

Ethical Considerations in Pervasive Health Research

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ABSTRACT

The pervasive health field has matured over the last few decades and the community has begun to converge on commonly accepted practices. In this work, we argue for a need to consider the ethical implications of the choices we make as researchers, particularly when working with vulnerable or sensitive populations. We outline a number of considerations that should be given more attention moving forward. We discuss these considerations as they have emerged from our work with people with rare diseases and with newly diagnosed breast cancer patients, both sensitive communities requiring a careful attention to ethics. We organize these ethical considerations around two main themes: the importance of involving participants in the research process and the need for flexible approaches to both research methods and the design of tools. We provide recommendations for researchers towards a successful, ethical future of pervasive health research.

CCS Concepts

• *Human-centered computing~HCI design and evaluation methods* • *Applied computing~Health informatics*

Keywords

Pervasive health; ethics; breast cancer; rare diseases; patient advocates; community based research; privacy; patient empowerment; research methods; personalization

1. INTRODUCTION

The past several decades of pervasive health research have provided us with a deepened understanding of various populations as well as new and novel sociotechnical supports and interventions to address the needs of those populations. As the field has matured, so has our understanding of research methods, design strategies, and evaluation techniques and we have begun to converge on commonly accepted practices.

Moving forward, we argue that there is a need to consider the ethical implications of the choices we make, particularly when working with vulnerable or sensitive populations. In this position paper, we outline a number of these ethical considerations that we argue require greater attention moving forward in the future of pervasive health research. These ethical considerations emerge predominantly from our work with two different populations:

1. *People with rare diseases.* Researchers at Indiana University have been working with people with a wide range of rare diseases for the past three years, towards understanding their needs and lived experiences, how they experience similar or unique challenges to common chronic illness patients, and ultimately designing tools to support those needs. Because of the rarity of these diseases¹ and the global nature of the online support communities, it has been necessary to conduct research remotely, recruiting from online communities and using methods such as video/phone interviews, surveys, and design activities conducted via Facebook.
2. *Newly diagnosed breast cancer patients.* At Georgia Institute of Technology, researchers are examining how mobile tools may help individuals manage cancer treatment in the context of everyday life. Developing holistic tools that support patients' medical and personal needs requires working closely with patients to understand their healthcare experiences; yet cancer diagnoses are overwhelming and emotional experiences. This tension necessitates research methods that consider patient needs during these vulnerable moments, such as working with patient advocates and creating tools supported by the existing healthcare system.

In this paper we discuss ethical considerations that have emerged from these research projects that we believe warrant further discussion within the pervasive health community. We organize these considerations around two main themes. First, we discuss the importance of involving participants in the research process. We provide illustrative examples of approaches to doing so from our own work with people with breast cancer or rare diseases, and suggestions for the research community to consider ways of involving participants in their own research process. Second, we discuss the need for flexible, customized approaches to research methods, as well as in the tools we design. Again, here we provide examples from our own work and encourage researchers to consider customization in their own work.

2. Participant Involvement in the Research Process

When working with sensitive and vulnerable populations, it is important to include participants in the research process. This is done to varying extents in common HCI approaches, such as user centered design or participatory design. In this section, we discuss our experiences working with rare disease and breast cancer populations, focusing on recommendations for partnering with patient advocates, building rapport through community participation, and balancing privacy with empowerment.

¹ A rare disease is defined as one that impacts less than 0.05% of a population [15].

2.1 Partnering with Patient Advocates

Over the past decade, several studies have utilized the expertise of healthcare professionals in technology deployments. These professionals provide knowledge of existing healthcare practices, as well as expertise working with patients during difficult moments. Beyond physicians, researchers have worked with various healthcare professionals who focus on supporting patients' self-management, such as diabetes educators [13] and child life specialists [2].

In our own work we have partnered with cancer navigators as we develop tools to help breast cancer patients cope with their disease and manage treatments while away from the cancer clinic [10]. Navigators are professionals who focus on providing personal support to patients, providing healthcare knowledge, access to social services, and counseling [8]. This partnership has benefited the research in several ways, while also providing value to the navigators.

From a research perspective, the cancer navigators have provided important knowledge about the ways patients' cancer journeys change over time, based on their experiences working with hundreds of patients every year. This information proved necessary for designing tools to support the breadth of challenges patients face throughout and after completing cancer treatments. As we began to deploy technology to patients, partnering with cancer navigators again benefited the study. Navigators introduced patients to the research study during their first meetings with the oncologists. By using navigators in this role, we were able to provide patients with potentially helpful technology immediately following their diagnosis, while also creating an enrollment process that considered the emotional impact of the diagnosis and was minimally invasive in the existing healthcare routine. The navigators also helped train participants on how to use the technology, increasing the trust participants felt towards to tool.

We were surprised to find that involving the navigators in the technology study also benefited the navigation organization. Introducing patients to the technology deployment was used as an ice breaker between patients and navigators, providing a way for navigators to introduce patients to both a new technology for patients to keep, as well as a services offered by the local navigation group.

This partnership with cancer navigators has highlighted the importance of developing relationships between research teams and healthcare professionals. Patient advocates in particular can greatly benefit technology studies. Yet partnerships of these kinds are scarce in the literature. An opportunity exists for the Pervasive Health community to develop best practices for including these healthcare professionals in patient technology deployments. Further many opportunities exist for facilitating the work these advocates offer to patients.

The pervasive health community ought to consider ways in which technologies may work in cooperation and coordination with these healthcare professionals.

2.2 Building Rapport Through Community Participation

In our work with people with rare diseases, we recruited from Facebook groups targeting specific diseases. We had initially joined these groups to recruit participants for an interview study [12] and generally found members of these groups to be enthusiastic about our presence and eager to be involved in research. We continued to build rapport with these groups

members by sharing results of our research with them, as well as contributing to the community in other ways (e.g., by helping to access academic articles of interest located behind paywalls).

We recruited from these same groups for additional studies [11], as well as new groups in order to increase our sample sizes. In groups where we had been active members for over a year, we found that members generally did not have a problem with our presence and any questions about the study were easily satisfied. If a group member had a question about the study, a different group member (usually a participant from a previous study) would often jump to the researcher's defense, vouching for the researcher's legitimacy and expressing gratitude for ensuring their rare condition was represented in research. In groups where our presence was new, we encountered a few individuals with concerns about the study, asking questions about researcher credentials, IRB approval, study procedures, and benefits/risks of participation.

Developing a long-term engagement with the cancer navigators and cancer clinic in Georgia has also proven valuable. Maintaining relationships within the community has provided the opportunity to develop multiple longitudinal projects. Such projects include understanding cancer navigation practices [8], comparing information sharing preferences and patients and providers [9], and assessing ways in which patients use technologies throughout treatment [9]. This work extends our understanding of how technology may support complex healthcare systems and patients, supporting all stakeholders and improving the overall cancer care experience.

We argue that researchers should participate actively in participant communities, providing additional benefits where possible.

2.3 Balancing Privacy with Empowerment

Part of building this rapport with community members involves not only disseminating the results of the research to participant communities (a key principle of community-based participatory research [7], which Unerti et al. [16] suggest applying to health informatics research), but also ensuring that they are comfortable with how they are represented before those results are published or publically disseminated. In all of our work with rare disease community members [11, 12], we provided participants with a draft of our paper before it was submitted to ensure they were comfortable with the content. This mitigates misinterpreting or misrepresenting comments and ensures participants have final say over how their data is used; we have never had a participant request changes to a paper.

Rare disease communities present unique challenges from a privacy perspective, because the diseases in question are extremely rare, thus it is easy to re-identify an individual using only a few pieces of demographic and contextual information. In [12], we provide summary information only about participant demographics, instead of a standard participant table. We use participant ID's (P1, P2, etc.) so that quotes can still be contextualized within a participant's story, but we omit many details from these quotes that could be identifying. In [11], we take this a step further. Because of the nature of the group and the participants' contributions, we omit participant ID's altogether. Because of the heavily skewed gender distribution (11 female, N=13), we use gender-neutral pronouns to refer to all participants. In the review process for both of these papers, we received push back from reviewers who wanted more information than we were comfortable providing.

As an alternative perspective, Jerolmack (in a conversation with Murphy [14]) argues there may be value in providing participants the choice of not being de-identified. He states, *“There was very little that I could offer my participants for all the time they gave me, but they viewed seeing their name in print as intrinsically rewarding. When I handed out copies of The Global Pigeon, most quickly thumbed the pages looking for their name and some excitedly took photos of the printed pages they appeared on and texted them to friends and family. This has convinced me that, at least some of the time, naming may be more ethical than masking.”* He further argues technologies like Google and social media have made it even easier to identify people by performing keyword searches, and the practice of using pseudonyms offers *“at best, an illusory promise to protect confidentiality”*.

We recommend researchers give careful consideration to the choices they make when reporting participant information, balancing the risks of loss of privacy against empowerment and recognition of participants. In any case, we strongly advocate for including participants in this conversation.

3. One Sized Designs Don’t Fit All; Neither Do One Sized Methods

Central to our work in both populations is a focus on people and their specific needs and unique circumstances. These populations call for a level of personalization, both in terms of the research methods we use to study them and in terms of the tools we create to support them. Here, we discuss our experience conducting needs assessments and developing personalized health tools for breast cancer and rare disease groups, drawing recommendations for the future of pervasive health research.

3.1 Needs Assessments

Over the years, certain research methods have emerged as being commonly used and widely accepted. Methods such as interviews, focus groups, diary/elicitation studies, design workshops, and role-playing have led to significant contributions and impact toward our understanding of various populations as well as the design of novel systems to address those needs. These methods are generally intended to be conducted in a co-located and synchronous manner with the study population. Co-located group-based studies are not always possible when participants have limited travel access or mobility issues. This may also be true when social or political climates inhibit a potential participant’s ability to assemble. In some cases, researchers may not have access to enough participants in their local area. Finally, participants may not feel comfortable in a given setting, whether being physically present or allowing researchers into their environments.

We need new approaches of conducting research with hard to reach populations to (1) ensure that perspectives from underserved populations are considered when designing new systems, and (2) improve the scientific merit of our research by expanding sample sizes to reach theoretical saturation or statistical power. There has been some discussion of remote interview techniques [3, 6, 17], but little discussion of remote group based methods.

In [11], we begin to take steps towards exploring new approaches, discussing Asynchronous, Remote Communities (“the ARC method”). In this method, we created a private Facebook group where participants could engage in discussions with the researchers and with each other. We provided participants with different activities over the course of 22 weeks; these activities were things like keeping a diary for 24 hours of interactions they had with other people about their disease, writing a script for a

scene from the movie of their life, or taking photographs of things or places that reminded of them of their condition and posting these to the group. We provide a thorough description of our method and a frank discussion of the lessons we learned.

We advocate for trying new approaches to research that allows for reaching underserved populations. We highly encourage researchers to report on their methods with rigor and transparency, allowing for other researchers to leverage and improve upon these methods moving forward.

3.2 Personalized Health Tools

As we create new research methods for reaching a broader population, we anticipate that the resulting technologies will also require novel designs that consider a diversity of needs and goals. Literature has already revealed that healthcare journeys are extremely personal. Patients cancer experiences, for instance, are influenced by one’s numerous factors including one’s ethnicity, socioeconomic status, religious beliefs, and social support [1].

Healthcare professionals, such as navigators, have found that personalized support is necessary, tailoring services to the individual. However, these professionals often face high demand and limited resources. An opportunity thus exists for technology to extend the personalized, adaptive support available to patients.

The field of human-computer interaction has looked to develop guidelines for developing adaptive interfaces over the past decade. These studies focus on primarily on menu displays [4, 5]. Researchers have only just begun to explore the use of adaptive interfaces in healthcare. While health tools often provide users with personal data, these tools rarely adapt based on user’s personal information.

Future work developing tools to support patients in complex healthcare situations ought to incorporate the unique health situations within populations to create tools and content tailored to the individual.

4. Conclusion

Using our experience across multiple research projects, we have discussed the ethical considerations that have emerged from working directly with vulnerable populations. We have advocated for involving participants in the research process by:

- 1) working in cooperation and coordination with healthcare professionals and patient advocates,
- 2) participating actively in participant communities and giving back to those communities, and
- 3) involving participants in a conversation about the risks of loss of privacy or benefits of recognition when reporting participant information in research.

We have additionally argued the importance of personalized approaches to research methods and designs, including:

- 4) adapting existing methods or creating new methods to better reach underserved populations, and thoroughly reporting on experiences with these methods, and
- 5) incorporating unique health situations within populations towards tailoring content to the individual.

Our goal with these recommendations is to bring attention to common issues in pervasive health research. As this field of continues to develop, focusing on these issues may help in developing best practices and a community of support for research directly involving healthcare systems and individuals grappling with difficult health situations.

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