone? Please describe them below.

Question 11.

Have you offered health advice to someone based on your own health experiences?

☐ yes

☐ no

Question 12.

How valuable it is for you to offer health advice to others based on your own health experiences?

☐ not at all valuable

☐ somewhat valuable

☐ extremely valuable

Question 13.

Have you obtained health advice from someone who has been through a similar health experience?

☐ yes

☐ no

Question 14.

How valuable is health advice from others who have experienced health situations similar to your own?

☐ not at all valuable

☐ somewhat valuable

☐ extremely valuable

Question 15.

When you have shared health information or talked to someone about your health, how often did you share for the following reasons?

	Never	Sometimes	Frequently
Getting Support or Sympathy	☐	☐	☐
Getting Help (such as rides, help around the house, prescription refills, etc.)	☐	☐	☐
Wanting to hear about someone else's experiences	☐	☐	☐
Helping someone else	☐	☐	☐
Talking through it with someone	☐	☐	☐
Alleviating anxiety	☐	☐	☐
Updating people about what's happening so they'll know	☐	☐	☐

Question 16.

How have you shared health information with your social network (anyone besides your health care providers)? (check all that apply)

☐ Talking in person

☐ Talking on the phone

☐ Emailing

☐ Giving out links to information online

☐ Instant messaging or chatting online

☐ Giving others physical documents (photocopies, brochures, etc.)

☐ Showing others physical documents

☐ Sending information through the mail

☐ Faxing information

Appendix C

Scenarios

Sally

Sally and her husband, Dan, have been able to spend more time together now that they are retired and they enjoy traveling in their RV to visit friends around the Northwest. After her last annual mammogram Sally's doctor asked her to come back for a needle biopsy, which indicated that Sally had breast cancer. Sally went in for surgery three weeks later and followed that with radiation. Now she is doing hormone therapy.

Throughout her treatment, her husband has accompanied her to doctors' appointments and treatments. Sally appreciates the support and also found that having another set of eyes and ears makes remembering details of the appointment easier. After her first few doctor's appointments, Sally and Dan had developed a system for preparing for appointments. In the week(s) leading up to the appointment, they both kept track of their questions –Sally types hers on the computer and jots them on whatever note paper is handy, and Dan keeps his list on a notepad he has always carries in his pocket. Some of these questions come from researching breast cancer online, some come out of conversations with others, and some are questions that just come to mind during day-to-day tasks. Before an appointment Sally and Dan sit down together and go through their list of questions and consolidated them into one semi-prioritized list (there is never time to get to all of them during an appointment). At the doctor's office their list helps them make sure they remember their questions because during the appointment it's easy to get side tracked and forget something important. During the appointment, Sally's husband also helps by taking notes and they always talk about the appointment afterwards in the car.

Demographics:
Older, Retired

Social Network:
Married, local brother

Health:
Surgery, Radiation, Hormone Therapy

Themes:
Valuable to have someone else come to an appointment

Appointment preparation
- thinking ahead of time
- making a question list

Collaborating on a question list

Appointment environment challenging
- easy to forget things
- difficult to remember or record what happened

Learning from others' experiences

Knowing what to expect is valuable, but difficult

Talking through it is valuable
- make sense of it
- get a second person's opinion

Sally and Dan have learned a lot about breast cancer in the past months, but they have also drawn on what they learned from watching friends and family go through cancer treatments. Sally's older brother was treated for colon cancer several years ago and since her diagnosis they've talked about his experiences and she's gotten advice on what will happen next. She found these conversations helpful because she learned about what to expect, for example, she knew that her radiation treatments might make her tired and that she should be sure to pay careful attention when they told her how to take care of her skin. She has also appreciated being able to talk through her treatment decisions with her brother and husband because it helps her make sense of everything and make plans for the future.

Demographics:
Younger-Middleaged, Works part time

Social Network:
Single, young children at home, extended family lives out of town

Health:
Chemotherapy

Themes:
Difficult to balance work, life, and cancer

Sharing information leads to offers of help

No knowing people want to help

People are often happy to be able to do something helpful

Social networks spread information

An informed network can offer help

Offers of help and other inquiries help patients know their network cares

Dispursed social network can help in different ways

Difficult to help from afar

Patients receive phone calls and email inqueries

Helen

Helen has two sons in elementary school and is trying to balance part time work in real estate and taking care of her boys after school. She recently started cancer treatment and it is difficult to maintain all of her responsibilities while also adding doctors appointments and chemotherapy treatments.

At her son's soccer game another Mom, Sherry, asked about how she's doing and they talked about her treatments and how she is having to take time off work because she is not feeling that well for the two days following the chemotherapy and is getting more and more tired. Sherry asked if she could help out by taking the boys after school on Wednesday when she gets her chemo infusion. Helen was surprised by this offer and after thinking about it felt relieved to have some help in the afternoons. Sherry was very happy to be able to do something to help and suggested that for the next few Wednesdays the boys take the bus to her house after school and she would bring them home after dinner and could bring Helen some leftovers if she was interested. Sherry also talked to a Dad on the team, a mutual friend, about Helen's treatments and how it sounded like she could use some help. This Dad emailed Helen to ask if he could help by taking the boys on Thursday afternoons and then taking them to soccer practice with his kids. Helen was again surprised by this, but was touched that her friends wanted to help out and accepted the offer since her doctor told her that her chemo side effects would probably continue to get worse as treatments progressed.

Helen also received offers of help from her family, but most of them live far away and were not able to help with everyday things like child care or help around the house. They often call and email to inquire about her health and let her know that they are thinking of her. When she found out she would for sure need chemo her sister sent a care package with a book of crossword puzzles, a novel, and a scarf.

Rebecca

Rebecca is a paralegal at a law firm and shows golden retrievers as a hobby. She has a large social network of friends from her dog shows and has lived in the same city her whole life except when she went away to college. She had a lumpectomy for breast cancer they caught early several years ago, but recently her mammogram showed what could be a recurrence. She has consulted with the surgeon she went to for her first surgery and he wants to perform a mastectomy this time and said she could consider a double mastectomy. She is upset about the recurrence and had some miscommunications with this surgeon last time, so she would like to get a second opinion.

After her troubling mammogram she confided in her best friend about her fears of recurrence and her discomfort with her surgeon from last time. On top of all this, she said, work has also been busy and she has travel scheduled for several weekends in a row to go to dog shows. She tells her friend she feels silly thinking about the impact that getting surgery will have on her upcoming dog shows and work schedule when she's facing something as serious as a cancer recurrence, but at the same time her dogs are important to her and she can't afford to take any time off work right now. When her friend asks if there is something she can do Rebecca asks if she knows of any good surgeons. Her friend can tell that Rebecca is somewhat overwhelmed, so she takes on the task of finding a surgeon for a second opinion. She looks for other breast surgeons in their area and also asks a friend who has breast cancer about how she liked her surgeon. After making the list, Rebecca's friend told her about what she'd found and encouraged her to call and make an appointment for a second opinion with a different surgeon. Rebecca ended up having a mastectomy with one of the surgeons from the list who she felt more comfortable with.

One of her dog show friends told her a story about an older woman who had surgery for breast cancer and couldn't show her own dog anymore. This conversation prompted Rebecca to talk to her surgeon about concerns that her surgery would impact her ability to take care of a show her dogs. She was somewhat reassured after they talked about some rehabilitation exercises she could do after her mastectomy and discussed the possibility of working with a physical therapist if necessary.

Demographics:
Middleaged, Works full time, physically demanding hobby

Social Network:
Single, large local social network

Health:
Recurrence, considering surgical options

Themes:
Fear

Physician-patient relationship can be difficult/unomfortable

Balancing work, life, and cancer

Financial concerns

Feeling overwhelmed

Social network can help find information

Learning from others' experiences

Important to ask questions and bring up concerns

Collaborating with clinician to problem-solve

Sara

Sara is an older woman who lives with her adult daughter's family. She helps take care of her younger grandchildren after school and has a close relationship with her two teenage granddaughters. She recently had a cancer recurrence after having a double mastectomy a few years ago. She is going through chemo and making decisions about her next step.

Her daughter has gone with her to almost all of her doctors appointments and one of her granddaughters drives her to chemotherapy. She is very open about her treatments and wants her family to know what is happening and wants them to be involved in her care. She thinks that communicating about her health with her family is part of being a close family. She is also concerned that they know enough about her health that if for some reason she got to the point where they needed to make decisions for her they would be able to make good decisions. She has a good friend with Alzheimer's and watching her progression has made Sara more conscious about the possibility of mental decline.

Although she wants her family to have lots of information, she is sometimes concerned about not overloading her younger grandchildren and she is concerned about worrying or burdening her teenage granddaughters. As a result, she sometimes withholds details from them that she tells her daughter and son-in-law, but when the children ask questions she tries to answer them honestly. Her daughter and her son-in-law are up to date on everything that's happening with her health and the three of them collaborate closely. They interpret test results together and throughout her treatment have been working

Demographics:
Older, caring for grandchildren

Social Network:
Single, lives with family

Health:
Recurrence, advanced stage, Chemotherapy

Themes:

Valuable to have someone else come to an appointment

Getting rides

Sharing health information because it is part of being a close to someone

Sharing information in case others need to make decisions for her

Concerns about planning for others to take care of patient if necessary

Nor wanting to share more inforamtion than someone can handle

Not wanting to be a burden or cause worry

Difficult to know how much to tell someone, especially children

Collaborating with social network to understand health

Planning – Knowing what to expect is valuable, but difficult

Balancing work (taking care of kids), life, and cancer

Social network can help find information

Seeking experts within the social network for help (e.g. radiologist) together to plan for the next steps. For example, Shara has been less able to help with the grandchildren since she started chemo and the family has made special arrangements to change their work schedules and get help from other family members. Between the three of them they have done a lot of reading online and in books and gathering articles about breast cancer treatment options. Her son-in-law even took her pathology report to a radiologist he went to high school with, and now plays softball with, to ask about some of the terminology they were confused about after she and her daughter went to an appointment with her oncologist.

Holly

Holly is 58 year old architect. She was diagnosed with breast cancer and had a mastectomy and then chemo last year. For several years she has been part of a book group with women from her neighborhood. After her diagnosis and during her treatment she told her book group members about her breast cancer. They are close friends and she wanted them to know that she might need to lay low for a while and might lose her hair. Many of them expressed interest in supporting her and did things to help out, like delivering meals and coming over to entertain her for the afternoon when she didn't feel well enough to go out. She also told them because she wanted to be sure they get screened themselves.

As a result of her openness, a member of the book group, Sandy, recently called her to ask questions because Sandy's Mom was just diagnosed with breast cancer. They talked about the upcoming surgery and Holly described the kinds of help Sandy's Mom might need at home while she recovers from surgery. After their conversation, Holly also looked back at her own records to find the name of the place where she did her physical therapy and sent the contact information to Sandy because she liked the physical therapists she worked with. She is pleased that she has had the opportunity to help her friend by sharing her own experiences and told Sandy to pass along a message of support to her Mom and to let her know that Holly would be happy to talk to her if she wanted someone to talk to or had questions. Holly did lots of research about reconstruction, which she chose to have, and thought that if Sandy's Mom was considering that option she might have useful information for her. She also encouraged Sandy to let her know if there was something she could do to make Sandy's live easier while she helped her Mom through this.

Demographics:
Middleaged-older, full time job

Social Network:
Single, part of a book group of local women

Health:
Survivor after surgery and Chemotherapy

Themes:
Sharing information so others know what to expect

Help from social network
- meals
- visiting

Sharing information to try to help others

Seeking information from people within the social network who know about cancer

Knowing what to expect is valuable, but difficult

Learning from others' experiences

Social networks can help find information (physical therapy referral)

People are often happy to be able to do something helpful

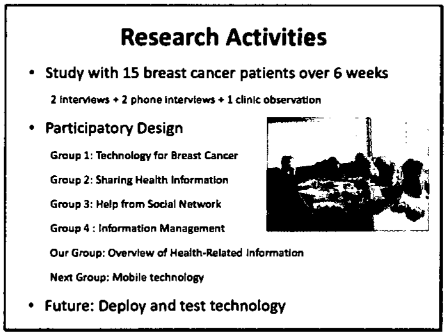
Appendix D

Meeting Introduction Slides

Personal Health Information Management

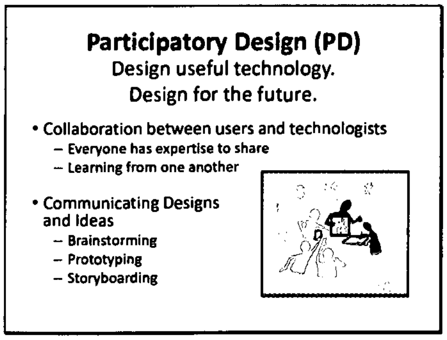
- What health-related information people keep
- How people use health information
- Ways to support this information management

National Library of Medicine NIH Grant Funding



Research Activities

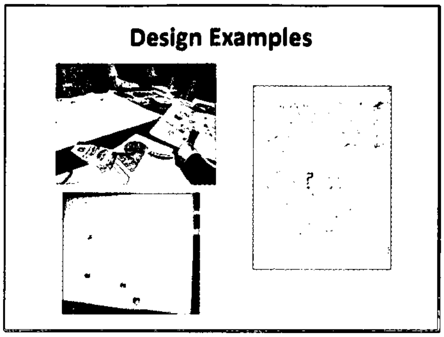
- Study with 15 breast cancer patients over 6 weeks
  - 2 interviews + 2 phone interviews + 1 clinic observation
- Participatory Design
  - Group 1: Technology for Breast Cancer
  - Group 2: Sharing Health Information
  - Group 3: Help from Social Network
  - Group 4 : Information Management
  - Our Group: Overview of Health-Related Information
  - Next Group: Mobile technology
- Future: Deploy and test technology



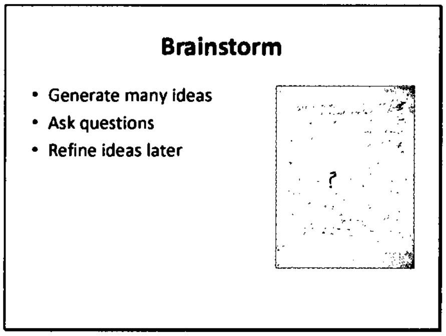
Participatory Design (PD)

Design useful technology.
Design for the future.

- Collaboration between users and technologists
  - Everyone has expertise to share
  - Learning from one another
- Communicating Designs and Ideas
  - Brainstorming
  - Prototyping
  - Storyboarding

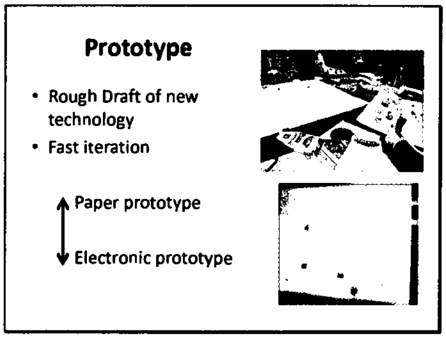


Design Examples



Brainstorm

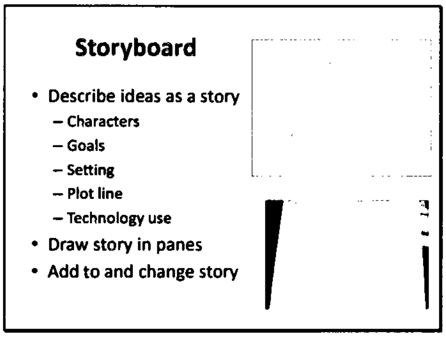
- Generate many ideas
- Ask questions
- Refine ideas later



Prototype

- Rough Draft of new technology
- Fast iteration

↕ Paper prototype / Electronic prototype

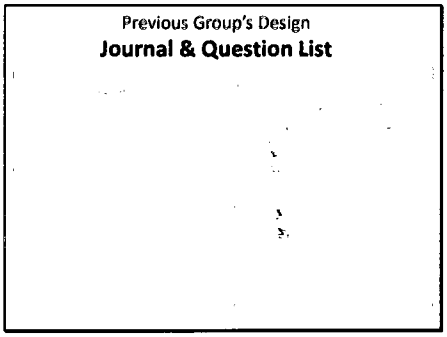


Storyboard

- Describe ideas as a story
  - Characters
  - Goals
  - Setting
  - Plot line
  - Technology use
- Draw story in panes
- Add to and change story

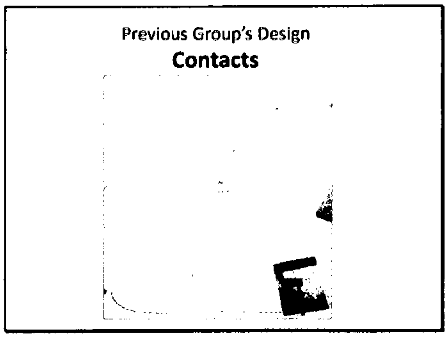
When you create…

- Things do not have to be perfect
  - Words, stick figures, lines, arrows welcome!
- Insight behind creation is important
  - Communicate ideas
  - Represent that idea with concrete image
- Incorporate new ideas and collaborate
  - Sketch/draw/write as others are talking
  - Modify sketches as we go along



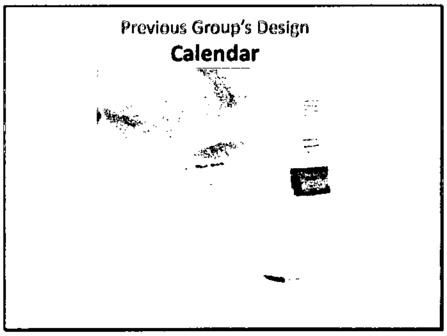
Previous Group's Design

Journal & Question List



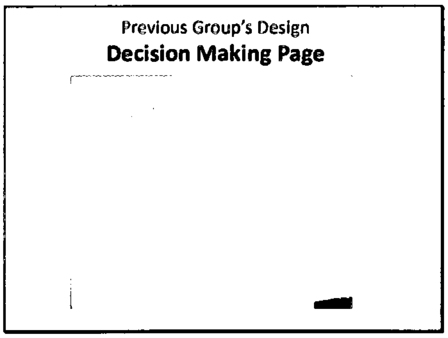
Previous Group's Design

Contacts



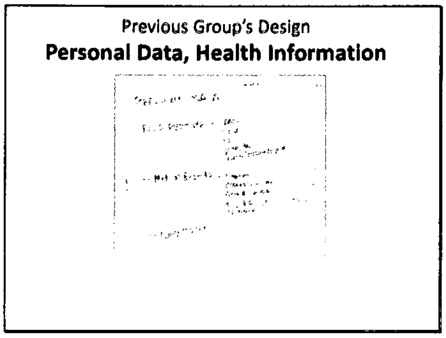
Previous Group's Design

Calendar



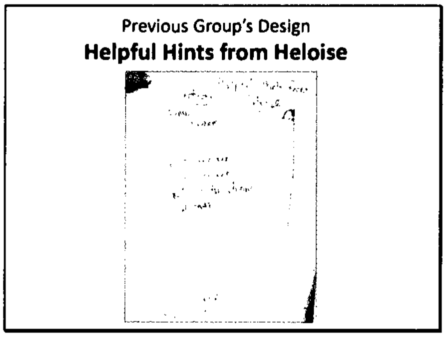
Previous Group's Design

Decision Making Page



Previous Group's Design

Personal Data, Health Information



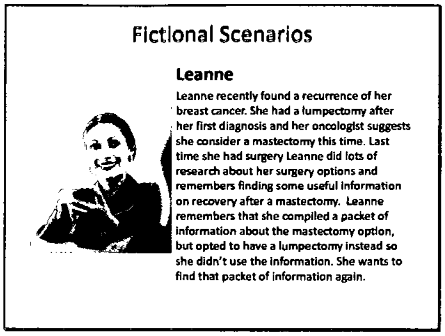
Previous Group's Design

Helpful Hints from Heloise

Let's get started… our topic

Overview to show everything

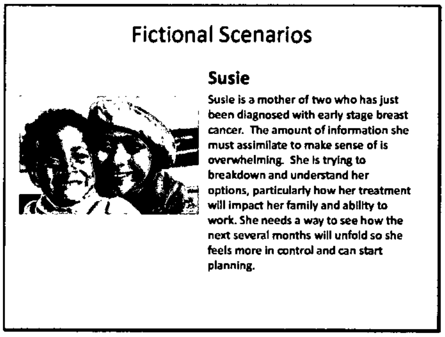
- Schedule and events
- Research (documents, websites, articles)
- "Bundles" – all the info you were looking at around an event/decision/topic
- Contacts
- What else?



Fictional Scenarios

Leanne

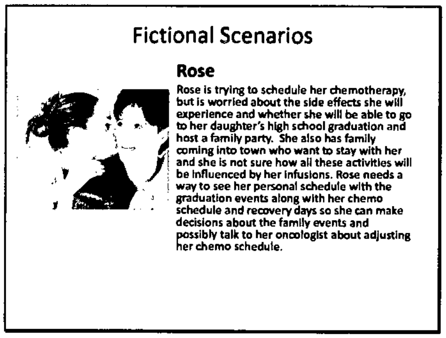
Leanne recently found a recurrence of her breast cancer. She had a lumpectomy after her first diagnosis and her oncologist suggests she consider a mastectomy this time. Last time she had surgery Leanne did lots of research about her surgery options and remembers finding some useful information on recovery after a mastectomy. Leanne remembers that she compiled a packet of information about the mastectomy option, but opted to have a lumpectomy instead so she didn't use the information. She wants to find that packet of information again.



Fictional Scenarios

Susie

Susie is a mother of two who has just been diagnosed with early stage breast cancer. The amount of information she must assimilate to make sense of is overwhelming. She is trying to breakdown and understand her options, particularly how her treatment will impact her family and ability to work. She needs a way to see how the next several months will unfold so she feels more in control and can start planning.



Fictional Scenarios

Rose

Rose is trying to schedule her chemotherapy, but is worried about the side effects she will experience and whether she will be able to go to her daughter's high school graduation and host a family party. She also has family coming into town who want to stay with her and she is not sure how all these activities will be influenced by her infusions. Rose needs a way to see her personal schedule with the graduation events along with her chemo schedule and recovery days so she can make decisions about the family events and possibly talk to her oncologist about adjusting her chemo schedule.

Appendix E

Transparency Evaluation Script & Questions

Introduction

Today you're going to try out a system called HealthWeaver. This system is designed to help cancer patients manage their own information and to help patients share information with their social networks. Patients can…

- upload and share documents
- make and share notes
- make and share lists
- create blog posts
- keep and share a calendar
- ask their network for help

Before we get started, we would like you to think about how you have shared health information with your own social network.

Approximately how many people, not counting your doctors and nurses, have you talked to about your cancer diagnosis? _____

Approximately how many people, not counting your doctors and nurses, have you talked to about the treatments you've had for cancer? _____

Have you ever talked about the cancer experience with people who fall into these categories? (check all that apply)

__ Close family
__ Friends
__ Distant family
__ Neighbor
__ Colleague
__ Manager
__ Another cancer patient
__ Acquaintance

Other:______________________________________

During the study today I will ask you to act as Terry, a fictional cancer patient who has been using Health Weaver. Terry has a social network of 74 people on HealthWeaver. These 74 people are friends, family, neighbors, co-workers, acquaintances, and classmates, just like you probably have in your own network. Terry can control who sees each piece of information that Terry posts. For example, when Terry creates a note and posts it Terry can then choose to keep it completely private or can choose specific people to share it with.

Make a new note

Go to "My Stuff" in the top menu and then click on "Notes." Then click "New note" at the top of the page to make a new note.

In the "Title" box enter: *Dr. Richman March 15th*

In the "Body" box enter: *Notes from my visit with Dr. Richman.*

Before clicking "Save," please answer these questions:

Will this note be shared with anyone else? (yes)
€Yes €No
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

If yes...
Approximately how many people from your network will be able to see this note? (less than half)
€Less than half my network
€More than half of my network
€Everyone in my network
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

Will Nicole Barnhart be able to see this note? (yes)
€Yes €No
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

Will Paula Kyes be able to see this note? (no)
€Yes €No
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

Click "Save" to create your new note.

CCreate1

Make a new list

Go to "My Stuff" in the top menu and then click on "Lists." Then click "New list" at the top of the page to make a new list.

In the "Title" box enter: *To Do May 17*

In the "Body" box enter: *get parking pass from reception, ask Nurse Ann for print-out of record, pick up skin cream from radiation oncology*

Before clicking "Save," please answer these questions:

Will this list be shared with anyone else? (yes)
€Yes €No
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

If yes...
Approximately how many people from your network will be able to see this list? (less than half)
€Less than half my network
€More than half of my network
€Everyone in my network
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

Will Claire Guthrie be able to see this list? (no)
€Yes €No
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

Will Ron Healy be able to see this list? (yes)
€Yes €No
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

Click "Save" to create your new list.

CCreate2

Viewing List: Good Websites

Now you are going to look at a list that Terry made a couple weeks ago.

Go to "My Stuff" in the top menu and then click on "Lists."

Each of these lists is shared with a different set of people from Terry's social network. Please look at the sharing information for the list titled "Good Websites" and answer the following questions.

To see the sharing information for list "Good Websites," hover your mouse over "Sharing information" next to the list to find out more about how that list is shared.

Is this list shared with anyone else? (yes)
€Yes €No
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

If yes...
Approximately how many people from your network will be able to see this list? (less than half)
€Less than half my network
€More than half of my network
€Everyone in my network
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

Can Brian Barker see this list? (no)
€Yes €No
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

Can Robert Nash see this list? (yes)
€Yes €No
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

ViewList2

Viewing List: Radiation Therapy Questions

Now you are going to look at a list that Terry made a couple weeks ago.

Go to "My Stuff" in the top menu and then click on "Lists."

Each of these lists is shared with a different set of people from Terry's social network. Please look at the sharing information for the list titled "Radiation Therapy Questions" and answer the following questions.

To see the sharing information for list "Radiation Therapy Questions," hover your mouse over "Sharing information" next to the list to find out more about how that list is shared.

Is this list shared with anyone else? (yes)
€Yes €No
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

If yes...
Approximately how many people from your network will be able to see this list? (less than half)
€Less than half my network
€More than half of my network
€Everyone in my network
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

Can Debra Cary see this list? (yes)
€Yes €No
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

Can Amanda Howard see this list? (no)
€Yes €No
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

ViewList1

Return to the page where you can see all your Lists.

For the List called **Radiation Therapy Questions**...
Make it so that William O'Keefe cannot see this list.
How confident are you that you made it so that William O'Keefe cannot see this list?
€Guess €A little confident €Fairly confident €Completely confident

Make it so that Camille Overby can see this list.
How confident are you that you made it so that Camille Overby can see this list?
€Guess €A little confident €Fairly confident €Completely confident

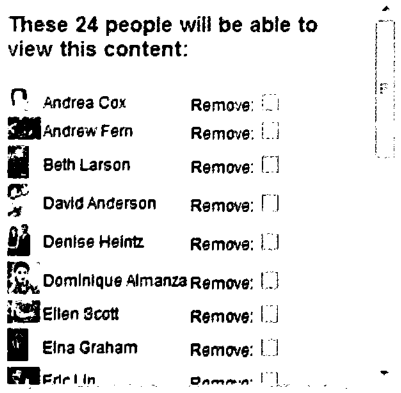
For the List called **Good Websites**...
Make it so that Tonya Mayer cannot see this list.
How confident are you that you made it so that Tonya Mayer cannot see this list?
€Guess €A little confident €Fairly confident €Completely confident

Make it so that Lily Gray can see this list.
How confident are you that you made it so that Lily Brown can see this list?
€Guess €A little confident €Fairly confident €Completely confident

You have used two different options for seeing who information is shared with.

Which of these do you prefer? (please check one)

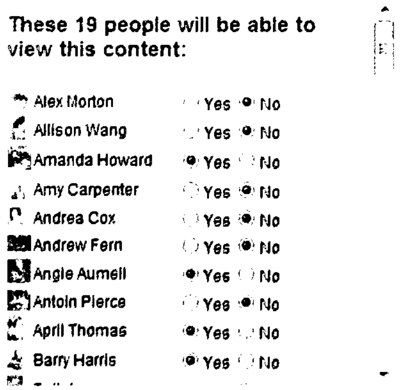
€



These 24 people will be able to view this content:

Andrea Cox	Remove: ☐
Andrew Fern	Remove: ☐
Beth Larson	Remove: ☐
David Anderson	Remove: ☐
Denise Heintz	Remove: ☐
Dominique Almanza	Remove: ☐
Ellen Scott	Remove: ☐
Elna Graham	Remove: ☐

€



These 19 people will be able to view this content:

Alex Morton	○ Yes ● No
Allison Wang	○ Yes ● No
Amanda Howard	● Yes ○ No
Amy Carpenter	○ Yes ● No
Andrea Cox	○ Yes ● No
Andrew Fern	○ Yes ● No
Angie Aumell	● Yes ○ No
Antoin Pierce	○ Yes ● No
April Thomas	● Yes ○ No
Barry Harris	● Yes ○ No

VizPreference

Viewing Calendar

Now you are going to look at Terry's calendar. Click on "Calendar" in the top menu. Then click on "Week" and use the "Next week" or "Previous week" buttons to move to the weeks in the questions below.

Calendar

Navigate to the week of May 9-15 to answer the following questions:
Is the appointment called "CT Scan" on May 10th shared with anyone else? (yes)
€Yes €No
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

If yes...
Approximately how many people from your network can see this appointment? (everyone)
€Less than half my network
€More than half of my network
€Everyone in my network
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

Cal1

Navigate to the week of May 9-15 to answer the following questions:
Is the appointment called "Biopsy" on May 11th shared with anyone else? (no)

€Yes €No

How confident are you in your answer?

€Guess €A little confident €Fairly confident €Completely confident

What information on the screen did you use to answer the question?

If yes...
Approximately how many people from your network can see this appointment? (left blank)

€Less than half my network
€More than half of my network
€Everyone in my network

How confident are you in your answer?

€Guess €A little confident €Fairly confident €Completely confident

What information on the screen did you use to answer the question?

Cal2

Navigate to the week of May 9-15 to answer the following questions:
Is the appointment called "Follow-up with Dr. Sanders" on May 12th shared with anyone else? (yes)

€Yes €No

How confident are you in your answer?

€Guess €A little confident €Fairly confident €Completely confident

What information on the screen did you use to answer the question?

If yes...
Approximately how many people from your network can see this appointment? (less than half)

€Less than half my network
€More than half of my network
€Everyone in my network

How confident are you in your answer?

€Guess €A little confident €Fairly confident €Completely confident

What information on the screen did you use to answer the question?

Cal3

Navigate to the week of May 9-15 to answer the following questions:
Is the appointment called "Dr. Richman" on May 14th shared with anyone else? (yes)
€Yes €No
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

If yes…
Approximately how many people from your network can see this appointment? (more than half)
€Less than half my network
€More than half of my network
€Everyone in my network

How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

Cal4

Navigate to the week of May 16-22 to answer the following questions:
Is the appointment called "Labs" on May 17th shared with anyone else? (no)
€Yes €No
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

If yes...
Approximately how many people from your network can see this appointment? (blank)
€Less than half my network
€More than half of my network
€Everyone in my network
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

Cal5

Navigate to the week of May 16-22 to answer the following questions:
Is the appointment called "Nurse Ann" on May 17th shared with anyone else? (yes)
€Yes €No
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

If yes...
Approximately how many people from your network can see this appointment? (everyone)
€Less than half my network
€More than half of my network
€Everyone in my network
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

Navigate to the week of May 16-22 to answer the following questions:
Is the appointment called "Pre-surgery visit" on May 18th shared with anyone else? (yes)
€Yes €No
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

If yes...
Approximately how many people from your network can see this appointment? (more than half)
€Less than half my network
€More than half of my network
€Everyone in my network
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

Cal7

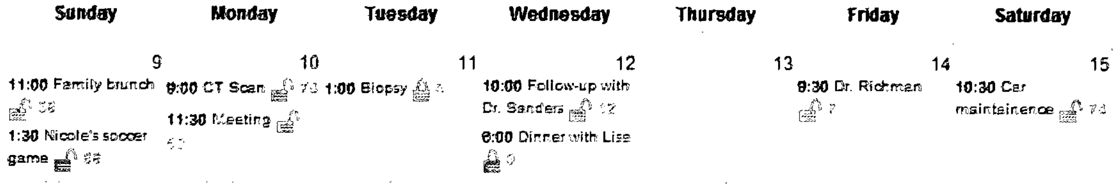
Navigate to the week of May 16-22 to answer the following questions:
Is the appointment called "Dr. Sanders" on May 20th shared with anyone else? (yes)
€Yes €No
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

If yes...
Approximately how many people from your network can see this appointment? (less than half)
€Less than half my network
€More than half of my network
€Everyone in my network
How confident are you in your answer?
€Guess €A little confident €Fairly confident €Completely confident
What information on the screen did you use to answer the question?

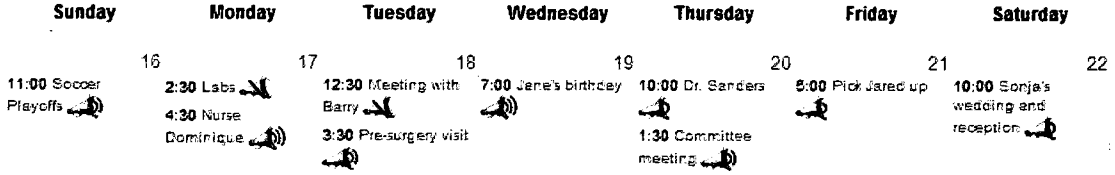
Cal8

You have seen two different icons for indicating whether calendar information is shared.

Which of these do you prefer? (please check one)

€ 

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
9	10	11	12	13	14	15
11:00 Family brunch **1:30** Nicole's soccer game	**9:00** CT Scan **11:30** Meeting	**1:00** Biopsy	**10:00** Follow-up with Dr. Sanders **6:00** Dinner with Lise		**9:30** Dr. Richman	**10:30** Car maintainence

€ 

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
16	17	18	19	20	21	22
11:00 Soccer Playoffs	**2:30** Labs **4:30** Nurse Dominique	**12:30** Meeting with Barry **3:30** Pre-surgery visit	**7:00** Jane's birthday	**10:00** Dr. Sanders **1:30** Committee meeting	**5:00** Pick Jared up	**10:00** Sonja's wedding and reception