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Examining the Needs of Patient Stakeholders as Research Partners in Health Data Networks for Translational Research

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Abstract

Patient stakeholders are getting increasingly involved in research health data networks, particularly as research partners. However, tools do not exist to help effectively orient, educate, and engage patient stakeholders as they take on these roles. Using a human centered design approach, we conducted a patient stakeholder needs assessment qualitative study to identify key user needs to drive design recommendations for development of an online education and engagement tool for research health data networks. We found three key needs related to multiple role identities, motivations and expectations for participation on research teams, and patient journeys. Design recommendations derived from the needs assessment are discussed that can support future tool design and testing.

Introduction

Electronic health record (EHR) data are increasingly being leveraged for health discoveries as we strive towards a Learning Healthcare System[1]. Large data sharing network efforts, such as PCORNet, Sentinel, eMERGE, and the NIH Collaboratory's Distributed Research Network [2–7], have developed to support use of EHR data in research. These networks facilitate access to health data for efficient reuse for research and quality improvement purposes while preserving privacy of the individuals whose data are represented. To ethically protect and share these data, many proponents consider stakeholder engagement a pre-requisite to construction and operationalization of research networks[8].

Strategies to effectively engage stakeholders including patients, caregivers, community members, and clinicians in research network governance and activities are emerging[9]. Recent progress in this area includes engagement of stakeholders in communicating the importance of research, determining research priorities, effective recruitment, and network decision-making and governance[10]. Stakeholders are generally open to data sharing for research[11,12]. However, they are not well versed in these complex data sharing networks and need clear, hurdle-free ways to quickly and easily learn about them, particularly as they take on increasingly more engaged roles in developing research as partners. Many existing self-service data tools allow for exploration of data and content with functionality for cohort discovery and rudimentary data profiling[13–16], but they lack freely available high level information to orient novices to the purpose of the network and general characteristics of the data being shared. In other words, stakeholders need not just information about the data in the networks, but key information about the network itself to contextualize the data in a way that is meaningful to them as they give input to and partner with research teams. In addition, these tools often require permissions to receive logins and training about privacy and research regulations, creating significant barriers to easy access for community stakeholders.

The pSCANNER (patient-centered SCAlable National Network for Effectiveness Research) network is a stakeholder-governed clinical data research network (CDRN), as one of 13 national CDRN's within the Patient Centered Clinical Research Network (PCORNet), that aims to make health data more accessible and usable for health research[9]. The pSCANNER network integrates data from health systems that represent 37 million patients, with patients and community stakeholders involved as members of scientific research teams. pSCANNER stakeholders actively contribute as co-designers and provide key voices and ideas on research teams. pSCANNER

stakeholders benefit from knowledge about the network, empowering them to contribute more deeply to the research.

Online tools are needed to offer quick and easy access to stakeholders across large geographic regions, who often participate in these efforts remotely. Human centered design methods offer a structured approach to capture stakeholder input and ensure that designs of such online tools align with the needs of the targeted users[17]. Developing empathy for and understanding of the needs and current state of users' experiences are key to developing a user-centric and highly successful tool.

As part of a human centered design approach to build such a tool for pSCANNER, we conducted a qualitative study to understand the user experiences of patient stakeholders and assess the needs they have in understanding health data and gaining knowledge about a data research network. Our study aimed to discover key user experiences and needs that will guide the design of a future stakeholder-centric online tool that shares knowledge about and promotes engagement as a partner in the data network and with research teams leveraging the network.

Methods

Recruitment. This study was conducted with stakeholders within the pSCANNER network. From 2014 - 2017 pSCANNER engaged almost 400 adult patient, caregiver, clinician, and research stakeholders through governance committees, advisory boards, online consensus panels, and research co-design teams, all of whom either had a condition related to heart failure, weight management/obesity, or Kawasaki Disease or were caregivers or clinicians caring for those who do. As previously reported, these stakeholders were recruited nationally through online patient and clinician groups, personally through pSCANNER investigators, and through snowball sampling from existing board and committee members[18]. Participants in the current study were recruited from this stakeholder group, as they were already familiar with research networks and had received an orientation to patient-centered outcomes research, but were not experts in either. In order to participate, individuals had to be 18 or older and self-identify as a patient in the heart failure or weight management/obesity groups.

One team member, a human centered design researcher, conducted 13 interviews between July and September, 2016 using a semi-structured interview guide. Participants were recruited by emailing stakeholders from existing lists of patient stakeholders maintained by pSCANNER. A majority of interview participants were age 45 or older and female (62%). Interviews took place via phone or video conference, lasted between 45-60 minutes, and were audio recorded and transcribed. Topics covered during the interview included motivation, methods, various attitudes, and desires for using data (see Table 1). Interviewees received $30 for participation in our study. All data collection activities were approved by the University of Washington Human Subjects Division's Internal Review Board (IRB).

Table 1. Topics covered in the semi-structured interviews with stakeholders.

• Motivation for taking part in pSCANNER • Engagement in other health research groups • Healthcare/patient interaction expertise • How health-related information is sought	• Attitudes toward technology/comfort using technologies • Perceived value of electronic health record data • How they might use a tool that visualizes data • Types of health information desired from pSCANNER data visualizations

Two team members, a human centered design researcher and communication and qualitative analysis expert, conducted qualitative analyses to identify relevant themes by independently reading transcripts and collaboratively developing a codebook to code each transcript using qualitative analysis steps guided by grounded theory[19]. Each coder served as the primary coder for half of the transcripts and validated coding on the other half. A list of crossed validated emerging themes was presented to the broader research team consisting of human centered design engineers, clinicians, and researchers for further refinement and conflict resolution.

Results

Three thematic areas of stakeholder needs emerged from interviews with patient stakeholders: 1) patient stakeholders' multiple roles; 2) patient stakeholders' motivations and expectations to participate in research networks; and 3) patient stakeholders' journeys.

1. **Patient Stakeholders' Multiple Roles – More than Just a Patient**

We found that participants often identified with multiple roles. For instance, they saw themselves as patients and patient advocates at the same time. Some were often patients themselves, family members and caregivers of patients, and professionals with community roles that they felt were key to being a stakeholder. One patient described how multiple perspectives contribute to their identity and level of engagement.

> "*As a patient, I have some of those experiences that the only way you could actually experience them is to live them as opposed to watch them and observe them and study them. I bring that to the table, and the fact that I'm a retired science teacher I think helps as well. I see the educational aspect, at least in my treatment and in my case, has been the number one piece that's allowed me to be able to stay at the level that I'm at right now.*" – P1011

As patients discussed how they would use an online resource for pSCANNER, they evaluated this experience from the perspective of multiple roles, often toggling between them.

2. **Patient Stakeholders' Motivations and Expectations for Participating on a Research Team**

Stakeholders expressed three primary motivations and expectations for participating on research teams: social support, empowerment, and education. The motivations and expectations expressed by each patient generally had many facets and were complex. They expressed strong desires to positively engage and impact many levels of the health community.

2.1 Social Support – Giving and Getting

Stakeholders expressed interest in both getting social support from a research network, while they also helped others through their participation and contributions on a research team. They expressed expectations that their own health data and experiences would help others that were experiencing similar issues. They wanted to build and contribute to a community focused on their health concerns. Many patients cited that their drive to be engaged in research came from a desire to help people. Other patients found value in the support of the community as this patient describes:

> "*I think those kinds of events, those kinds of gatherings with other people who've had similar experiences, is really key to help educate yourself but also to feel like you're part of a community of people that suffer from the same condition.*" – P1003

2.2 Empowerment – Shifting Healthcare to be Patient-Centric

Stakeholders expected their involvement in research would be empowering to themselves and to other patients. Specifically, they wanted to help healthcare become more patient-centric, more clearly focused on their needs, and more supportive of patient autonomy. As stakeholders they were in a position of having data and experiences that were valuable to others. In one patient's words:

> "*It was…a huge sense of empowerment... It's almost humbling that these guys wanted to know what we wanted.*" –P1012

Many stakeholders talked about thwarting current hierarchical power dynamics between clinicians and patients by arming patients with information to join decision-making processes and increase their self-management and self-reliance. One patient expressed a sense of empowerment in sharing access to data with experts.

"*I may not understand [the data] completely but if I start receiving it I can start to understand it. I can start working out the understanding part, so first I got to see what does the data look like? What you make your decisions on if you were a professional? And I'm a professional patient now, so I want to be ...an informed patient.*" – P1004

Stakeholders also described the value of empowerment through a collective patient voice. They envisioned participation with pSCANNER was one way to register the concerns and priorities of collective groups of patients and patient advocates.

"*There's more of a voice than we would have singularly, collectively we might have more of a voice, get some more attention and start partnering more with the doctors rather than they tell us to do stuff and we go yes, but we don't really. It doesn't feel like a partnership.*" – P1004

2.3 Education – Getting Reliable and Useful Information

Stakeholders were driven to get key information about their conditions of interest, feeling like it was often too difficult to access. They were interested in several types of health information resources including clinical recommendations, summaries, and best practices. They specifically wanted easily interpreted, consumable, and synthesized answers to questions relevant to them. One patient described the overwhelming feeling of not knowing how to navigate or interpret information.

"*There's a bunch of information out there, but it's like I'm not sure which one to go by.*" – P1006

Stakeholders wanted key clinical information like how to best self-manage their condition and to be able to trust that information. The desire for more information was often shared in the context of frustration with navigating large amounts of health information coming from unofficial sources that may not be credible. In one patient's words:

"*The problem is that so little information is available to the patient, at least when they first are diagnosed. I'm looking at pSCANNER as being able to be the vessel for the education that new patients need in order to start managing their own care.*" –P1011

3. Journeys – Evolving and Life Changing

Stakeholders were on a journey, often involving discovery and acceptance about their health conditions. These journeys often involved complex navigations through healthcare systems and health information and were emotionally charged. Stakeholders expressed confusion, deep senses of discomfort and amazing change and acceptance, as well as deep desires to reduce the pain of these journeys for others. Engagement in research was deeply personal, complex, and with high stakes. One patient characterized the dynamic information needs based on their healthcare journey.

"*There's such a difference between the kinds of educational materials that are available to patients up on first diagnosis, which can have a long term effect on their lives because they're following different things. They don't know where to look for the information. They don't even know what the questions are.*" – P1011

For many of the stakeholders, the engagement with the community was also part of the journey, which added a new value to their experience in research.

"*I don't want other people to have to go through some of the stuff that I've gone through and some of the other people have. Also one of the really unique things about pSCANNER when we got into the RAM part, listening to other people who had my condition and their priorities and their problems and their experiences, I was not unique. This experience was not needless.*" – P1011

Discussion

We successfully identified key experiences of patient stakeholders that infer needs they had as they oriented as stakeholders with research teams, working as part of a large data network. Human centered design includes a needs assessment of the user, to develop an understanding and empathy for their needs as a key step in developing a user centered tool. In this case, these findings serve as that needs assessment, with an aim towards guiding key design features for online tools that help patient stakeholders gain information about research data networks and the data they aim to share, as they onboard as new partners. Overall, stakeholder experiences and needs are complex. Developing tools to more effectively engage stakeholders in research teams will require deep appreciation and consideration of their life-changing experiences as both patients and advocates.

Several specific recommendations for design features for online tools can be derived from these findings. Online tools must acknowledge that stakeholders will be relating to content and messages in the tools from multiple roles, multiple points within their journeys, and with multiple motivations and expectations. The following are specific design recommendations for online, hurdle-free tools designed to help educate and engage stakeholders in health data networks:

- **Education:** Provide basic educational information about the definition of research (i.e., asking scientific questions and using the "right" data to answer them), to give context to why the data in the network are important and play a role; provide basic information about the data in the network (i.e., high level descriptions of the types of data in the network); provide basic education about the limitations of raw data within these networks (i.e., they help find answers, but do not provide direct clear answers on their own – that is what research is for).
- **Clear and Simple Content:** Content should be succinct, to the point, and respectfully delivered with a meaningful and intentional design to the flow of the information. When people have high emotions, the content needs to be presented as simply as possible in order to maximize comprehension at this difficult moment in time. Key points of information can include:
  - What the network does and why
  - Who the network does it with (who are the partners)
  - What the data are – high level only and with no room for misinterpretation (i.e., simple visualizations that can be understood quickly and cannot be mistaken for conveying population health or treatment erroneously)
  - Clear ways to get involved as a stakeholder
  - What makes the network credible
- **Start Basic:** Make sure to orient the user to basic information with adequate context before moving to other topics.
- **Multiple Pathways:** The design should provide multiple pathways to access information.
- **Empower:** Lay out clear ways stakeholders can contribute or connect; these communities may be other research related groups or advocacy groups.

The generalizability of the study is limited because participants included only patient stakeholders from pSCANNER's stakeholder community, which may not be representative of all patient stakeholders. Generally the participants were well educated professionals, many of whom had other connections to healthcare organizations and who have investment and continued interest in helping to shape research. However, participants offered diverse perspectives and were well represented across gender, age, and health condition.

Conclusion

Hurdle-free tools are needed to help orient novice patient stakeholders to growing health data networks as they partner to guide research. We identified key patient stakeholder experiences that infer user needs the tools must address, namely consideration of their multiple roles, motivations and expectations for participating in research, and life journeys related to their health conditions of interest. Several design recommendations derived from the user needs are suggested can be used to develop and test a prototype of an online tool to ultimately serve as a "front door" to health data networks for patient stakeholders.

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