

Bringing the Field into Focus: User-centered Design of a Patient Expertise Locator

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ABSTRACT

Managing personal aspects of health is challenging for many patients, particularly those facing a serious condition such as cancer. Finding experienced patients, who can share their knowledge from managing a similar health situation, is of tremendous value. Users of health-related social software form a large base of such knowledge, yet these tools often lack features needed to locate peers with expertise. Informed directly by our field work with breast cancer patients, we designed a patient expertise locator for users of online health communities. Using feedback from two focus groups with breast cancer survivors, we took our design through two iterations. Focus groups concluded that expertise locating features proved useful for extending social software. They guided design enhancements by suggesting granular user control through (1) multiple mechanisms to identify expertise, (2) detailed user profiles to select expertise, and (3) varied collaboration levels. Our user-centered approach links field work to design through close collaboration with patients. By illustrating trade-offs made when sharing sensitive health information, our findings inform the incorporation of expertise locating features into social software for patients.

Author Keywords

Expertise locating, collaboration, user-centered design, recommendation systems, personal health informatics, CSCW

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H5.3. Information interfaces and presentation: Group and Organization interfaces; J.3 Life and Medical Sciences: Health

General Terms

Design

INTRODUCTION

Lily was recently diagnosed with breast cancer. While recovering from surgery, she considered whether to work

full-time during her upcoming chemotherapy. Could side effects interrupt her productivity? How would she cover her piling bills if she leaves her job? After talking with her health-care team and exhausting her personal network, Lily turns to an online health community for advice from peers who have first-hand experience with this difficult decision. This community shares a wealth of personal health expertise, drawn from the stories of patients, survivors, and their families and friends. Yet which of the hundreds of users can offer expertise that best meets Lily's needs?

As growing numbers of patients turn to online communities for health information and support [6,13], users like Lily face the challenge of locating those members with expertise that best suits their needs. Although profiling the expertise of community members could help, existing health forums and social networking tools (e.g., www.patientslikeme.com) do not support this. Our research goal was to systematically explore this design space to understand trade-offs when designing health-related social software that facilitates expertise sharing among patients. Building on our understanding of patient expertise [2] and practices patients use to exchange that expertise [3], we designed a patient expertise locator for users of an online health community that is sensitive to the interests and social circumstances of members who might offer and consume patient expertise.

In this paper, we report on our design iterations guided by focus groups that link our field work on everyday patient expertise locating practices to concrete design features of a patient expertise locator. Before detailing this user-centered design process, we describe related work, including our field observations of patient expertise locating, which grounds our design. We then walk through the four phases of our work in which we describe our design iterations and the responses of focus groups to those designs. We conclude by noting the value of our user-centered approach and the contributions our work makes to the design of social software tools for sharing personal health information.

RELATED WORK

Patients develop significant expertise from personally managing the day-to-day experience of illness. This experiential knowledge reflects practical strategies for

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coping with personal health issues of daily life, such as managing the home, work, self-care, and social relationships in the context of illness. Similar to specialized knowledge observed in other informal knowledge sharing contexts (e.g., ‘craft knowledge’ [16]), we refer to this valuable form of knowledge as **patient expertise** [2]. Patient expertise differs from the expertise of clinicians because it emphasizes the management of personal, rather than medical, aspects of health, such as coming to terms with hair loss from chemotherapy or negotiating a reduced work load with an employer. By merit of managing similar issues, other patients can be well-suited specialists for personal aspects of cancer, distinct from clinicians who are specialized in the medical management and treatment of the disease. Thus, creation of tools that help patients find peers with the expertise they need is a valuable design focus.

Growth in health-related use of social software [6], such as online communities, helps peers share an abundance of patient expertise. Many individuals now use these tools more often to exchange information and advice than to obtain emotional support [13]. Yet, it can be difficult for users to relate to the health experiences of other users [12] and to gain awareness of the expertise available from other users without multiple interactions that build relationships [8]. Whether a user locates peers for advice by posting personal health data to their personal profile [7] or by posting forum questions, this common broadcast strategy works only if those peers with the requisite expertise notice and respond. Once the user garners that expertise, they must determine the suitability of peers who provided the expertise for meeting their needs.

Although some online communities offer people finders to locate community members with similar diagnoses (e.g., ‘breast cancer’), having the same diagnosis is not necessarily the only marker of patient expertise. For example, shared tips on managing hair loss from chemotherapy can be useful to people diagnosed with many forms of cancer. Thus, searching only for people with the same diagnosis can exclude good sources of expertise with different diagnoses. In addition, as community membership grows, coarse search based on a general diagnosis alone will result in an unwieldy number of sources. Enhancing health-related social software has the potential to overcome these limitations. Yet, as we expand our understanding of the practices patients use to locate expertise from peers in their everyday lives [3], how can we move from field observations into design for such enhancements?

Expertise sharing research in other settings offers insights for helping users determine who can offer expertise that best meets their needs. For example, field work of natural expertise sharing practices in workplace organizations has informed the design of expertise locators for use by professionals [10,11]. Prior work suggests that an effective expertise locator requires both helping a user understand what expertise another person has, as well as the social circumstances in which that expertise would be shared [10].

For example, enhancing awareness of users’ expertise with contextual details about their social relationships [14], reputations [9], and other cues about their knowledge and interests extracted from indicative source of data [11,15] can augment efforts to locate expertise.

Design enhancements can also be guided by investigations of user behavior with existing expertise locators [4] and other collaborative tools, such as forums [1], newsgroups [5], or ‘how-to’ web pages [16]. For example, Ehrlich and Shami [4] point to important trade-offs made when professionals select expertise locating tools, such as speed and ease of use versus reliability of results. Others offer insights from examination of structural characteristics evident in user interactions. For example, Adamic et al [1], through a study of knowledge sharing activity in Yahoo! Answers, found that answer length, number of competing answers, and track record of question answerers can predict an answer being selected as ‘best’. Understanding such trade-offs and leveraging such structural cues in existing tools better positions designers to facilitate expertise locating.

Reflected by our user-centered approach, we provide a strong basis for exploring supportive design enhancements by coupling field work on everyday patient expertise locating practices with development data drawn from an existing online health community. Next, we summarize findings from the field work we conducted to ground our design in a detailed understanding of the expertise locating practices that patients use in their everyday lives.

PATIENT EXPERTISE LOCATING

Our design is tightly tied to the everyday expertise locating practices we observed in our field study with breast cancer patients [3]. Through this in-depth work, we discovered that patients, much like professionals [10], locate expertise from peers through complex, iterative, and often interwoven behaviors to determine which peers have the requisite expertise (i.e., **expertise identification**) and to narrow down that pool of candidates to approach for help (i.e., **expertise selection**).

Table 1 shows the expertise identification strategies we observed during our field study. Identification strategies allowed patients to determine ‘who knows what’ by helping them come to know about potential sources of expertise. Like professionals [10], patients commonly identified expertise by relying on past experience with family and friends and by relying on gatekeepers, who connected them with useful resources and people. In contrast to professionals, patients made extensive use of expertise localized in groups with whom they shared common interests (e.g., support or hobby group), but relied less on tangible artifacts (e.g., books or websites) to locate expertise. Like other informal expertise sharing settings, patients frequently identified expertise after receiving advice volunteered by others [16].

Strategy	Description
Personal networks	Knowing of knowledgeable peers from past experience with family and friends
Gatekeeping	Learning of knowledgeable peers through introduction by a third party
Grouping	Learning of knowledgeable peers through interaction around a common interest
Artifacts	Learning of knowledgeable peers from a tangible resource (e.g., book or website)
Unsolicited advice	Learning of knowledgeable peers as a result of receiving volunteered help

Table 1. Strategies for identifying patient expertise

In addition to identifying ‘who knows what’, patients relied on a number of socially-embedded selection criteria. Table 2 shows the range of social circumstances patients considered when selecting ‘who to approach’ for help. Mirroring professionals, patients often approached candidates who offered high levels of specialized knowledge (e.g., works in a health-related field), who were accessible and responsive, and with whom they shared close, long-standing, and trusted relationships. In contrast to selection criteria commonly expressed by professionals, patients put much consideration into issues of transparency and cancer connection due to a similar diagnosis, treatment, or side effect. Patients also preferred candidates with whom they shared common lifestyles and interests, such as world views, hobbies, professions, or health preferences.

Criterion	Description
Source knowledge	Type and level of knowledge offered by candidate
Transparency	Trustworthiness, traceability, and clarity of candidate’s information
Connection to cancer	Candidate’s relationship to cancer, such as cancer survivor or caregiver
Availability	Candidate’s accessibility and responsiveness
Strength of social tie	Closeness of one’s social relationship with the candidate
Lifestyle & interests	Kinds of personal interests and outlooks shared with candidate

Table 2. Criteria for selecting patient expertise

Patients’ expertise locating practices, including these identification strategies and selection criteria, serve as a central reference point for our design of a patient expertise locator that facilitates targeted requests to peers best suited to meet a user’s needs. The patient expertise locator is designed to help users identify the kinds of expertise that members of an online health community can offer, as well as the social circumstances in which those members would share their expertise. Through a user-centered approach, we combined iterative design with focus groups to explore design features that can extend online health communities

by supporting the expertise identification strategies and selection criteria that emerged from our field study.

METHODS

Our goal was to design a patient expertise locator that is grounded in a deep understanding of patients’ everyday expertise locating practices and guided by design feedback obtained from potential users. Our user-centered design spanned four iterative phases. In Phase 1, we used our field study findings to create an initial design of the expertise locator. Then, we obtained design feedback through a focus group with breast cancer survivors in Phase 2. In Phase 3, we used input from the focus group to iterate on the design. Finally, we obtained feedback on our redesigned expertise locator through a second focus group with a new set of breast cancer survivors. We detail the specific focus group activities in the sections describing Phase 2 and Phase 4.

Rather than implementing a tool from the ground up for new users to populate, we chose a simulation of a structured Q&A forum as a first step towards design enhancements. Serving as a development corpus of data, we seeded our design with publicly accessible breast cancer-related questions and answer (Q&A) threads from Yahoo! Answers (answers.yahoo.com). Using their web services API, we began with a queue of seed questions based on a search for "breast cancer". We mined each question for its answers and the users who contributed those answers. After purging threads unrelated to breast cancer, we added questions asked by those users to our queue and repeated the process until no new questions appeared. Throughout this process we recorded connections between users as an integer score that increments every time one user answers another user's question. This representation of user connections guided our selection of interconnected data to illustrate with our design.

In our development corpus, we replaced user names with identifiers, and then constructed a database of questions, answers, and user profiles containing identifiers. We used this data to design interface mock-ups for an online cancer community that includes a Q&A forum, user profiles, and features to support patient expertise locating. Because Yahoo! Answers was not designed to support extensive profiles, we embellished our profiles with fictitious personas. The attributes those personas illustrate are directly informed by thread content and characteristics patients consider when selecting expertise (see Table 2). Next, we describe each phase of our user-centered design.

PHASE 1: INITIAL DESIGN OF THE EXPERTISE LOCATOR

Our initial design supports expertise identification through artifacts (Table 1). Because patients made minimal use of this strategy in our field study, we leveraged this opportunity from examples used in professional settings [10,11,15]. Answers posted to questions in the Q&A forum serve as artifacts from which community members’ expertise is ascertained. A **topic search** for members ‘who know about’

entered terms (e.g., ‘wigs’) uses those artifacts to identify a pool of community members who have mentioned those terms in their answers. Although this technique does not ensure expertise, the kinds of topics members discuss convey useful insight into their central interests. We assume that members are likely to know something about those topics they discuss frequently in answers. To select the most suitable candidates to approach, a user explores profiles returned by the expertise locator, which are organized around the selection criteria from the field study (Table 2).

Serving as a use case for our initial design, we return to the scenario of Lily, which illustrates common work-related issues that emerged for cancer patient in our prior studies [2,3]. Unlike online health communities that search for users with common diagnoses [7], the patient expertise locator couples topic search with detailed user profiles to provide Lily with awareness of patient expertise available from community members. Lily begins at the Q&A forum (Figure 1), which lists questions and answers posted by community members. Lily clicks on a Q&A thread to view the question and its answers. She browses several threads, but does not find the work-related advice she seeks.

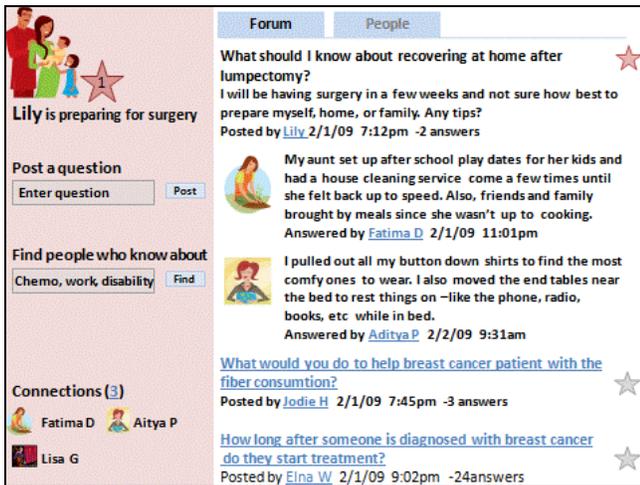


Figure 1. Forum: Q&A threads contributed by community members are displayed on the right panel

The left panel of the forum provides Lily two choices for locating expertise: (1) broadcasting a request to the entire community by posting a question to the Q&A forum (i.e., ‘Post a Question’ input box), or (2) using the patient expertise locator, labeled ‘Find people who know about’, to target her request to members who are most likely to offer expertise relevant to her dilemma. If Lily chooses the patient expertise locator, she would enter terms, such as ‘chemo’, ‘work’, and ‘disability’, to identify members who have discussed those topics in their answers to forum questions. The patient expertise locator returns a set of synopses linked to the user profile of each matching candidate (Figure 2).

Lily explores the profiles of returned candidates to select whom to ask for help. Lily clicks on Alysa to view her profile, which is organized around the selection criteria

patients use when determining which peers to approach for their expertise. Table 3 maps the selection criteria from our field study to design features of user profiles. We highlight selection criteria and corresponding design features in the remaining use case to illustrate how we incorporated them into the initial design.

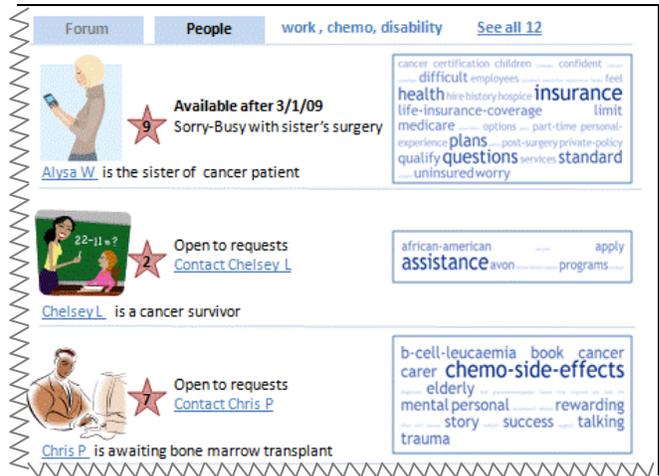


Figure 2. Patient expertise locator results: a brief synopsis, pulled from user profiles, is displayed for each candidate

Selection criterion	Design feature of profile
Source knowledge	Knowledge cloud
Transparency	Answers, recommended resources, & star award
Connection to cancer	Status line & health situation
Availability	Contact information & last login
Strength of social tie	User connections
Lifestyle & interests	Personal information

Table 3. Expertise selection criteria and corresponding features of user profiles

The right panel of Alysa’s profile (Figure 3) provides insights into the types of knowledge she can offer. The tag cloud at the top, which we refer to as Alysa’s **knowledge cloud**, represents **source knowledge** by depicting the terms that appear in answers Alysa has posted in the Q&A forum. Frequent terms appear larger than infrequent terms, indicating the major topics Alysa is likely to know about. We generated a knowledge cloud for each profile by filtering common English stop words from the member’s answers and extracting significant terms and phrases using Yahoo’s Content Analysis Web Service.

Other profile elements provide Lily contextual details to narrow selection to the most suitable candidates. Alysa’s forum answers are displayed below her knowledge cloud. Lily gains insights about Alysa’s **transparency** by reading the first few lines of her **answers**. Alysa has also **recommended resources** by posting websites below her answers, providing Lily with examples of the kinds of information resources she might expect.

Figure 3. Profile view: Alysa’s profile provides details patients need when selecting among sources of expertise

The left panel of Alysa’s profile displays her picture and a **star award** that indicates the 9 threads she has participated in that other members have found helpful. Any member can award a star to a thread they find helpful in the Q&A forum. Once a thread receives a star, each member who participated in that thread, by asking or answering the question, is also awarded a star on their profile. Related to **transparency**, star awards are intended to provide insight into the potential quality of expertise a member could offer.

Alysa’s **status line** (i.e., ‘is the sister of a cancer survivor’) is displayed below her picture, which communicates her **connection to cancer**. Alysa can update her status line to reflect her evolving experiences as a support person for her sister. Since Alysa is the sister of an individual facing cancer, Alysa lists her sister’s **health situation**, including her sister’s diagnosis and treatments, to provide more detail about her connection to cancer.

Below the status line, the date of Alysa’s **last login** cues members about her **availability** for requests. Alysa will be busy with her sister’s upcoming surgery and communicates this with a note beside her picture. When ready to accept requests again, she will replace this note with a link to her **contact information**.

A list of **personal information** captures Alysa’s **lifestyle and interests**, such as her livelihood. Lastly, the bottom of the left panel displays Alysa’s **user connections**, which represent **social ties** she has made by participating in forum threads with other members. The 26 connections that Alysa has interacted with through the forum are listed.

Given the choice between posting a question to the Q&A forum and using the patient expertise locator, how should Lily locate expertise for her dilemma? If she broadcasts a question to the entire community, who might respond and what expertise might they offer? Alternatively, if Lily searches for knowledgeable community members with the expertise locator, which of the returned candidates should she approach for advice? We posed this choice to target

users through a focus group to inform our iterative design, which we describe next.

PHASE 2: FEEDBACK ON THE INITIAL DESIGN

The goals of the focus group were to (1) gain insights into the perceived usefulness of the patient expertise locator, and (2) obtain guidance on design enhancements to support expertise selection. We recruited four breast cancer survivors to take part in storyboarding, profile sorting, and discussion during the 2-hour focus group session.

Participants (P1-P4) ranged from 45-60 years of age and were diagnosed 2-11 years ago. All were college educated with livelihoods ranging from teaching, to theater and real estate. All described themselves as very experienced in daily computer use, both at home and at work, and had used online communities, such as discussion forums or Facebook. Each participant described personal experiences exchanging breast cancer advice with peers, which they drew upon from the perspective of both advice seeker and advice provider during the session.

We first presented low fidelity mockups of our initial design to participants as a storyboard using the use case of Lily. We then facilitated discussion to assess participants’ perceived usefulness of the patient expertise locator by asking them whether Lily should post a question to the Q&A forum or search for knowledgeable members with the patient expertise locator. We encouraged participants to draw on personal experiences to describe situations best suited for the Q&A forum and for the patient expertise locator.

Finally, we engaged participants in a profile sorting activity to seed discussion to inform design enhancements. We gave each participant paper copies for 3 of the 12 candidate profiles the patient expertise locator returned to Lily in the use case (i.e., formatted as in Figure 3). The group explored the 12 profiles together to determine whom Lily should approach for advice. Thus, this exercise is an expertise selection task in which participants compared profiles along social circumstances of interest (see Table 2). Through this sorting activity, we enhanced our understanding of the selection criteria patients attend to most.

Perceived Usefulness of the Patient Expertise Locator

Although participants thought that both the Q&A forum and the patient expertise locator could help people locate patient expertise, they found the expertise locator more useful for identifying community members with knowledge and specific social circumstances matching Lily’s needs (e.g., generation, family status, ethnicity): “So it’s like finding specific similarities, the people finder [expertise locator] helps you do that-find someone who’s really in your niche.” (P1)

Participants found the expertise locator to be useful when: “I just want to know about people who know about this [topic], and then I want to know what they know” (P4). They agreed that the expertise locator’s functionality to “weed out ... people who are in such a different place” (P1)

is not supported well by social software they use. P3 described the time and effort the expertise locator could save when searching for expertise in tools that segment discussion topics into separate forums: *“I have to go to that particular forum ... go through and read all of the stuff to find someone that matched ... so there’s no way to go search and say find ‘somebody that knows this’. I think that’s something that one [expertise locator] would help.”*

Participants discussed a range of situations for seeking expertise from peers using either a Q&A forum or patient expertise locator. Yet, the nature of the problem and specificity of advice sought was a factor that could determine which they would turn to. They found the Q&A forum more suitable for situations requiring broad and general advice, but found the expertise locator more useful for situations requiring highly specific advice. One participant explained this difference through an example: *“What’s good for Q&A is a question that’s going to have multiple answers ... so you can get all of their answers and decide which ones to use or not. Whereas with this [expertise locator], I want to find that one person ... the more serious the diagnosis or news, then I would be more inclined to use this [expertise locator]. Q&A for more general, for new things. But like for recurrence and mets ... I think that the more serious your diagnosis ... someone who is stage IIIB is going to have more specific questions, more urgency ... the questions are different.”* (P1)

Associated with usefulness of both the Q&A and the patient expertise locator, the need to disclose personal details to be able to locate expertise (i.e., personal disclosure) versus the desire to preserve personal privacy surfaced as an important trade-off. Although participants clearly found value in locating expertise by making personal information available on profiles, they also found it vital to provide users of the tool with private space to interact and with an option to hide segments of their profile from the view of others. Participants also agreed on the need, particularly for new members, to view content anonymously: *“Early on, I think any of us could say ‘I did not embrace this’, I lurked.”* (P2) The sensitive nature of disclosing health information underscores the importance of user control and privacy management in the design of expertise locators [11].

Enhancing the Initial Design

After participants indicated that such a patient expertise locator would be useful, the profile sort and participants’ suggestions for improvements helped to guide our redesign.

Going Beyond Topic Search to Identify Expertise

We presented participants with just one method for identifying patient expertise: topic search. Supporting expertise identification through artifacts, topic search returns a list of candidates with terms in their knowledge clouds that match queried terms. Participants suggested sorting and filtering features to compare and select returned profiles in personalized ways. Underlying this design

enhancement is participants’ expectation that users would have highly specific, but variable needs for particular kinds of knowledge and social characteristics of matching candidates, rather than a single ‘best expert’. P2 suggested using drop down lists to sort profiles along various selection criteria that *“hone in”* on user characteristics of interest: *“I’m a drop down person...you have to help people get to where they need to go”*. Filters could refine the list of profiles to candidates meeting a specified set of selection criteria. Although sorting and filtering would require more structured entry of profile information, such features could aid comparison of candidates in highly personalized ways that expand upon relevance ranked lists common to expertise locators in professional settings [11,14].

Participants found topic search useful, but were enthusiastic about incorporating additional identification methods, such as leveraging user connections to identify community gatekeepers and discovering like-minded members through ‘friend of a friend’ social ties [14]. Because *“questions are different”* (P1) for people with different health situations, the formation of special interest groups fits patients’ natural tendency to localize expertise through grouping. For example, P3 expressed interest in using the expertise locator to find local patients who are teachers. Participants also had interest in identifying knowledgeable members through suggestions offered by the expertise locator. For example, the tool could ‘watch’ the search terms a member uses, and then suggest new threads or members that have since mentioned those terms as ‘information gifts’ [16]. P1 commented on this option as a low effort alternative: *“That’s what’s nice about suggestions because if I’m dizzy and I don’t know what to do I can just click. It’s easy, it’s one click, and gets me to something related.”*

Polishing Profiles to Serve as Expertise Selection Aids

Profile sorting led participants to suggest profile refinements and enriched our understanding of key selection criteria. As participants explored the 12 profiles to determine whom Lily should approach, they attended most to a member’s connection to cancer noted in their status line (e.g., patient, spouse), their health situation, personal information, knowledge cloud, answers, and recommended resources. Unlike professionals [15], participants attended little to social connections or availability cues. They suggested profile additions, such as family status (e.g., children’s ages) and adding the date the member joined the community as a quality marker for transparency. Participants found the availability cues useful for maintaining awareness about members’ activities, but did not consider it a key selection criterion.

Although user connections failed to enter discussion about ‘who Lily should approach’ during the profile sort, participants later noted the potential utility of enhancing user connections to discover community gatekeepers: *“is there any one person who is connected to all of these people?”* (P1). Similarly, connections could cue like-

minded ‘friends of a friend’: “*what I would love to see though is a counter on that [connections] ... to see that she and ‘Lisa’ have exchanged questions and answers 30 times, whereas with ‘Lena’ it’s been 10. Now that could perhaps tell you that Lena is recently diagnosed and for Lisa it’s been a while. But it also tells you that this is someone simpatico*” (P1). In addition to incorporating cues for connection strength among community members [14], this feedback points to the inclusion of expertise identification strategies, such as gatekeeping and personal networks.

Unlike award-based mechanisms that flourish in other contexts [9], star awards held little value for participants as a selection criterion because they did not relate to Lily’s specific needs. Participants preferred the contextual detail of other profile information over general, consensus-based star awards for determining highly specific matches along multiple selection criteria: “*Since every situation is different, ‘Carol’ could be great when it comes to mastectomy, but you could have 25 people that that is not their diagnosis. So, it doesn’t matter if it is a thumbs up or not, because they don’t have to deal with that. So it’s 9 stars for those who are going through mastectomy, but its zero for [the others].*” (P2)

PHASE 3: REDESIGN OF THE EXPERTISE LOCATOR

Using the feedback obtained through the focus group to guide our redesign, we revised profiles and incorporated a broader range of expertise identification strategies into an interactive HTML version of the patient expertise locator. We connect those revisions back to our field work in Table 4.

Identification strategy	Design feature
Personal networks	Provides private messaging with user connections
Gatekeeping	Lists members with the most user connections and most recommended web pages
Grouping	Lists community groups
Artifacts	Incorporates profile sorting and filtering into topic search
Unsolicited advice	Provides profile suggestions based on recent searches
Selection criterion	
Transparency	Adds date joined to profiles and removes star awards
Connection to cancer	Adds ‘connection to cancer’ to profiles
Lifestyle & interests	Adds ‘geographic network’ and ‘family status’ to profiles
Strength of social tie	Adds ‘connection strength’ to user connections on profiles

Table 4. Mapping between expertise locating practices and features of redesign

Using the redesigned patient expertise locator, Lily can identify expertise through a range of strategies available under the tab labeled ‘People’ (Figure 4). The main panel

lists the profiles of all 300 community members to browse. Three community groups and two community gatekeepers are displayed above the listing of community members.

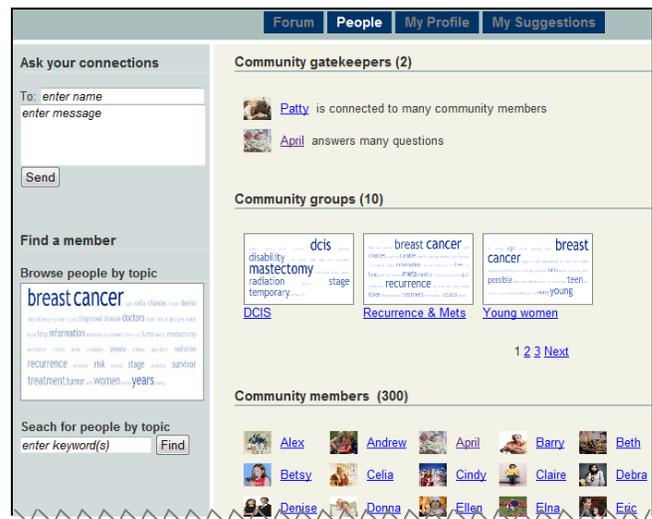


Figure 4. People view

A tag cloud overviews the kinds of subtopics discussed by members in each community group (e.g., ‘young women’). Using this **grouping strategy**, Lily can identify expertise as a result of interacting with others around a more specific shared interest than breast cancer. Lily, for example, could traverse members of her ‘Yoga’ group for those who can provide stretching exercises to facilitate recovery from breast cancer surgery.

Community gatekeepers are displayed above community groups in the main panel of the ‘People’ view. The patient expertise locator counts members’ user connections and recommended web pages, and uses those counts to suggest gatekeepers. A link to Patty’s profile is shown because she has the most user connections. April, on the other hand, has recommended the most web pages. Using a **gatekeeping strategy**, Lily could ask April for information resources or ask Patty for introductions to other community members.

The left panel of the ‘People’ view provides an easy way for Lily to “ask a connection” with whom she already interacts by sending one of her user connections a private message. With this strategy, Lily leverages the expertise available within her **personal network**. The left panel also allows Lily to “find a member” by topic. The tag cloud summarizes the topics discussed across answers on the forum, which Lily can use to browse to profiles of members who mention a particular topic in their answers. Lily can also ‘search for people by topic’. Like the initial design, Lily enters a term, such as “mastectomy”, into the input box and is shown a list of matching candidates (Figure 5).

Lily can use the drop down box at the top right to add characteristics that interest her most (e.g., family status), then sort the list to compare profiles along selection criteria that suit her own needs. These features offer Lily flexible personalization as she identifies expertise through **artifacts**.

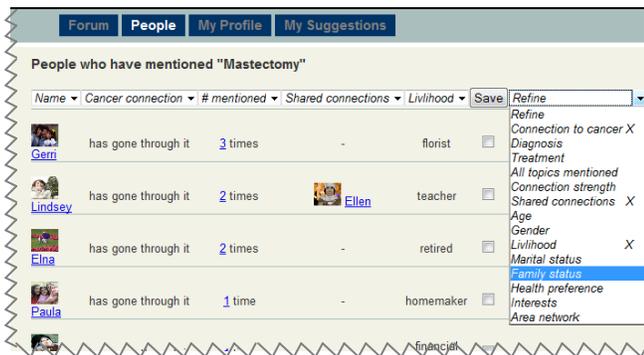


Figure 5. Results from topic search

In addition to supporting expertise identification through personal networks, gatekeepers, grouping, and artifacts, the redesign incorporates **unsolicited advice** through the 'Suggestions' tab (Figure 6). The last time Lily used our tool, she searched for Q&A threads about 'insurance'. Based on this most recent search, Lily is shown candidates who mentioned this term in their answers since her search.

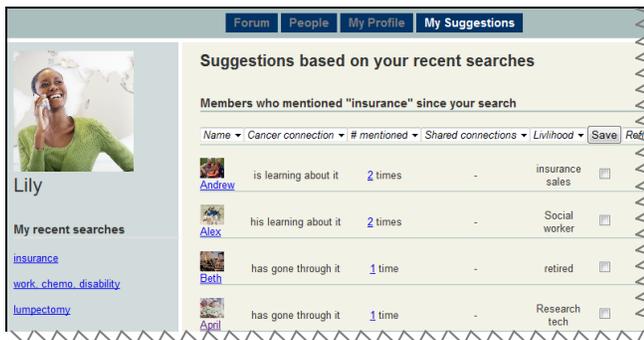


Figure 6. Suggestions view

Like results from topic search, Lily can sort and filter profiles of suggested candidates. Lily clicks on 'April' to view her user profile (Figure 7). The redesigned profile incorporates additional fields suggested by the focus group, including family status and geographic network. April's status line, on which she notes her evolving experience, is clearly differentiated from her 'connection to cancer' (i.e., "has gone through" the breast cancer experience). Each of April's user connections is associated with a numeric 'connection strength', which counts the number of times they have interacted on the Q&A forum. We next describe redesign feedback obtained from the second focus group.

PHASE 4: FEEDBACK ON THE REDESIGN

We obtained feedback on our redesign through a second 2-hour focus group with a new set of breast cancer survivors. Our goals were to gain additional insight into the perceived usefulness of the patient expertise locator and guidance on further design enhancements. In this group, we shifted our focus from expertise selection towards design features for expertise identification through interactive storyboarding, an expertise identification task, and discussion.

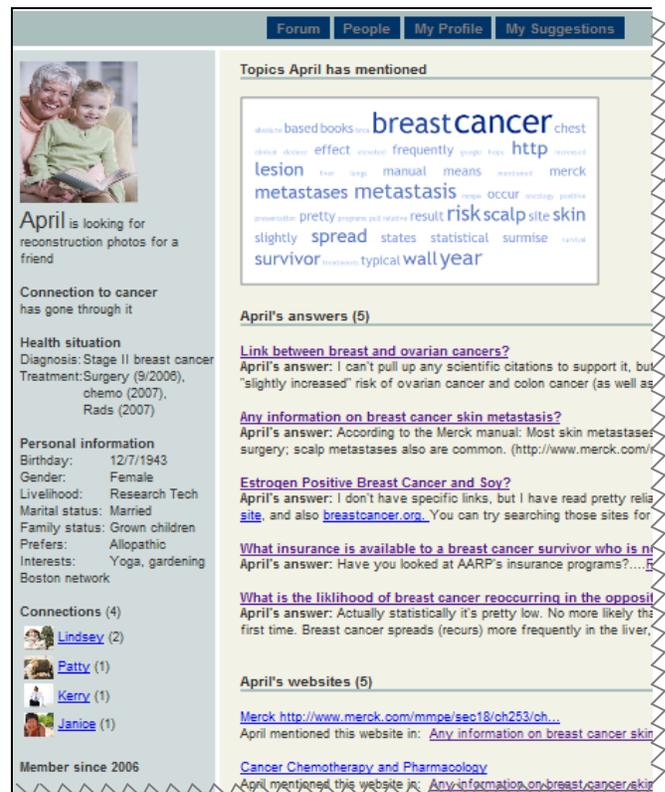


Figure 7. April's redesigned user profile

The four focus group participants (P5-P8) ranged from 39-77 years of age and were diagnosed in the past 2-5 years. All had some college education with livelihoods ranging from accounting, to administrative work, and teaching. Two participants described themselves as very experienced in daily computer use, both at home and at work. The other two participants had some computer experience and used computers on most days. Three participants had used online communities before.

We presented our redesign as an interactive storyboard through the use case of Lily, and then participants discussed the perceived usefulness of the patient expertise locator. We then engaged the group in an expertise identification task. We asked each participant to share a personal experience in which they sought health-related advice from a peer, and then together map out the expertise identification strategies (Table 1) evident in those concrete personal experiences. We asked participants to elaborate on identification strategies that fit either well or poorly with their personal experience and how they relate to Lily's use case. This task geared discussion towards determining which identification strategies the expertise locator should incorporate. Issues raised by participants seeded discussion about further design enhancements.

Perceived Usefulness of the Patient Expertise Locator

Like the first focus group, participants found the Q&A forum more suitable for general issues, such as "What kind of questions do you ask for your first appointment?" (P7).

They found the patient expertise locator more useful for identifying members with similar circumstances and opening a private channel for dialogue about sensitive issues, such as embarrassing side effects or experiences with a particular cancer center: *"I would use the people finder [expertise locator] if I had a really personal question and I wanted to know 'is there someone who's had a similar situation'? Cuz all of their stories are different. You could have the same cancer, you could even have the same treatment, but still have a different cancer story, and I would want to talk with someone who is closer to my story and I don't want it out for the whole group to see."* (P6).

Thus, the delicate trade-off between personal disclosure and personal privacy appeared again as a vital design consideration. Expanding on the range of trade-offs expertise locating tools expose [4], participants understood that effectively locating patient expertise requires at least some personal disclosure about one's situation. Yet, they discussed measures for community members to preserve their personal privacy [11] by controlling how much detail they disclose on their profiles and by restricting how their profiles are viewed by others because *"you might not want everyone to see everything"* (P5). Like the first focus group, participants suggested support for private dialogue, such as giving members a way to *"click on them [a member] and send them a nice little private message"* (P6).

Enhancing the Redesign

During the expertise identification task in which the group mapped out the expertise identification strategies evident in the personal experiences they shared, it became clear that the expertise locator should incorporate support for the full range of identification strategies rather than a select few. This task led to further discussion about the need for varied levels of commitment to collaborate in an online cancer community. We describe each of these design insights next.

Tailoring the Fit: Offering Multiple Identification Strategies

Participants mapped expertise identification strategies evident in their own personal experiences of seeking advice from peers on issues ranging from managing social relationships (e.g., dating during treatment) to finding an oncologist and managing hair loss during chemotherapy. Similar to the field study, participants' stories conveyed the common strategy of turning to one's personal network for expertise. Yet, participants also received unsolicited advice and used gatekeepers, artifacts (e.g., blogs), and groups (e.g., dance group). It was not the case that certain strategies took priority across participants, pointing to a universal identification strategy to support. Instead, participants made evident the value of offering a suite of identification strategies to tailor to their specific situation: *"all these things [strategies] intermesh to make things easier for you"* (P7).

As participants described breakdowns in the identification strategies they used in their own lives, it became evident

that the conditions under which expertise is shared vary from situation to situation. Although participants, like professionals [14], relied on strong social ties of their personal networks in some situations, they pointed to the need for social distance in other situations. For example, P6 was unsuccessful when she turned to her friends for advice on helping her spouse deal with her diagnosis because they were too close and thus carried too much baggage about her personal life: *"they were all very sweet, but very ineffectual in that situation to help me"*. She then turned to a gatekeeper to whom she *"filtered"* details about her personal situation and found a more effective source of help. A similar preference for greater social distance was expressed by P7: *"The [support] group that I went to were completely, I didn't know any of them, we had nothing personal, no relationships, and in some ways that was very good."* These examples suggest that providing a choice from among a suite of expertise identification options is one way to help users make such delicate trade-offs.

Setting Collaboration Levels for Expertise Requests

A second major design insight offered by participants was the need for users of the expertise locator to control their level of commitment to collaborate through our online cancer community. P8 asked: *"With the people finder [expertise locator], how are you going to ask them your question?"*, which led participants to suggest a mechanism to protect members from getting *"bombed"* with requests: *"I just don't want to obligate myself to a lifetime of answering"* (P5).

First, participants agreed that community members should be able to indicate on their profile whether they wish to limit their activity in general to question answering alone or are open to being contacted directly for expertise: *"maybe when you are signing up you can set your parameters for how active you want to be"* (P6). P8 suggested: *"So check maybe a box 'yes, I am willing to answer email or no I am not'"*. This option is somewhat analogous to setting one's collaboration level in Google Knol (knol.google.com/k).

Further, participants discussed the utility of setting their collaboration level with respect to topic. For example, a community member might volunteer to serve as a gatekeeper on a particular topic or respond to a request related to a specific answer they posted: *"You could volunteer to become an expert on something. It kind of gives people permission to contact you ... and if you responded to it on the forum, you could add a little 'will answer private follow ups' [on that specific question]"* (P5). P6 suggested that such volunteer gatekeepers could play a larger role in approaching a community member in need: *"Lily could check a box 'really need to talk with someone about blah blah blah...then your gatekeeper could say 'oh o.k. here is somebody that needs to talk', then send an email, you know 'yeah I am here for you, I'd love to talk with you, let's set a time', or you know how you can do those live little chats back and forth"*.

CONCLUSION

Our design of a patient expertise locator illustrates the value of linking field work with specific design features by applying user-centered methods. Our focus groups clearly valued the expertise locator because it can meet patients' critical needs for awareness of 'who knows what' and the broader social circumstances in which peers share patient expertise. Their specific design suggestions provide a first glimpse into the types of health information sharing features that can enhance social software for patient expertise locating.

Although prior work illustrates the value of expertise locators in professional settings [10, 11,15], our systematic investigation adds critical insights for meeting the needs of patients in less formal expertise sharing contexts through social software [16]. Multiple mechanisms to tailor expertise identification, detailed profiles that serve as expertise selection aids, and protections in the form of designated collaboration levels can position designers to meet the expertise locating needs of patients. Design enhancements that provide users with granular control for custom tailoring and personalization appear particularly useful for patients who make vital trade-offs (1) between social distance and closely tied social connections [14,15], and (2) between disclosing sensitive personal information to obtain help and safeguarding their personal privacy [11].

We limited our approach by basing our design on the structured format of a Q&A forum and carried our low fidelity paper and HTML mockups through two design iterations with focus groups in a simulated environment. Future work could investigate supportive features to enhance other social media through which patients share expertise (e.g., discussion forums, blogs), a broader range of patient expertise locating scenarios, the value of importing profile updates from other tools (e.g., personal health records, Facebook), and the practical significance of patient expertise locators evaluated through individual patient use.

In conclusion, our main contribution is the illustrative case made by our user-centered approach for the promising direction of expertise locators for patients. Given the sensitive and protected nature of personal health information, working with small groups of real patients, in carefully structured, iterative design cycles allows for a systematic exploration of varied perspectives on information sharing trade-offs and subsequent design space. Patients need help from peers, and our work illustrates the contribution a user-centered approach can make to meet this critical need.

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REFERENCES

1. Adamic, L.A., Zhang, J., Bakshy, E., & Ackerman, M. S. Knowledge sharing and yahoo answers: Everyone knows something. *Proc. WWW 2008*, ACM press (2008), 665-674.
2. Civan, A., & Pratt, W. Threading together patient expertise. *Proc. AMIA Symp* (2007), 140-44.
3. Civan, A., McDonald, D.W., Unruh, K.T., & Pratt, W. Locating patient expertise in everyday life. *Proc. GROUP 2009*, ACM press (2009), 291-300.
4. Ehrlich, K. & Shami, N. Searching for expertise. *Proc. CHI 2008*, ACM press (2008), 1093-1096.
5. Fisher, D., Smith, M.A., & Welser, H.T. You are who you talk to: Detecting roles in Usenet newsgroups. *Proc. HICSS 2006*, IEEE (2006), 59b.
6. Fox, S., & Jones, S. The social life of health information. Pew Internet & American Life (2009). <http://www.pewinternet.org/Reports/2009/8-The-Social-Life-of-Health-Information.aspx>
7. Frost, J., & Massagli, M. Social uses of personal health information within PatientsLikeMe, an online patient community: What can happen when patients have access to one another's data. *JMIR* 10, 3 (2008), e15.
8. Hoey, L.M., Ieropoli, S.C., White, V.M., & Jefford, M. Systematic review of peer-support programs for people with cancer. *Patient Educ Couns* 70, 3 (2008), 315-37.
9. Kriplean, T., Beschastnikh, I., & McDonald, D.W. Articulations of wikiwork: Uncovering valued work in Wikipedia through barnstars. *Proc. CSCW 2008*, ACM press (2008), 47-56.
10. McDonald, D.W., & Ackerman, M.S. Just Talk to me: A field study of expertise location. *Proc. CSCW 1998*, ACM press (1998), 315-324.
11. Reichling, T. & Wulf, V. 2009. Expert recommender systems in practice: Evaluating semi-automatic profile generation. *Proc. CHI 2009*, ACM press (2009), 59-68.
12. Rimer, B.K., Lyons, E.J., Ribisl, K.M., Bowling, J.M., Golin, C.E., Forlenza, M.J., & Meier, A. How new subscribers use cancer-related online mailing lists. *JMIR* 7, 3 (2005), e32.
13. Sarasohn-Kahn, J. The wisdom of patients: Health care meets online social media. California HealthCare Foundation (2008). <http://www.chcf.org/documents/chronicdisease/HealthCareSocialMedia.pdf>
14. Shami, N.S., Ehrlich, K., & Millen, D.R. Pick Me! Link selection in expertise search results. *Proc. CHI 2008*, ACM press (2008), 1089-1092.
15. Shami, N.S., Ehrlich, K., Gay, G., & Hancock, J.T. Making sense of strangers' expertise from signals in digital artifacts. *Proc CHI 2009*, ACM press (2009), 69-78.
16. Torrey, C., Churchill, E.F., & McDonald, D.W. Learning How: The Search for Craft Knowledge on the Internet. *Proc. CHI 2009*, ACM press (2009), 1371-1380.